aaina

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Editorial

In the last few months, two of our user friends "disappeared". Upon contacting the families, we were warned not to try to establish contact with them. We were refused information on where they were institutionalized. One friend was isolated and picked up at 5 AM in the morning and forcibly taken to a plush tri-star facility in Bangalore. The physical comforts she got there did not compensate for the lock up and other forced treatments she received. She came away terrified and vivid with the trauma of institutionalisation. Both the private institutions where they were taken, created nearly impossible barriers for us in talking to them over the phone. We were told that the families have prohibited us from meeting them or otherwise getting in touch. Recently, another user whispered to us about how a private institution "kidnaps" patients in vans. He was not aware that there is a law (Mental Health Act) which allows involuntary admissions, without prescribing what is the method for doing this, leaving people to their own imagination on how to 'catch people' and institutionalize them. Another user gave us a full story of her abduction and being kept fully drugged in a private institution [excerpted and presented in Puja Modi's write up] for over a month. It took very determined efforts on her part to get out of there.

In this time, we also heard of Faisal Khan, Aamir's Khan's brother, whose forced treatment got press coverage and some encouraging judicial pronouncements, discussed by Amita Dhanda, in this issue. Kevin Cremin also published his report (excerpted here). Among various other dimensions of mental health service delivery in this comprehensive report, the topic of force brought up significant data. Some service providers, very concerned about choice, started reporting about the serious victimization of women diagnosed with a mental illness within the civil and family courts, also covered here.

The UN Convention on the Rights of Persons with Disabilities [CRPD] was ratified by India and other countries. It comes into force in early May. The CRPD work has really foregrounded user and survivor concerns about forced treatments, involuntary admissions, and the future role of mental hospitals, if any, in the process of recovery. While looking at other more loving alternatives to address crises, we stumbled upon the Soteria project, a well known peer support project. Peter Lehmann and his friends wrote about their project, for this issue. Gitika Talwar too has reviewed a book for this issue, which provides a humane perspective about choice in emergency situations. Finally, we very much look forward to the work of Gábor Gombos, mental health activist from Hungary, to bring his skills and expertise, as well as hope, for the invisible and silent consumers of mental health services, living in India. He shares his life and work with us in this issue.

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aaina a mental health advocacy newsletter

Aaina is a mental health advocacy newsletter.

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

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

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

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

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Reflections

Why are institutions inhumane?

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Let me first introduce myself to the readers of Aaina. I am a survivor of psychiatry who was hospitalized in psychiatric units four times between 1977 and 1991. My mother was also a patient labeled with a diagnosis of a severe mental illness. Unfortunately she did not survive, she died when she was a subject in a clinical drug trial without her consent. She died from a heart failure that might have been a side effect of the medication she was given.

I changed my career in theoretical physics into human rights advocacy after my mother's death. Eleven of us, all users or former users of institution based, often coercive mental health services founded an organisation to help each other and to make our voice heard. In the beginning much of our activities were driven by anger: We were angry with a system of no choice, of force, of disrespect, of invalidation. We were seen by others as incapable, as defects of society, failed human beings. A predictable route for us was there: after years of being revolving door patients going in and coming out from psychiatric units we could easily end up in long term institutions. From where, we knew that very well, there is no way back.

We did not want this to happen to us. We did not want this to happen to anyone. Anger gradually gave place to sophistication. We learned how to advocate for ourselves, how to overcome shame and stigma, how to be proud of our madness, how to change the bad for the good. We started to change ourselves and started to learn about lives of our peers and also tried to understand the system, which is centred around institutions. We had to understand why institutions are bad if we wanted to demand for something better.

When I am writing these lines I am looking forward to spending time and working in India. I am willing to share my experiences with my friends, peers in that huge and for me unknown country in this article and later also in person. I want to do this not because I think I can teach you. I know that I know nothing of your country, of your institutions, of your everyday difficulties, of your sorrows and of your happiness. But I strongly believe in mutual learning. I want to learn from you and I want you to have my experiences available to you.

