



## Editorial

Come August 6<sup>th</sup>, and yet another year passes since Erwadi 2000. The Supreme Court has made no gestures towards resolving any of the many issues pending before it on the Erwadi petition this year.

Meanwhile, in Madhepura, Bihar, this July, yet another Erwadi happened, wherein many people labeled mentally ill were chained, beaten, and subjected to other barbaric treatments. The Bihar State Legal Services Authority intervened, issued a letter, and activated the district magistracy. The "center", run by a local entrepreneur of the mentally ill, was disbanded, and people dispatched to Ranchi. Bihar has absolutely no mental health services, Ranchi Arogyashala now being in Jarkhand, and once again, the law substituted for the bureaucracy. It is said that the Bihar State is building a mental hospital as a progressive step!

The Social Justice and Empowerment Department has asked the civil society to comment on the PWDA in order to amend it. A good thoughtful step, and indeed welcome, coming 7 years after the National Amendment Committee submitted its final report to the Government of India. Consultations are rife, in the disability sector, and once again, with little representation from the mental health NGOs. The date for sending in comments is extended to the end of the year.

The PWDA amendment activity running full steam in the country is quite uninformed by the UN Convention on Disability Rights, a document which will most likely be finalized this August in New York, and which will demand a fundamental paradigm shift in disability thinking in India. The PWDA amendment should happen using the UN convention as a point of reference in order to be meaningful.

Carer groups as well as mental health professionals of all shades, and even activists in the sector, believe that schizophrenia is a medical condition, and "curable" by drugs. However, a contradictory view about curability also equally prevails in the belief that life long medication is necessary. A belief regarding the chronic, untreatable 30% cases of schizophrenia is usually cited as evidence to prove the enormity of the problem. Drugs are also expensive, they say, and WTO agreements are a threat. In this situation, which seems hopeless, why are we not trying less expensive, more nourishing treatments with proven effectiveness for schizophrenia? This issue of *aaina* makes a persuasive argument on this subject.

This issue of *aaina* brings forth data and information on the use of alternative mental health techniques, particularly in the context of schizophrenia.

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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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## Bridging the Worlds

A case of brief one-to-one dramatherapy

**Anand Chabukswar, WCCLF, Pune**

The systematic application of Dramatherapy<sup>1a</sup> is very new in India. The combination of the words 'drama' and 'therapy' in itself may raise eyebrows! Dramatherapy is the use of theatre and drama processes – building images, weaving metaphors, actions, movements, sounds, stories and much more – by the client and therapist with an intention to heal and experience wholeness. It is not a 'performance'

for an audience, put up by a group of patients! Dramatherapy is a "safe space" for exploration, participative co-creation and rehearsal, created with the aim of reaching areas of pain and illness – to observe and untangle them through artistic exploration and not by direct assault.

In the dramatherapy space, the participating individuals / group journey through stories, suspend disbelief and create 'other worlds', worlds that allow expression of what

is hidden / blocked so far, they also show possibilities and provide new, creative insights. Dramatherapy uses the 'as if' or 'pretend' or 'play' to access, experiment, and rehearse with possibilities and roles. E.g. The trickster (someone who has the ability to shake-up the expected order of things<sup>2</sup>), the hero, the healer within and so on. People may make direct connections between metaphors and life. The experience of creativity and play helps one get in touch with positive, active parts

<sup>1a</sup>Dramatherapy is being consistently practised in India under the aegis of the WCCL Foundation in Pune, an NGO dedicated to Arts-Based Therapies (ABTs). ABT is a comprehensive term to denote Drum Circle Therapy, Individual and Organisational Health and Dramatherapy. WCCLF makes projects using ABTs for institutions and people with 'special' needs or issues. It has been primarily used as a group-based therapy for many years through the Foundation's projects, but the dramatherapeutic approach has touched, and is being found useful, even in individual – one-to-one work with clients.

of oneself that get shadowed in the presence of a demanding illness or disability. People realise that they have the power to choose and to create; that they can ideate and rehearse alternative choices and ways of being. This gets translated as the ability to relate, respond and take responsibility for well-being.

This article is a reportage of how with dramatherapy sessions, a client moved from being 'stuck' in the script to an onward journey! This story is of a middle class man of 23 called Ramesh<sup>3</sup>, who experienced mild to severe schizophrenia in the last 8 years. Medication, psychotherapy, support group helped Ramesh cope with the most severe parts of his illness. Over the last 2 years, he'd begun to struggle on the margins of illness, but never really well. His interaction with his therapist had "hit a wall"- as she described it, which is when she called me to explain the scenario.

Ramesh had begun to use words, meant to be used for therapy, upside down i.e. he was using the same language to create a wall, and defend himself against any possibility of change or breakthrough. He had digested so much information and jargon about his diagnosis, that he was adept in its analysis at the drop of a hat. He would begin with the standard and systematic statement of symptoms: "I am unconscious". "I have difficulty in thinking" (that is why I can't understand anything, that is why I have problems, but what to do, I can't think only!) and, "I do not feel the upper part of my brain, it is missing". All kinds of medical tests and doctors explaining to him the falsity of his belief were completely useless. He strongly believed he was ill.

There could be no continuous conversation with him without the mention of one of the above, every two minutes. Despite logically agreeing with the impossibility of these conditions, he would reiterate verbally that they did exist in him!

All this was upsetting the possibility of establishing anything close to a regular life for him. This is when his therapist called me in. My agreement to work with him was conditional – that we check the 'use' of dramatherapeutic methods after two sessions, and that his therapist be my supervisor and sounding board for this case. It is important that a therapist explore his/her observations, hunches and blocks in a safe, professional, exploratory space of shared wisdom with another.

My intention was for Ramesh to get moving on the road, an intention shared by his therapist. Given the conditions, I decided that it would be a short-term exploration – either we find dramatherapy effective and things change, or we stop after two sessions. My training and apprenticeship of years has taught me that one of the key strengths of dramatherapeutic approach is to get the individual in touch with inner healing resources as also help the individual focus on self in the context of the world ('others' and community<sup>4</sup>), i.e. work towards opening the possibility of connecting to one's usual life and community at the earliest.

Ramesh and me worked together for five weeks, meeting once a week, and a follow-up with family a month later. I gathered that besides his current therapist, Ramesh had been exposed to various approaches and therapists over the years. Ramesh corroborated in the first session when he dropped more than large hints (or baits!) about "my mother and problems caused by her" and even initiated a long list of "possible reasons for my illness". I listened and reminded him that we were engaged in evolving a contract and focus for our work together. In practise we sidestepped these possible routes of verbal exploration for the moment.

What was most significant was the agreement on a "*healing contract*" or

the *intent* of why we were meeting. We started off with Ramesh explaining what he thought were the reasons he was meeting me (this is when he stated the causes of his unwellness, straightaway), I exhorted him to tell me what he would like to see happening for himself. This was tricky, because stating the goal (i.e. the state of health), in itself was a step away from the sick role that he seemed attached to. Then, over a conversational volley he stated what his problem was, and I asked him a question of the type "do you want it?", he replied "No, BUT.....," and thus we reached the classic "as if" of theatre where 'if' became important in opening a new possibility - " 'IF he were in health....IF his problems were going away....IF there was a state of health destined for him – what would that be?". I also explained to him that IF we make "wellness" rather than illness the focus, then we needed to see what "wellness" would look like – so that when we see "it" we stop and have no more sessions!!

Together we arrived at 3 core objectives for his meeting me in the healing space. I wrote them down for him, and read them back to him, seeking his permission and agreement. He agreed:

1. *To feel 'conscious'*
2. *To be able to think with ease*
3. *To feel the upper part of brain*

Setting a clear healing agenda and stating it, is one of the significant gifts of my collaboration with other therapists within our WCCL Foundation team. To formulate, articulate, and accept the healing intent is usually the first big step<sup>5</sup>.

Thereon I explained to Ramesh (within the story of who I am) that we would use the media of play and imagination for our journey, and that this journey is undertaken to reach our Goals. 'How' it will happen, is unknown and that's the *journey* part! He seemed hesitant to accept

'playing' as a way to 'meaningful stuff'. Over the next weeks, I noted that despite enjoying playing and doing brilliantly well with scenes, word-associations, and developing themes and stories, his "comfort" lay in 'talking'. After the initial self-surprising creative jumps, he would not allow the creativity to sustain. Infact, over a period of 5 weeks, Ramesh's creative abilities or play did not increase in sustenance.