What is an institution?

When talking about mental institutions we often think of large, old, Victorian style buildings in a bad state of repair, warehousing thousands of inpatients. Even human rights literature criticizes the physical conditions, overcrowdedness, lack of hygiene and the like. In the past 15 years I visited hundreds of institutions in a number of European countries and in North America. In poor countries and in rich countries. I had the privilege to work in post war Kosovo, where I had to witness how foreign funding was used to refurbish an old institution. They made a four star hotel looking building from a ruined down block of houses. The renovated institution had marble stairs, luxury bathrooms with expensive Italian tiles. And then I became angry again. The bathrooms were closed all the time I visited the place. I could hardly see any residents outside their bedrooms where they spent their time sleeping, sedated by strong medication, or purposelessly wandering in the corridors. They had to wake up and get up at 6 o'clock in the morning, they were given their meals when it was scheduled, not when they were hungry. They had no opportunity to choose what they wanted to do in their spare time. They had no say in whom they wanted to live with. They had to follow house rules on which they had no influence at all. They were treated as objects in a factory. The luxury institution was certainly not a home but a service to keep residents alive.

I saw institutions in rich Finland. Every unit had its seclusion room with special bed and sophisticated restraint tools. In the States I visited a so called group home where residents were not allowed to talk to me directly. The social worker spoke on their behalf. The house rules were more rigid than in some of the large institutions I had seen before. Literally every minute of the residents was controlled by the social worker on duty and users had to ask for permit for virtually everything.

Institution, in my understanding, is about power. Goffman published his famous book on total institutions decades ago. At a time when deinstitutionalisation had just started. Mental health professionals often say, and many of them genuinely believe that those total mental institutions belong to the past. There are several problems with this approach. Firstly, deinstitutionalsation has happened only in the smaller part of the world. In poorer countries institutions are just being built nowadays. Like in India, where the Supreme Court obligated states to build and run institutions for people with mental health problems. But India is not an exception. In my country, Hungary, which joined the European Union, one of the most propsperous regions of the world, proud of their sensitivity to human rights for all, the government decided to build new institutions, each housing up to hundred people.

Another problem with deinstitutionalsiation is that institutions form their own infrastructure. In an economy driven age like ours existing infrastructure needs to be used. And institutions can hardly be used for any other purpose. Thus instead of deinstitutionalisation even in 'progressive countries' one can see transinstitutionalisation. Former mental institutions are being transformed into elderly houses. And too often those elderly people living in these elderly 'homes' are the very same people who used to live in the very same buildings as "chronically mentally ill".

The third problem is that even small scale residential facilities can be total institutions. The typical attitude towards people with mental health problems is paternalism. Even "best people" act "in the best interest" of the person with psychiatric labels. The presumption is that those people, like myself and some of my readers, are incapable of understanding what is good for us. Consequently others need to decide what shall happen to us. Where we shall live, what we shall do in the 24 hours of the day, 7 days a week, 52 weeks a year...till we die. Our right to make our own choices are taken away "in our best interest". The power of the managment of the institution and also of the staff is unlimited. Residents of institutions, of large or small ones, are deprived of the power over their own lives. One of the non-negotiable rights in modern democracies is liberties. If a person has no power over his/her own life, he loses his/her liberties. His/her humanity is taken away from him/her.

Do evil people run institutions?

One cannot deny that total institutions attract antisocial people. It is so easy to abuse those whose rights, whose power have been denied. Physical and sexual abuses in any kind of institutions is wide-spread. But it would be unfair to say that only bad people work in institutions. I met and spoke to hundreds of nurses, social workers, managers working in mental institutions. Many of them are committed professionals who want to help their users. When I meet these professionals I always feel frustrated. How to explain them that what they do from their heart, for very low wages and even lower societal prestige causes more harm than do good? I found that facilitating unconventional interactions between residents and staff can be helpful. When staff meet residents only as vulnerable and disabled needy beings they cannot discover the capabilities and strengths of their users.