This had manifold reasons: During playtime he experienced an amount of wellness (because the sick Ramesh would temporarily disappear or get shadowed under this bright, joyful one!) that would make him feel stretched and long to retreat to the usual mode. Hence, after encouraging him a bit, I would press him no further. Another reason is that he too reflected the societal attitude and belief that puts-down playing and creativity as either 'childish' (and dismisses it) or as artistic (and puts it on a pedestal). Hence, we- 'the commoners'- are absolved of practising or indulging in it, though 'connecting' to art forms, provides us life sustaining and strengthening power.

Two *dramatherapeutic* principles (as we practise it) were at play in our work:

>> Imaginative warm-ups loosened and freed 'thinking-feeling' energy. In making mini-sculpts or images, something 'new' 'original' 'his own' emerged without the fear of judgement or ridicule. We were using *as if* and 'lets play' to propel this.

>> Using some of the freed energy and focussing on "creation" – what is wanted - rather than analysis of *what is*. The focus is on the power to Create from nothing.

During his visits, the healing agenda worked as a powerful anchor and a safety net too. During one session, he asked me if I really understood his illness and proceeded to state that he thought I did not understand

his illness. A loop? A trap? How to respond...or not?? I decided to acknowledge that he was right, that I did not specialise in his illness. I specialised in wellness, and that I was interested in taking a journey with him towards the objectives we had formulated. I was simply not interested in discussing his ill-health (lots of discussion about it had happened in previous 8 years!). This destroyed the mental trap! He had agreed before that he wanted to feel well, to be conscious - and like a staunch mule I would push only towards that desired state of experience!!

The creative play of our sessions quickly yielded one concrete, undeniable output – that Ramesh was 'thinking' – clearly, logically, imaginatively, wonderfully! I adopted the roles of 'trickster-healer' but the stories, funny word association games (everything!) belonged to him. I just laughed and enjoyed his creations. Listened, praised-obliquely or directly - and at appropriate times, shrugged my shoulders and pointed out that all this was "his" creation. He made it. He owned it. And how good it was! In closures (where we mainly bridge the metaphor and play to make real life connections), we spoke about his abilities and his strengths as a person, as a young man.

I spoke to his mother on telephone and suggested that they stop treating him like an unwell person, that they need to slowly but surely realise that he is OK, that he is whole and relate to him so. That would be one of the powerful ways to help create and sustain a state of wellness in him.

Ramesh did encounter a fear of feeling OK again. He called half an hour before time, to report that he had fever and would not come to the session. The trickster in me almost threw a tantrum, and asserted that he would *have to pay* me anyways, because I had kept the appointment. That he should have told me earlier, and that I expected him to show-up

with a pill down his gullet. When he emerged (sharp on time!) I showed all sorts of concern and found out soon enough, that he was perfectly well – no fever! Well, drama for a dramatherapist! His parents later reported that they had refused to support his pretences. They decided that they would not bend this time to make fake calls to me on his behalf; instead they allowed him to choose and take responsibility – either ways. Ramesh tried this twice – and gave up...or shall we say, it just fell off....

Within sessions, he explored issues of 'what was within his control' and what was not. A significant outcome was his own agreement and exploration that 'himself' was his area of control. It was important to acknowledge his long period of suffering, lost opportunities of education, friendships, and other rites of passage a young person experiences from teenage to young adulthood. It was also very important for him to focus on his 'now' and 'now on'; stop grieving about the lost time and start dreaming. This was then followed-up by the story of two frogs –one is 'deaf' to the catcalls of negative voices – so he can come out of the pit in which he is fallen. Other one dies, listening to 'others'. Ramesh said after the story " I want to be the one who lives".

We journeyed through the most crucial question - 'what does being conscious mean?'. As Ramesh talked about it, he kind of defined it as 'awareness' of things, deliberately being and doing. We ventured to apply this by doing a 'reality check' – to life and people in general: traffic, roads, cities, population and such broad things first. It seemed (to him as well as to me) that many people were not really 'conscious' or aware of what is happening around. The words *shuddhi* – being conscious or aware of something, and *shuddha* – pure / clean, come from the same Sanskrit root. We deliberated on this – played

and sang old Marathi song about *Shuddha* – pure heart.

We used poetry and songs, but also invented conversations and dialogue (as noted before, Ramesh was more comfortable talking, than playing). We discussed, challenged, asked questions, sought answers, but even allowed the questions to be. One of my questions to Ramesh was about his “hero’s journey” – mission in his life. And of course, he knew it not. And wasn’t it an exciting journey ahead to go on and find – what was he meant to do – to create.....?

Ramesh, for the first time said “I know I can and want to find life like this – but there are these voices that tell me not to”. That session we “saw” what dramatherapy techniques could show<sup>6</sup>, More than that, Ramesh (probably for the first time) directly confronted the ‘voices/they’, who he said, were controlling him. He juggled between ‘Ramesh- the victim’ and ‘Ramesh- the Creator’. He listened and explained what the ‘voices’ dictated, and responded as The Creator, as the original Ramesh by asking the voices to ‘shut-up’. He announced that he did not need them anymore, told them to “go away”, firm and loud. I paced him through a couple of ‘techniques’ meant to be used in responding to the negative voices, and to keep alert. We rehearsed the techniques. I also told him when *not* to use them, for example, when Mom is asking to wake-up, not to say “No. Thank you”!. It was a light closure of a serious dialogue.

Ramesh came willingly to the fourth session. We reinforced large-small insights and learning. He acknowledged that he could think, that consciousness is a continuous journey and he had ‘created’ the upper part of his brain. It was now important to close, feel whole and follow that up with practice, ensuring (in consultation with his therapist & family) that he does not slip back. His mother reported that he was doing much better at home; he was

more willing and regular at the small job they had found him, regular with medicines, exercise, and slightly more positive, connected to life in general. During this session he said, “I feel Ok, there are these moments of clarity when I feel absolutely myself. Then I am unwell again”. He lamented that these were few fleeting seconds during which he felt ‘free’. This was big news from him! He’d found a window - albeit a tiny sky-hatch of clarity - being and feeling himself totally. I exhorted him to hold on to these moments, to pull the veil apart, remain alert and expand the time of such clarity. That would be his road ahead.

Sensing that the short term we shared was nearing closure – we moved towards ‘reconnection to real’ and ‘grounding’ processes. Ramesh made a drawing of his family, drawing a thought cloud to one of the figures, he wrote a formula in it and on being asked, he explained “This is me. I want to become a scientist”. This was his lead. He was looking at possibilities – at dreams! In the last session he made a mandala<sup>7</sup> - life’s beliefs, creative ability, life’s mission/direction, skills, and difficulties - a reflection of the whole in the moment. As yet, he could not see many skills on his list. His difficulty still was his ‘illness’, in the area of creativity he had his sense of humour listed out, and his mission/dream was to be a prize-winning scientist.

In this short span of 5 sessions, Ramesh touched new spots within – of creative power, of dreaming. He also ‘saw’ in practise that he could think, feel and be Ok. We had traversed a long way. The main task now was to create, repeat, practise, rehearse, and enable all this in real time and life. His family, therapist, support group, environment had a role to play in it. For this, I eventually met his family in a joint session with his therapist, and suggested new approaches and techniques. It would be a function of long-term follow-up to see what he sustains. The hope

is that he will strengthen the process of integrating his self and abilities into one flow that will hold the power to choose and make a life from that understanding and personal power.

Ramesh had moved away from the ‘wall’ he was at.

At my suggestion, and Ramesh’s choosing we brought our meetings to a halt. We’d had a journey where he saw what “driving himself” could mean. Hereon, Ramesh would have to prove that he could travel - by himself – and cross that bridge again.

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<sup>3</sup>Name has been changed to preserve confidentiality and anonymity

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<sup>7</sup>The Mandala method developed by Dr. Sue Jennings that examines the holistic image of life rather than just being problem focussed. See: Jennings, Sue. *The Traveller: Healing Theatre in Magilligan Prison*, Dramatherapy Vol 21 no. 2 Autumn 1999.



## Green Therapy

Radhika Sharma

Plants and people in distress... does it strike any connection?

Most of us are aware of the relationship plants and people in general share, and the symbiotic liaison and their mutual interdependence could be discussed. But plants and people in distress?

These were my initial thoughts after hearing about Green/ horticulture therapy. But as I delved into my own experiences since childhood, and started reading up on Green therapy, I realized that I did not need to establish a connection between people in distress and plants, because it already existed, a connection that even I had very subconsciously utilized many a times for my own well-being.

Working with plants through gardening, horticulture has constituted one of the oldest healing arts. But it has only recently been visible for the systematic, scientific and therapeutic value that it possesses. As of today, though more and more professionals are using it for its therapeutic value, we have growing research data to corroborate on the therapeutic experiences of the same. As horticulture is being widely used in various therapeutic settings, an understanding of its value and the mechanisms by which it works is also gradually widening.

To put it plainly, Green or horticulture therapy (HT) is a process in which plants and gardening activities are used to improve the body, mind and spirits of people.

The American Horticultural Therapy Association (AHTA) describes horticultural therapy as a method that uses plants, gardening activities, and the natural world in professional therapy and rehabilitation programs. Therapeutic benefits occur when people are exposed to plants, and when they take part in planning, planting, growing, and caring for plants.

At one end of the range, HT is used to mean any gardening activity that helps anyone in any way however, this approach implies that to receive horticultural therapy, all you need to do is plant a seed; and that to be a horticultural therapist, all you need to do is tell someone to plant a seed. While some are of the view that although horticulture is good preventative medicine to help overcome the stress and frustrations of daily life, it is an oversimplification to call any use of horticulture, horticultural therapy; just as going for a walk is not the same as physical therapy. The oversimplifications in their opinion make it difficult to truly understand the nature of this therapy, why it works, and how to implement it.

It is used worldwide in hospitals, rehabilitation and vocational facilities, nursing homes and senior centers, community gardens, botanic gardens, schools, farms, horticultural businesses and prisons. It can be an effective and beneficial treatment for people of all ages, backgrounds, and abilities.

In the 19th century, Dr. Benjamin Rush, who signed the Declaration of Independence and is also considered to be the "Father of American Psychiatry," reported that garden settings held curative effects for people with mental illness.

As Charles Lewis of the Morton Arboretum puts it "The plant world is non-threatening and non-discriminatory." It thus makes it extremely approachable to most people. According to Stamm and Barber, in the more severe emotional disturbances, such as schizophrenia, patients often have a long-standing fear of people that is believed to have developed at a point in their lives before words were used to communicate. They report that the "task orientation of horticultural therapy is ideal for such a patient, for it allows her / him to enter gently into a relationship with another person in a non-verbal way without the threat of being confronted with interpersonal

closeness too soon as may occur in a one-to-one verbal psychotherapy."

At Melwood, mentally retarded young adults raise foliage plants in a modern greenhouse. These are taken to plant sales in the lobby of various federal buildings in Washington, D.C. While the public shops, they make positive comments about the high quality of the plants. These comments not only enhance the retarded person's self-esteem, but also reinforce the public's increasingly positive image of the abilities of disabled people.

A person who has paraplegia because of a car accident thinks of her/himself as a helpless cripple who "can't even stand up." In green therapy s/he learns to stroke the plants and comes to see concretely that s/he can also be a support along with being supported. The person can also review her/his attitudes towards seeking support and peoples intentions of providing support to them.

C. F. Menninger, in writing of his peonies, expressed many of the individual gains of the therapy. He stated- "There is a gratification of the sense of sight in color and color combinations, of the sense of smell in perfumes and odors, and to that inner aesthetic sense of beauty a charm that has, I believe, made a better physician of me. My whole nature was improved, my horizons wider and my appreciation increased in a way that aided me in my vocation."

As a cognitive therapy, it helps clients learn new skills and regain the lost ones. It improves memory, initiation of tasks and attention to details. These are benefits of Green/ horticulture therapy.

Social growth occurs, as people caring for plants learn responsibility and experience hopeful and nurturing feelings. It can be constructively used in physical rehabilitation to retrain muscles and improve coordination, balance and strength.

In vocational settings (especially

vocational rehabilitation of differently abled), through this therapy, people learn to work independently, solve problems and also follow directions and instructions. It could be done by identifying objectives of the program and using it as a training medium.

World War I and II, veterans' hospitals increasingly used gardening as therapy in the treatment and reeducation of disabled soldiers. Volunteers from garden clubs brought the delights and benefits of their hobby to thousands of men recovering from battle.

Gardening with individuals with disabilities has also shown surprising results in improving motor skills and in reducing stress. Even twenty minutes of watering and tending plants produces visible calm.

Tom Ogren says, "Plants are not judgmental. You take good care of them and they thrive. In the garden our minds are free to wander, to daydream, to relax. Good things happen in good gardens."

The individualized therapeutic-treatment goal in Green/ horticulture therapy is achieved through a series of treatment objectives that are clearly attainable and measurable. Each treatment objective is written to include: the desired behavior or response, the circumstances under which that behavior will occur and the minimum acceptable performance of the behavior

Examples of horticulture treatment activities vary from greenhouse crop production to learning to make terrariums and bonsai, from harvesting flowers to dried flower arranging, and from pulling weeds to transplanting trees appropriately modified. The ultimate goal of these programs is the improved physical and mental health of the individual. The benefits may be seen in intellectual, social, emotional, and physical development or functioning.

Intellectual benefits could include; attainment of new skills, improved vocabulary and communication skills, aroused sense of curiosity, increased powers of observation, vocational and

prevocational training, stimulation of sensory perceptions. Social benefits would involve increased interaction within as well as outside of the any given group while parameters for increased emotional well-being would be improved confidence and self-esteem.

Friends Hospital, founded by Quakers in 1813, has used horticultural therapy from its beginning. Since Friends was originally designed to be self-sufficient, it included 30 cultivated acres of grass, corn, potatoes, and wheat. Meat and butter were supplied by dairy cows, and a kitchen garden produced the vegetables. Medicinal plants and "salutary" herbs were also cultivated. Large areas of grass and quiet forest paths were left for recreational use. Friends provided a serene atmosphere where patients could feel safe. Today, Friends Hospital uses horticultural therapy as an "active" treatment.

The therapists use plants of all stages to also represent the cycle of life, which can then be used for specific therapeutic objectives.

To a user, alternative therapies provide sensory and mental stimulation, along with therapeutic benefit—without the drudgery and frustration of being urged to "walk two more steps." Instead, alternative therapies, such as putting in the garden, enjoying the tactile stimulation of a massage or just sitting and absorbing sights, smells and sounds, can relieve them of their ennui. Green Therapy encourages many of the same goals as traditional therapies, by helping people perform the same exercises without their being perceived as "work." For example, users for instance those with Alzheimer's and dementia-related diseases can still retain hand functions by squeezing the soil instead of a rubber ball.

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The softer side of therapy: Therapeutic benefits without the "work" - Feature Article

[Nursing Homes](#), [March, 2002](#) by [Sandra Hoban](#)



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# Women with Disabilities

■ **By Tina Minkowitz**

This presentation will address three levels of perspective on human rights issues affecting women who are users and survivors of psychiatry: first, my personal perspective as a woman and a survivor of psychiatry; second, some themes that I have encountered among women users and survivors; and third, a human rights overview of our main areas of advocacy.

## A. Personal experience

When I was a child, I thought that my role in life was to make things convenient for other people, to take care of myself and not ask for anything. My mother was emotionally needy and not able to give me the kind of guidance and nurturing I wanted, although she loved me. In my mind, I had become a woman already, and this self-abnegation was a mature woman's role. Then in my teenage years I saw that no one else was living this way, other girls were doing what they wanted, so I also became a little freer. At this time I learned about women's liberation and I affirmed my own belief that women should be able to do anything that a man can do. When I was on the cusp of adulthood and trying to decide about my course in life, and also to come to terms with the lack of nurturing in my childhood, I experienced an emotional breakdown. I didn't know where to go and felt that I was making irrevocable mistakes, no matter what I did. It was at this time that my mother, influenced by her own psychotherapist, instigated putting me in a psychiatric institution against my will.

Imagine: as a young woman, I was struggling with my self-determination in a world that was trying to accept women's freedom. Now, instead of making self-affirming choices, I was required to act passive again, to revert to my childhood role of giving others what they wanted from me. Not only that but nothing I did could please those in authority or escape what they wanted to do to me, which was aggression: they insisted that I take a drug that I knew would change my soul, split my personality and change me forever. Something in me gave up and it would be a long, maybe lifelong process to heal that despair.