I shall never forget a head nurse in a long term institution in Hungary. Back in 1995 I visited the place. In a separate building there were 19 caged beds, in each of them at least one naked resident. These caged beds were their "homes", they spent all their time in those cages. When we asked the head nurse why those people were kept in cages, she answered that they were so disabled that cages were the only way to protect them. Years later caged beds were prohibited and I returned the place. All the former cage bed "users" (what a bizarre term, isn't it?) were doing well without the cages. It is true that the work responsibilities and schedule had to be restructured but it went surprisingly well. Then the head nurse came to me. With tears in her eyes she told me she could not understand how she had been so stupid that she could not have believed that those people could live without cages. And that human caring and share of power is a much better protection than any mechanical restraint.

This head nurse is just one of the many victims who have never seen the capabilities of their users who were trained in a way that people with "severe mental illnesses" are hopless cases, they can't grow, they can't recover, they can't exercise power over their lives.

This false presumption, in conjunction with fear from madness and mad people, maintain total institutions.

What can be done?

I don't belive in universally applicable recipes. In Hungary the user/survivor umbrella have adopted a multi-track approach. While we advocate for deinstitutionalisation at every possible fora, local and national, we endorse and run alternative services. We also maintain close contacts with peers who live in institutions. We also offer training for staff to challenge their stereotypes. We help set up residents' councils in institutions and if needed mediate between them and the institution management. Empowerment is crucial, if residents regain power over their lives and are allowed to decide on what and how they want to do then we make an important step forward. We are often criticized that through these activities we endorse institutions. I disagree with that criticism. We must not ignore that ten thousands of people live in institutions in my country and in the foreseeable future this is unlikely to change. We, the privileged ones who, due to our luck, to our social support networks, friends or families could avoid life-long institutionalisation have moral obligation not to forget about those who live in institutions.

I live in a big house with 150 flats. This building could easily be an institution. And still it is my home. It can be my home because I do have my privacy, there is no total power controlling my life. Naturally residents of the house need to accommodate each other in a reasonable manner, but besides that I can decide what life I want to run and how. Also the rules to be followed by all the residents are democratically decided by the assembly of the house. Residents' councils if properly empowered, trained and respected by management and staff can play a similar role. This will not resolve all the difficulties of institutional life but can result in important improvement of lives with dignity.

Together with other disability groups we are advocating for a moratorium to new admissions in long term institutions. However, we need to be aware that a meaningful deinstitutionalisation will happen only if a range of alternative, non-coercive services are available for people in need. Neediness should not negate strengths and choice may enhance recovery. Instead of total institutions that deprive persons of the basic rights we want services that build on the capabilities and strengths of the persons and that enable growth.

Adjudicating Illness and Capacity

Notes from a Custody Trial

Vasudha Nagaraj[1]

The legal terrain is replete with struggles of women, charged with mental illness, fighting to retain their statuses of being a wife, a mother or as a holder of property. Our knowledge of women's engagements with the law is mostly sourced from a reading of legal judgements of appellate courts. There are very few accounts of the everyday details of the courtroom trial in which a woman has to bring together critical resources to defend herself and claim her rights. Through this narration I wish to problematise the codes in which the law promises its 'protection' to the woman. Even as a woman appeals to the law to declare her as 'capable', she has to consent to the protocols of the pleadings and evidence demanded by legal practice. Such consent implies an ability to produce witnesses and documents to corroborate her account, a courtroom performance that is coherent and systematic, a readiness to subject oneself to medical examinations to prove her wellness and doggedness in the face of an ambivalent rigidity demanded by legal procedure. What follows is an account of a particular case of a woman's struggle, using the legal forum of Guardian's and Ward's Act, to state to her marital community that her illness did not incapacitate her to be a mother to her six year old child. I recount here as her lawyer the difficult decisions and strategies that went into arguing this petition.