I saw a woman put in a straitjacket for refusing to take the drugs. Somehow I had already known that this would be the consequence. I was scared that I would die, and at one point I went into a short-term coma from an overdose of the drug. When I got out of the institution, I quickly got my own apartment and tried to resume my life. Whatever else I did, something in me remained empty and anguished. I have succeeded in doing many things. Yet because of this experience it's hard to measure my life from an internal perspective. Instead, I have to prove my worth by showing my external accomplishments.

I am telling this story because I think it shows something about the intersecting discrimination related to gender and to disability. It was oppression I faced as a girl and young woman that led to an emotional crisis, and oppression my mother faced as a woman that led to her putting me away so violently.

The psychiatric regime reinforced messages of oppression that affected me in ways related to my gender. When I got out, I still had to face gender oppression. I often felt disempowered from dealing with it effectively.

Women's lives do not always tell a story of triumph. Sometimes our stories are of how to accept where we have been and still affirm life and possibility. The ideal of individual triumph may be a reflection of, or desire for, privilege – male privilege, racial and class privilege. Yet, self-determination, experiencing and seeking to fulfill one's own aspirations, should not be a privilege, but a right for all. This is the understanding we have come to in the movement of users and survivors of psychiatry, advocating our human rights.

## B. Additional issues for women as users or survivors of psychiatry

1. Women are twice as likely as men to receive electroshock. Electroshock is an even greater assault than drugs, because it can cause irreversible memory loss and more extensive brain damage. Electroshock has been used by husbands and male psychiatrists to punish women for self-assertion and to brainwash a woman into being a more docile mate. It is especially ironic that women's memories are being eradicated, when so many are struggling to recover memories of childhood sexual abuse.

2. Girls and women often hold inferior places in their families, making it easier for husbands,

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<sup>1</sup> This is a print of a presentation made by Ms Tina Minkowitz, Joint Chairperson, World Network of Users and Survivors of Psychiatry (WNUSP), at a recent Cairo conference on "Women with Disabilities". Tina Minkowitz is also one of the leading spokespersons for the International Disability Caucus at the UN Disability Convention. In this article, Tina Minkowitz lays out the major lobbying points of the user / survivors of psychiatry with respect to the UN Convention.



parents, or adult children to accuse her of mental illness and have her institutionalized and deprived of civil rights. In one situation I know of, an abusive husband who had friends in the police department told them that his wife was mentally ill because she was cutting down a tree with a chain saw. The woman, a member of an organization that I also belonged to, knew how to use a chain saw and the tree was blocking her view. The police came into her home while she was taking a shower, and male officers forced her to come out and dress as they watched, before taking her away. This happened only a few years ago, in the United States. I have also heard of male relatives putting women under guardianship because they want the woman's property.

**3. Women who are mothers at the time they are put into a psychiatric institution risk losing their children.** I have known many women who lost their children in this way, and only one who succeeded in getting them back.

**4. Girls and women in any kind of institution are likely to be survivors of gender-related violence,** according to Laura Prescott of Sister Witness International. Many women who were admitted voluntarily or against their will to psychiatric institutions have found solidarity with other women there who shared similar experiences of rape and incest. This has led to "trauma initiatives" designed to minimize retraumatization of women entering the psychiatric system, by substituting non-violent interactions instead of violent repression of women's pain and distress. Women who self-injure as a way of coping with trauma have also challenged a one-sided view of this behavior as a psychiatric symptom, and should be listened to as the experts on their own lives.

**5. Forced psychiatric procedures can prevent women from defending**

ourselves against violence. The use of restraints that prevent women from fighting back or closing their legs (such as four point restraint in which each arm and leg is tied to a separate corner of the bed) facilitates rape. Two electroshock survivors have told me that after the shock they were unable to resist rape but instead cooperated passively. Neuroleptic drugs may have a similar effect since they are acknowledged to cause "psychic apathy and indifference." In locked wards where women are held together with men, this also enables rape.

### **C. Analytical human rights perspective**

For women who are users and survivors of psychiatry, the exclusion we face as a matter of law, because of our disability status, is of the highest concern. It is useful to look at the intersection of disability and gender discrimination, but our priority in human rights advocacy is to eliminate the disability-based exclusions.

#### **1. Legal capacity**

Legal capacity is what a human being can do in the context of a legal system. It includes such acts as testifying in court, voting, serving on a jury, entering into contracts, making financial and health care decisions. Legal capacity can affect every aspect of a person's life, yet it has historically excluded women and continues to exclude many people with disabilities.

CEDAW Article 15 guarantees to women a legal capacity identical to that of men, and nullifies any private agreements to restrict women's legal capacity. This has been amplified by CEDAW General Recommendation No. 21, which emphasizes the importance of legal capacity for women's autonomy within families and equality in society, as well as being able to provide for oneself and one's children.

Autonomy is especially important for women with disabilities, since we face paternalism on both counts.

At the same time, we recognize that some of us may need support in exercising legal capacity. Some people may not be able to access information, come to a decision, or express their will and preferences independently. In the UN Disability Convention we want to recognize the full legal capacity of people with disabilities to make our own decisions, and to ensure support for those who need it, so that everyone is included and can enjoy the self-authority that is so important to leading a full life. Safeguards are provided for to ensure that support is not subverted to exploit a person or do something against his or her will. This provision in the UN Disability Convention, if our text is accepted, will remedy the exclusion that women with disabilities have faced from our rights under CEDAW, and extend the same rights also to men with disabilities.

#### **2. Forced interventions are torture**

Analysis of the international definition of torture shows that forced drugging and electroshock, and related



assaults in psychiatry, should be considered torture. While the distinction between torture and lesser forms of cruel, inhuman or degrading treatment or punishment does not always need to be emphasized, we believe that such practices meet the higher threshold for torture.

In particular, forced psychiatric procedures are intentionally inflicted with the knowledge that they are likely to cause serious harm, ignoring the will of the victim. Psychiatric professional literature is rife with information about the brain-

damaging effects of neuroleptic drugs and electroshock, but these types of harm are either considered desirable for people labeled with mental illness, or they are considered of less importance than the objective of curing the so-called illness – even if the person does not want to be “cured” in this way. This amounts to dehumanization of the victim by seeing her entirely in terms of the disability she is perceived to have, which is given an exaggerated importance to the exclusion of all else, including her own will and desires. Pursuing a harmful end against a person’s will, for reasons based on disability, constitutes discrimination, which is a relevant purpose of torture under the UN Convention Against Torture. In addition, forced psychiatric procedures are inflicted for the purpose of coercion – enforcing a change in the person’s behavior or consciousness against her will, and by the use of methods that prevent her from resisting. Coercion is also a relevant purpose of torture in the Convention Against Torture. The definition also requires acquiescence by a public official, which exists when forced procedures are done in a government-run institution, or when laws authorize or fail to protect against such practices.

The Convention Against Torture can be used even now to advocate for an end to forced interventions and for reparations to victims, while also working for specific provisions in the UN Disability Convention.

Nonconsensual medical interventions should be declared to be torture or cruel, inhuman or degrading treatment or punishment, similarly to nonconsensual medical experimentation. There is also a specific provision prohibiting forced institutionalization or forced interventions related to an actual or perceived impairment. It is crucial to delete provisions in the current text that would allow medical or psychiatric interventions against a

person’s will. If those provisions remain, the Convention would be anti-human rights and should not be accepted by the disability community.

### **3. Equal right to liberty**

Deprivation of liberty is degrading to the person and confers an inferior status. Often it also entails restriction of legal capacity and civil rights. While deprivation of liberty is not prohibited absolutely in international law, it is undeniably a harmful act without benefit to the incarcerated person. Human rights law requires that deprivation of liberty not be arbitrary, unlawful or discriminate in any way.

Mental health laws allowing forced institutionalization exist in most countries. Such laws discriminate based on disability and do not serve any legitimate social purpose. People who commit crimes can be dealt with by law enforcement, with relevant rights and guarantees, and reasonable accommodation for disability. People who are merely annoying to others, or who are harming themselves, should not be punished or deprived of rights.

In some countries, there are no laws regulating deprivation of liberty in psychiatric institutions, but the practice exists without any legal regulation. Often people are incarcerated based solely on the will of their families, and not released unless the family is willing to take them back.

We want the Disability Convention to prohibit deprivation of liberty based on disability, to make sure that forced institutionalization is ended.

### **4. Include people with psychosocial disabilities in definition of “disability” or “person with a disability”**

Psychic distress or difficulty can be a disabling experience, especially within a social context where it is not well understood or accommo-

dated. In addition, being labeled with mental illness, institutionalized, and victimized by forced interventions is a radical life experience that changes a person’s way of seeing the world. World Network of Users and Survivors of Psychiatry brings together people with diverse first-hand experience of madness or mental health problems, or who have used or survived the mental health system. We use the term “people with psychosocial disabilities” to identify ourselves in international disability and human rights work.

It is important for people with psychosocial disabilities to be covered by the Disability Convention, and to be included in national disability legislations, and in umbrella coalitions of people with disabilities. In many countries there is resistance to our inclusion, despite the fact that we are already covered by the Standard Rules and participate in the panel of experts advising the Special Rapporteur on Disability. For this reason, we are advocating that there be a definition of “disability” or “person with a disability” in the Convention, which should include psychosocial disability within an overall social model of disability, and should also include imputed disability to cover those who are labeled by others.

### **Conclusion**

This presentation has given an introduction to some issues facing women who are users and survivors of psychiatry. I hope that we will have a chance to talk more as women with disabilities and explore our commonalities and our differences, and dialogue about our human rights.



## Erwadi Memorial Day, Maharashtra

### *A human rights day for persons with psychiatric disabilities*

**Jan Manasik Arogya Abhiyan**, a people's campaign in mental health in Maharashtra, co-ordinated by the Bapu Trust, is proposing to dedicate August 6<sup>th</sup> as the Erwadi Memorial Day and a human rights day for persons with psychiatric disabilities.

On August 6th, 2001, 25 people labelled as 'mentally ill' in the Badhusa mental home in Erwadi, Ramanathapuram, Madurai District, Tamil Nadu, perished in a fire. The Erwadi holocaust caused a lot of public outrage and became a tragedy of national scope. The tragedy highlighted the dire conditions under which many persons with psychiatric disabilities are treated in our country.

In the Indian history of human rights activism, this event stands as a landmark event. For the first time, newspapers, professionals, NGOs, the state government, the Supreme Court, the National Human Rights Commission, human rights activists and lawyers, all made immediate responses. For the first time, the Human Rights machinery in the country was activated in the interests of persons with psychiatric disabilities. The event brought national focus and set up a human rights and policy debate in the country, which still continues. The event has had its impact on Maharashtra also. This is why we are seeing this day as an eventful day, which must be commemorated.

In April, 2000, diarrhea deaths were reported at Erwadi. Recommendations made, following this, included provisions for a ward at the district hospitals in Tamil Nadu, training programmes for doctors, paramedical staff and for NGOs. On the 6<sup>th</sup> August, 2001, the hutments in which the inmates were housed, chained to their beds, caught fire.

11 women and 14 men died when the fire broke out early in the morning. In all, 43 persons were kept there. 3 persons died later in the hospital. "Compensation" was given to the family members, who had dumped their mentally ill relatives in these places. A swarm of brokers encamped in these places, soliciting customers who were willing to relieve themselves of their relatives for a meager fee. According to earlier investigations in this area, the conditions in the majority of the asylums were deplorable. No proper rehabilitation was offered. Mostly untrained workers were employed to take custody and the "treatment" always included physical torture. The government responded to this tragedy by starting more psychiatric hospitals in Tamil Nadu and establishing a district mental health program.

Following the Erwadi tragedy, the Supreme Court, in 2001, started a *suo moto* law suit against all the state governments of India for non-implementation of the Mental Health Act. In the meantime, an NGO filed a petition raising some pertinent human rights issues, such as solitary confinement, direct ECT, physical restraint, etc. The SC asked every state to comment on these issues.

Rs. 190 crores was released by the Health Government, GOI, to strengthen the mental health sector in the country, as part of the Tenth Five Year Plan. The monies are to be used mainly to improve the infrastructure, strengthen the psychiatry departments, including medical education. Very little resources have been allocated for community mental health work. Even though the SC case was a human rights petition, the government response has not addressed the rights issues at all.

The state of Maharashtra has also filed an affidavit before the supreme court, giving information about facilities available, use of ECT, traditional healing places, etc. Monies have been released to the GoM to strengthen the mental health sector.

There are two immediate and relevant issues for us in the context of Maharashtra.

1) What finances were released to the state of Maharashtra for strengthening the mental health sector, and how is this money being spent? Does the government of Maharashtra envisage a state level policy for strengthening the mental health sector? Or is the money going to be spent in an ad hoc manner, or diverted to other causes?

2) What information has been submitted by the state of Maharashtra, before the Supreme Court, and what is the authenticity of this information? For example, in Maharashtra, direct ECT is still being practiced, despite a High Court judgement restricting the procedure. What is the position of the GoM on the human rights of persons with psychiatric disabilities, and their rehabilitation?

Maharashtra has a total of 4 state run mental hospitals. The total bed strength is 5695 in the 4 mental hospitals, which is one fourth the entire bed strength of mental hospitals in India. Long stay patients (who have stayed for more than 2 years) is the greatest in Maharashtra, indicating that these facilities are perceived as dumping grounds by the communities.

In the Thane mental hospitals, the NHRC found that all the wards were locked wards. Most of the wards are overcrowded. Only 10% admissions

are voluntary admissions. All others are involuntary court ordered commitments. 26% of patients are "long stay", who have been there for five or more years. Facilities for medical emergencies are poor. The hospital does not have a casualty and emergency service. There is no short stay ward or half way home. Patients reported that bathing facilities are not adequate and clothes are dehumanizing, as they are not changed as frequently as they would like. Although the quantity of food may be adequate, it is not sufficient in terms of nutritive value. Management of patients is mainly medical, with the use of drugs and modified ECTs. Solitary confinement is being used. Patients complained that they were not being able to contact family members. There is hardly any psychosocial intervention. The occupational therapists have had no training in dealing with psychiatric conditions. Very few patients attend these facilities.

The situation is more or less the same in the other hospitals as well- Pune, Nagpur and Ratnagiri. In the Pune mental hospital, both direct and modified ECT are being used. Physical restraint and solitary confinement are being used. The occupational therapists have had no training in dealing with psychiatric conditions. Very few patients attend these facilities. Newer drugs are not available. In Nagpur, only 14% are voluntary admissions, the rest being court ordered. Direct ECTs are administered in OPD. Modified ECT is being given only to the inpatients.

There is a huge deficit of human resources in Maharashtra, as in the rest of India. For a population of approx. 10 crores, with a case load of 1% severe cases and another 10% of common mental health problems, there are only 6073 beds in the government sector, and another meager 652 beds in the private sector. There are only 481 registered psychiatrists, 75% of

them being in the private sector. Only 33 clinical psychologists are available as against an ideal number of 484. So also, there is 90% deficit of psychiatric social workers.

In 1996, a blue print for the DMHP (District Mental Health Program) was made for India. The models developed in the state of Karnataka, by NIMHANS, were proposed to be replicated everywhere. In Maharashtra, there are 6 DMHP programs running, of which the one in Raigad district is the oldest. These programs have not been evaluated. The quality of services in these programs is very poor, being limited to drug dispensing at the community level. Psychosocial interventions are absent in all of the DMHPs dotting the country, and also in Maharashtra. Over half of Maharashtra is not covered by the DMHP.

On Erwadi Day, we demand transparency and accountability from the state of Maharashtra Health department, on some of these concerns. We will debate about the need for a state level mental health policy document, in which all stake holders in the mental health sector will be consulted.

JMAA will also challenge the silence of the Disability department, Maharashtra, on the plight of persons with psychiatric disabilities. The PWDA promises the Rights to education, employment (sec 47), social security; rehabilitation, unemployment allowance, special concessions and other rights. The right to education under the Act includes, access to free education till 18 years, the integration of PWD in normal schools, setting up special schools for those who need them, schools with vocational training facilities, schemes for non-formal education, teachers' training institutions, etc. Various employment rights provisions have been made in the PWDA for persons with disabilities, including 3% reservation in jobs, flexible working conditions,

social security (insurance, unemployment allowance), preferential allotment of land and job security.

Recently a Maharashtra High Court Bench headed by Justice AP Shah had given a judgement in which a nurse, Mrs Desai, was reinstated in service after being summarily dismissed following a diagnosis of schizophrenia.

This was a wake up call for the Maharashtra Disability Department. One more time, it was proved that the law has to come in for the bureaucracy to function in the mental health sector. The Disability Department of Maharashtra has not at all recognized the plight of persons with psychiatric disabilities. Schemes available to other disabilities have not been opened up for this constituency. Obtaining a disability certificate is an insurmountable task. The certificate format is not suited to persons with psychiatric disability. The disability office is even known for its corrupt practices. Complaints are not settled for years together. Mental health agencies are not represented in the State level co-ordinating committee of the state level disability commission.

On this day, a range of activities will be undertaken by the people's forum, which will waken the state of Maharashtra to the plight of persons with psychiatric disabilities. A 2 day photo exhibition presented for the occasion by Anjali, Kolkatta, and panel discussions on the theme of "Status of mental health services in Maharashtra" is being planned. This will be held at the Balagandharv Kaladalan, Pune, on 6<sup>th</sup> & 7<sup>th</sup> of August. For details, contact [bapustrust.mumbai@gmail.com](mailto:bapustrust.mumbai@gmail.com); [wamhc@vsnl.net](mailto:wamhc@vsnl.net)

The proposal to commemorate Erwadi Day every year needs to be considered nationally.





## Music Therapy: A research review

■ **Ketki Ranade**

Arts Therapy Treatments offer clients therapy primarily through non-verbal means and using art forms such as music, art, drama or dance movement. The Association of Professional Music Therapists describes music therapy as a “framework in which mutual relationship is set up between client and therapist. The growing relationship enables change to occur; both in the condition of the client and in the form that the therapy takes. The music therapist works with a variety of clients of all ages in group and individual settings. Their problems and handicaps may be emotional, physical, mental or psychological in nature. By using music creatively in a clinical setting, the therapist seeks to establish an interaction, a shared musical experience leading to the pursuit of therapeutic goals.”

Music has the propensity to draw people together into a group. Music is made up of simple rhythmic patterns, which provide means for groups of people to play together at the same time. Without reference points (in music) it would be impossible for people to make the necessary anticipatory and planned adjustments to bring their behaviour into coordination with others and thus make musical behaviour the structured social phenomenon.

Music can make sense to people where other forms of communication cannot be understood. Music can be an immediate form of expression where words cannot be found or may seem too dangerous. Music therapy works on the assumption that music can be used by anyone, with any level of disability.

Music so closely correlates with body rhythms, intonation and mobility of emotions that it provides

a unique interface between sensations provoked in the mind and other neurological events. Music can function to bypass other areas of the brain which may be damaged or make links to underdeveloped areas; it organizes many disparate events in a global way. Here research evidence is presented.

The efficacy of music therapy has been investigated with individuals with a wide range of disabilities, for example: autism (Wager, 2000), dementia (Korb, 1997), acute brain injury (Nayak et al., 2000), Parkinson's disease (Pacchetti et al., 2000), Alzheimer's disease (Aldridge, 1998), attachment disorder (Brotons & Pickett-Cooper, 1996; Burkhardt-Mramor, 1996), chronic schizophrenia (Zhang & Cuie, 1997), depression (Suzuki, 1998), and multiple sclerosis (Davis, 1998). The positive outcomes reported in the majority of these studies suggest that it is an efficacious treatment.

Clinical evidence shows that arts therapies reduce symptoms such as depression and anxiety (Odell-Miller 1995b; John 1992; Davies 1995)

Dr. Connie Tomaino, director of the Department of Music Therapy, Institute for Music and Neurological Function in Bronx, New York, discovered that when people with irregular or weak brain rhythms, such as individuals with Alzheimer's disease, listened to music with strong rhythms, their brainwaves became more organized, pronounced and higher in frequency.

Trevarthen and Malloch (2000) shows how as the earliest parent-infant communications cannot rely upon linguistic meaning, communication takes place through the use of expressive sounds or 'the prosody of the infant-directed

speech', together with facial and gestural movements. Music therapists have adapted these intuitively improvised and non-verbal methods of communication for expressive and therapeutic ends.

Pacchetti et al., (2000) studied the impact of weekly choral singing, voice exercises, and rhythmic and free body movements were used with a group of 16 individuals diagnosed with Parkinson's disease. Improvements were subsequently noted in their emotional functions, daily living and quality of life.

Other demonstrated benefits are in: social interactions, mood and participation rates of people with traumatic brain injury and stroke (Nayak et al., 2000); emotional states of persons with schizophrenia (Zhang & Cuie, 1997); agitation in Alzheimer's clients (Brotons & Pickett-Cooper, 1996), and depression in elderly (Suzuki, 1998).

Meta-analysis of music therapy as an intervention with 335 dementia patients, demonstrated significant results (Koger, Chapin, & Brotons, 1999).

A review of clinical music therapy (see Tervo, 2001) showed that rock music can give adolescents “the possibility to express, be in contact with and share among themselves feelings of anger, rage, grief, longing and psychological disintegration”.

Burkhardt-Mramor (1996) reported that insight-oriented music psychotherapy addressed the attachment problems of an 11-year old male with a history of physical and emotional abuse.

Krueger (2000) incorporated the use of information technology with a 10<sup>th</sup> grade student with behavioural

problems, to allow him to “eventually be able to focus on music making for 45 minute periods”.

Wager (2000) found music therapy was a “valuable on-going leisure activity” for a 36-year-old male with autism and mental retardation.

Davis (1998) reported that music therapy created closer family bonds and improved psychosocial and spiritual well-being for a 48-year-old male with multiple sclerosis.

Studies also reveal that musical activities are beneficial to therapeutic communities.

Robert Lawrence Friedman, a leading drum therapist and author of *The Healing Power of the Drum*, has done extensive work with drumming as a healing tool. He has worked with couples having relationship difficulties and used drumming as a means for them to become more synchronized with their personal rhythms. Drumming is a nonverbal way for people to communicate in a positive and healing way.

Tang et al (1994) in his study with people with schizophrenia shows that music therapy cut down negative symptoms, increased the ability to converse with others, and an increase in outside events was shown as a result of a randomized trial over a period of one month.

Reker (1991) described the impact of music therapy on 30 patients diagnosed with schizophrenia. The subjective evaluation and rating of the music therapy was registered using a specially developed questionnaire. The primary results are: Music therapy has a high level of subjective acceptance among patients. No negative effects are recorded despite the therapy being introduced in the post-acute phase. The positive therapeutic effects quoted are

relaxation, activation, reduced anxiety, easier contact making, and improve opportunities for emotional expression. The duration of the effects is limited. The training-related concept and the clearly structuring behavior of the group leader are given a positive rating by the patients.

W. Tang, X. Yao, and Z. Zheng (1994) compared music therapy with classical treatment for schizophrenia. Music therapy significantly diminished patients’ negative symptoms, increased their ability to converse with others, reduced their social isolation, and increased their level of interest in external events.

Music therapy goals for Schizophrenia symptoms may include:

1. Re-establish client with reality
2. Draw client away from delusions and hallucinations
3. Open communication with people around client
4. Identify and express emotions
5. Reduce stress and anxiety
6. Control aggressive and destructive impulses
7. Learn adaptive behaviour patterns, which allow client to function normally in society

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## Resources in Mental Health

**Eva Edelman, "Natural healing for Schizophrenia and other common mental disorders." III Edition. 2001. Borage Books.**



Those who practise holistic medicine are of the firm belief, that one day schizophrenia will be more fully understood in terms of body metabolism and nutrition. Medical evidence over the past 50 years or so, starting with the works of Abram Hoffer, suggests that schizophrenia may not be a "brain disorder". It may not be a purely psychological event, but a metabolic event with bio-psychological "hues". Schizophrenia may be a reflection of the deficiency of certain essential nutrients (vitamins, fats and proteins) necessary for optimum brain function.

Edelman's classic book is a comprehensive review and presentation of this literature, linking food and psychiatry. The classic orthomolecular psychiatric materials, and new evidence from integrative psychiatry, are presented with interesting examples and recommendations for clinical practice.

For example, the brain needs an adequate supply of sugars for its work. Low blood sugar interferes with emotional balance, mental clarity and perception, causing schizophrenia like experiences, depression and explosive rage. In a remote village in Central America, most of the men of the Quolla tribe of the Andes are in some way or the other involved with violence and crime. They have been called the

most violent people in the world. These behaviours must definitely have resulted in poor relationships and increased domestic violence. The incidence of homicides, assault, rape, robbery and arson are the highest. Their diet is very low in sugars. Researchers working with them determined that the lower their blood sugar, the greater was the extent of their hostility. It has been suggested that the tendency to emotional disturbance and the resulting violence may be associated with associated adrenalin rushes, which increases the amount of sugar available to the blood and the brain.

Naturally, from this understanding, eating the right kind of food or taking the right kind of supplements may cure a class of people with a primary diagnosis of schizophrenia, of the disturbing symptoms. Clinical trials with Vitamin B3 supplements in mental hospitals in the US have shown a 10% recovery among patients.

This perspective is very relevant for India, where malnutrition linked to poverty is very high. The link between poverty and schizophrenia has been well known. However, before we fully psychiatrise the poor by supplying them with antipsychotic drugs, a thorough evaluation is necessary to rule out nutritional deficits and the resulting health compromises.

Equally, the shift from locally available foods and culturally ingrained food habits to readily available, mass produced and culturally blind, processed or engineered foods results in malnutrition among all class groups. For example, when American sweet

corn was introduced into Europe for mass consumption, people suffered and even died of pellagra.

Nutritional cures offer many benefits over conventional psychiatric care for schizophrenia, as Edelman enlists.

**a)** The cure leads to overall nutritional correction and well being.

**b)** Nutritional correction does not cause harm. Overdosing with natural treatments is rare. Even when it occurs, it is reversible.

**c)** Research has shown that 90% of acute patients recover, and the chances of recovery are good for the remaining 10%. The 30% “life long” or “chronic” patients that psychiatry has produced do not hold for nutritional treatments, according to Edelman.

**d)** The quality of life of persons treated naturally is better. Particularly, their level of social participation is high.

**e)** The mode of treatment is co-operative, as natural treatments are not stigmatising and patient resistance is low.

**f)** Nutritional treatments may also help to enhance the effects or minimise the side effects of conventional psychiatric treatments.

Eva Edelman’s book also reviews a vast plethora of nutritional basis of medical and psychiatric diagnosis, along with physiology. The role of essential fatty acids (Omega-3 and Omega-6), vitamins (B, C and E) and micro-nutrients (such as selenium and sodium) are being studied, with good results. Interesting mental health information about various essential nutrients can be obtained from this book. For example, Vitamin C works as an anti-psychotic agent and is a natural tranquilliser. It is as powerful in action but it doesn’t cause the harmful side effects of drugs. Vitamin B12 helps in

producing neurotransmitters and its deficiency may cause permanent nerve damage. Vitamin E has been used as nutritional supplement in treating schizophrenia. Vitamin B2 deficiency has been associated with tremors, depression, fatigue, moodiness, irritability, compulsive eating, hysteria, nerve damage, and sometimes psychoses. It enhances brain circulation, increases concentration and memory span, lightens moods and depression. EFA (Essential Fatty Acids) deficiency is a condition present in 2 out of 3 cases of schizophrenia. EFA is essential for developing the cell membrane and other structures within the brain. EFAs are sometimes also known as Omega 3 and Omega 6. The imbalance of minerals, such as Selenium, Calcium, Copper, Magnesium, Sodium and Potassium may also cause frank psychosis. Imbalance of amino acids and metal toxicity (lead, cadmium and mercury) may also cause psychotic symptoms. Sources of food and supplements are also given in the book, though this may apply mainly to western contexts.

The DSM (Diagnostic and Statistical Manual) does detail the metabolic and health related criteria which must first be ruled out by the physician before coming up with a psychiatric diagnosis. It will be heard again and again in the Indian professional circles that “this information is not new” and “it is all there in the DSM”. However, in practice, the prescribed diagnostic rules are not followed. As a result, misdiagnosis is rampant. A common list of evaluative techniques given by Edelman includes:

- ▶ Dietary history and nutritional status
- ▶ Basophil count (to rule out histamine deficiency)
- ▶ Syphilis

- ▶ Thyroid / endocrine status
- ▶ Glucose Tolerance Test / HbA1c
- ▶ Allergies and toxicity (Lead, cadmium and mercury)
- ▶ Use of street drugs
- ▶ Kidney, liver function tests
- ▶ Rule out pyroluria and porphyria
- ▶ Drug interactional effects (e.g. cancer agents, pain and malaria medicines)

The cost factor has to be taken into account in prescribing diagnostic tests. However, clinical diagnostic finesse and multi disciplinary work (involving nutritionists also) will go a long way in preventing psychiatric misdiagnosis. The costs of taking life long psychiatric drugs versus the costs of nutritional / health evaluations, along with the costs of improved or diminished quality of life and productivity, must be considered all together.

Repeated hospitalisation, a long history of psychiatric treatment, present psychiatric crisis, a high level of family problems, overall familial or community neglect of health, poor environment, the lack of nutritional services, the lack of nutritional diagnostic facilities, conflict and the widespread socio economic deprivation may be barriers to accessing this type of care. Also in the Indian context, nutritionists tuned into mental health problems are only recently coming into the forefront of mental health work.



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## The Bill of Rights Conference, Bangalore

NAAJMI (National Alliance for Access to Justice for Persons with Mental Illness) is a forum initiated and established by Ratnaboli Ray (Anjali, Kolkatta) and Bhargavi Davar (Bapu Trust, Pune), supported by the Law For All Initiative, of the Ashoka (Innovators for the Public), a private foundation supporting the work of social entrepreneurs. The first BoR consultation happened in Kolkatta, reported in an earlier issue of *aaina*. In this meeting 3 regional and 1 national multi-stakeholder consultations were proposed, to finalise a Bill or Charter of Rights for persons with psychosocial disability for national advocacy purposes. This report carries news from the 2nd consultation of NAAJMI held at the United Theological Seminary, in Bangalore, June 2006.

The process of dialogue and learning, through the consultations was reiterated as an important objective of “NAAJMI”, and not just the output (of a Bill of Rights). The dialogue process is central in mental health advocacy work, as there is a need to articulate dilemmas and controversies, and resolve the extreme division, which exists in the mental health sector.

Around 20 people participated in this round of consultations from the southern region, including psychologists, psychiatric social workers, counsellors, rehabilitation professionals, carers, human rights activists, doctors and mental health advocates.

Even though many international instruments existed it was important for a local discussion on what rights should be considered and accepted by the mental health community. This will allow everyone to understand, process and internalise the rights discourse in the mental health sector. We have to “rediscover the wheel in our own way” as each

region brought its own “flavour” to the discussion.

Each session proposed a panel discussion on a particular theme, and speakers were enjoined to speak about their view of rights, drawing from their own services. From these presentations, a list of rights was drawn up. The group brainstormed on the written text of the rights thus compiled, and worked around controversies. For example, consent, the clinical experience of “lack of insight” and the need to create imaginative solutions to respectfully intervene were discussed vis a vis coercive treatment.

The list of human rights enumerated by the group were as follows:

### 1. Right to inclusion

- Inclusion in disability
- Entitlements across sector for persons with psycho social disabilities
- Right to form support groups and associations
- Right to inclusion in any development process
- Right to life free from Stigma and discrimination in all walks of life
- Right to dignity
- Right to find inclusion in mainstream life

### 2. Right to information

- Relating to policy and law
- Services , resources structure
- All types of treatment
- Consent in medical non medical research

### 3. Right to life

- Right to violence free environment
- Right to bodily integrity

### 4. Right to food security

- Right to nutritious food

### 5. Right to policital participation

- Right to vote and contest elections

- Right to hold public office
- Right to be a member of statutory bodies: state national level committees MHA

### 6. Right to Liberty

- Minimise involuntary treatment and maximize participation
- Right to least restrictive environment
- Right to free movement

### 7. Right to livelihood

- Right to poverty alleviation and employment
- Right to free vocational and skills training
- Right to entrepreneurship and alternative employment
- Right to equal wages as any one else

### 8. Right to integrated, quality mental health care

- Right to rational, affordable and accessible medication
- Right to non drug approaches, addressing well being and not just symptom reduction
- Right to quality health care
- Right to information about diagnosis, prescriptions and treatment – both medical and non-medical
- Right to early psychosocial intervention for esp. children and young adults
- Right to have different means and services in the community including bare foot workers
- Right to quality time
- Right to privacy
- Right to standardized comprehensive and multi- axial assessment and care
- Right to continuity in care
- Right to socially and technically audited system of care
- Right to non-hierarchical and non abusive forms of care
- Right to be respected
- Right to confidentiality
- Right to dignified treatment

- Right to decide who is one's family/support system

### **9. Right to self determination**

- Right to Family, love, relationships
- Right to positive identity construction
- Right to choose treatments
- Right to consent to treatment-medical/nonmedical
- Right to refuse treatment- medical/non medical
- Right to autonomy

### **10. Right to Inclusion in Law & Policy Making**

- Right to legal aid
- Right to grievances redressal
- Right to participation in review of acts and rules relating to mental health

- Right to laws which enable rehabilitation
- Right to inclusion in all statutory decision making bodies
- Right to be recognized as equal before law
- Right to necessary assistance
- Right to simplified procedures in accessing justice

### **11. Right to Well Being**

- Right to Health
- Right to Play, recreation and leisure activities
- Right to participate in social, cultural and community life
- Right to well being at all 3 levels-preventive, promotional and curative
- Right to self understanding, self care and self growth
- Right to routine, recognition and

resilience

- The role played by care givers to be recognized

### **12. Right to socio economic security**

- Housing
- Insurance
- Property

### **13. Right to education**

- Right to continuing free education beyond the age of 18
- Right to non discrimination in all educational settings

### **14. Right to rehabilitation**

- Right to non custodial care
- Right to safe environments



## **Lobbying materials created for the United Nations 8 Ad Hoc Committee Meeting**

Tina Minkowitz and Amita Dhanda, representing the World Network of Users and Survivors of Psychiatry, compiled a set of 17 first person testimonies to be presented at the 8<sup>th</sup> Ad Hoc Committee Meeting in New York in August this year. The testimonies come from around the world and are focused on experiences relating to forced treatment and legal capacity.

"We have often been told that informed law making requires information on the subject of the law. Even as the law engages with the lives of persons with psychosocial disability it is an involvement which is informed with voices of the non disabled world and presumes on the silence of disability. We believe that unless this silence is broken it would be difficult to obtain an informed, empathetic and empowering legal regime for persons with psychosocial disability. Therefore a few of us, from different parts of the world, in order to share and inform, have put down our real life experiences.

Through these real life narratives we want people to know the reality of what our lives are like. It is a complex reality and each person's story shows how others intervened at crucial points in harmful ways. Some people also show what supported them or how they found the strength to reject messages of inferiority and oppression. The point is that we are experiencing and conscious at every stage, we know what is being done to us and we don't like it. And we are struggling against something that is both irrational and absolute tyranny. The social power given to psychiatry creates a catch-22 situation where there is no way to fight for our rights successfully unless we break out of the tyranny.

A battle made all the more difficult by the fact that similar to rape and other gender-based violence, there is a social stigma attached to psychiatric assault and talking publicly about what has happened to us. It ends up re-victimizing us. When there is no social context in which to talk about it, or even if there is only a limited social context (such as psychiatric survivor groups) the trauma stays within a person.

The discourse of the normal requires to create the abnormal. We do think there is need to break out of these forced divides and to appreciate and celebrate humanity in its manifold diversity. We are with these narratives wanting to share with you the different ways of thinking, feeling, believing and healing. This diversity we hope will cause us to appreciate the difference between uniformity and equality. Let the Convention on Disability Rights guarantee equality of respect and dignity to all of us by outlawing force and coercion, and providing to all of us the opportunity of developing our capabilities according to our own genius". Tina Minkowitz & Amita Dhanda

The full text can be viewed and downloaded from [www.wnusp.org](http://www.wnusp.org) and [www.camhindia.org](http://www.camhindia.org) websites soon. The materials were produced for the WNUSP by the Bapu Trust, Pune, a member organization.

## Useful links

We summarise here a fascinating exchange of facts, ideas and speculations among experts on the *Integrative Psychiatry Yahoo e-group*, on schizophrenia.

### **Hearing voices**

A survey done around 1987 found that approximately 60-70% of people in general hear voices with some regularity. Some people hear voices all the time, but are not schizophrenic. It has been a “way of life” for them. They develop strategies about voices, such as focusing in and out of them. Almost everyone would have at least “one little voice in their head”. This is a normal process, that some are not able to deal with or control very well.

Various metabolic/drug/nutritional/toxic events makes one more susceptible to such experiences. By addressing these factors, one’s ability to function improves or normalizes. Some communities such as Native Americans, (this is true in India also) have “spirit walks” and “vision quests”, where they see visions and hear voices. These are not to be treated unless they are experienced as distressing.

Clinicians treat voices as top priority and address it right away. Not everyone may want the voice to go away, or find it distressing. Some patients may ask to be rid of the voices. “Voice” treatment has included the following strategies: (1) Using energy medicine techniques (Bio feedback, Auditory Brain Wave Training), identify the source and the meaning of the voices (2) Encourage the person to get rid of the voices right away: encourage them to find the body and the face that goes with the voices and to stand up to the voices and start a dialogue (3) Always ask if the voice bothers them. Some of the voices may be encouraging and may be keeping the person company. (4) Treat command hallucinations that may result in self harm or harm of others (5) (In culturally appropriate settings) the person is told that negative spirits want to cause them great harm and ultimately kill them. This makes the voices ego-dystonic and the patient stops listening to the voices. (6) Fish oil, vitamins (niacin, vitamin C, vitamin E) and Omega 3, the latter being particularly helpful in stopping the voices (7) Treatment for allergies such as gluten allergy (found in wheat). (8) Diagnosing mineral toxicity especially copper toxicity. (9) The voice may reflect psychodynamic conflicts. Resolve the conflicts, and the voice may go away. (10) Small and timely doses of neuroleptics. An expert wrote, “It’s sad that we make up labels and reify them, like “hearing voices.” It keeps us from unpacking the label and asking which voices, which contexts, what do they say, is it comforting or disturbing, does it improve your life, etc.”

How does the clinician make a distinction between a spiritual voice and a non-spiritual or distressing voice? It is widely acknowledged by the experts subscribing to this egroup that meditations and dream states can bring on “higher order” voices. Qualities characterizing such voices are: auditory clarity, accuracy of information, compactness of delivery, high speed, connection with context, helpful and beneficial, rare or momentary, providing wisdom beyond what the person knew. This is perhaps what is in Indian epistemology called “direct knowledge”. In meditation the “good” voices speak. They are protective. “I have heard one voice, it was good. It said it was going to take good care of me, it did. I’m still standing, and I have been through many “battles”. I wouldn’t want to risk blocking out good voices with medications.” In aboriginal (tribal) settings, intuitive and telepathic connection with the animal / spirit / ancestral world is also common. In such cultures, it is completely natural for animals to talk to people and vice versa. “Lower order” voices are characterized by: persistence, lacking in knowledge or wisdom, berating the person, negative content. The “higher order” voices will not respond to physical intervention such as nutrition as they go beyond the mind / brain / body dimensions.

Experts have also said that the diagnosis of schizophrenia is congruent with the diagnosis of delayed trauma or PTSD relating to infant separation. John Nash depicted in “The Beautiful Mind” is supposed to have suffered from delayed PTSD. Apparently, John Nash’s symptoms disappeared with the death of his last parent. In this case, the person returns to the earlier feelings, behaviour, reality, body movements and level of affective expression of the precise time when initially traumatized. Studies have shown that separation from nuclear families (for five years at least) has helped in recovery from schizophrenia.

The members of this group are open in their minds to the idea that those labeled with schizophrenia may be tuning into other realities that are as valid as our observable one, but “not so open that their brains will fall out”. Speculations and experiential validation was rife in the egroup about the existence of god and spirits. A Raja Yoga Meditator and teacher noted point blank, “As for God, I guess that would depend on definition: An Old Man with a white beard, no; but a creative intelligence, yes.”

If you are interested in the links between psychiatry, medicine, nutrition, energy medicine, and other alternative evidence based treatments, join [integrativepsychiatry@yahoogroups.com](mailto:integrativepsychiatry@yahoogroups.com)



## CHALLENGE

When you call me mentally ill,  
I will struggle to develop my will!

I will prove to the world one day,  
I am beyond what you do and say!

I am powerful intelligent and brave,  
For your pity, I will never crave.

Time has come for me to develop,  
Opportunities for my brethren to envelop.

Entrepreneurs, we shall become for sure,  
And hire you people all the more.

Kings and queens in our own domain,  
Nurturing love and harmony, removing pain,

Turning over the tables on you all,  
Proving our own strengths without a fall,

God please give man some sense to believe,  
That we can fight folding our sleeve!

I am born to prove the word EQUALITY!  
Only in your PERCEPTION IS THE DISABILITY !

RATHNA  
8.12.2005

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.