Gauri, the petitioner, comes from a middle class teaching family. From the inception of her marital life she felt what she terms 'ill'. During her illness she sensed a foreign body within her and heard voices. Her husband, angry with her condition, returned her to her natal home from where she was taken to a psychiatrist. The psychiatrist treated her with medication and told her that her experiences are common for newly married women. Following her treatment, Gauri returned to her marital home. Despite her recovery, her husband's family was unhappy with her, suspicious that she was 'mad' and continuously made remarks that they had been cheated by her parents. Her school and college certificates were examined and she was also demanded to go through an IQ test. Gauri suffered their taunts and sometimes confided in her parents who consoled her by telling her that 'things will settle down in the future.' Within a year of marriage, Gauri gave birth to a baby girl and the harassment took a different turn after the baby arrived. Gauri was told that she was not attentive to the child's needs as she was often sleepy and dreamy; and that she was ill-treating the child. The child was soon separated from her on the ground that its welfare was at risk. After a series of fights over many years, Gauri was asked to go away but leave the child behind. Unable to face this harassment, Gauri along with her daughter, ran away to her natal home. Soon after, the husband and his family made many attempts to recover the child from Gauri's custody. Fearing that she would be separated from her child indefinitely, Gauri moved the family court for a protection order and thus began the legal proceedings for child custody.

Pleadings

Gauri's husband was livid with rage that she had not only taken away his child but also appealed to the court seeking protection. He pleaded, in his counter, that Gauri's petition was false and full of lies, and that she was continuously sick and prone to hearing voices. He also added that she was not social, never fulfilled her duties as a wife and daughter-in-law, and was always drowsy and inactive. He reiterated that all along it was he who had taken full responsibility for the upbringing of the child. He filed two dozen prescriptions issued by three psychiatrists and records of Gauri's visits to the healing centres. In other words, he argued that Gauri was ill and thereby incapable.

As Gauri's lawyer, I had spent many hours with her, and had discussed her case in detail. Yet, the allegations came as a shock. Indeed, the pleadings were silent about Gauri's illness except at the initial phase. When I consulted Gauri as to why she had not revealed the extent of her illness to me, she said that she did not think it to be so serious. Her parents confirmed that though Gauri was under medical

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treatment, she was a capable and hardworking woman. Moreover, Gauri firmly believed that her illness had been precipitated by the harassment she experienced in her marital home. According to Gauri and her parents the issue was not so much the illness as her husband's uncompromising attitude towards her that led to the present situation.

The trial proceeded along this principal node of tension. While her married life of ten years revolved around the axis of her illness, her pleadings in the court erased the issue altogether. We pleaded for a general cruelty experienced in the marital home rather than foregrounding her illness as an effect of the cruelty that she suffered. At this stage we could not introduce any fresh lines of reasoning except what we had pleaded. By hindsight I see that we could have pleaded and proved that this illness was temporary and made worse by the ill treatment of her marital family. Now we were forced into a difficult situation of fighting on the ground that Gauri was *never* ill except for the initial phase.

As her lawyer, I was worried about the other complications in the case. First, the child was not too fond of her mother and yearned more for her father. Preference of the child is an important consideration in deciding custody cases. Second, the husband may examine the doctors who issued the prescriptions as witnesses. Third, brief research indicated that the medications in question are often prescribed in cases of severe mental illness. It should be qualified, however, that neither Gauri nor her husband knew the nature of her illness and everyone, referred to her illness as 'depression;' a point in our favour. Fourth, I worried that Gauri would have to undergo a medical examination to prove her bonafides to the court.

Gauri attended court regularly and the current psychiatrist scaled down her medication considerably. He said that Gauri was in relatively good health now and that the natal home had given her a sense of security. Asked about her earlier prescriptions of heavy dosage of drugs, he said that the ill treatment in the marital home could have exacerbated her illness. He also hinted at the malpractice of the earlier psychiatrist who could have prescribed these drugs on the basis of information given by her in-laws.

Evidence

Preparing for Gauri's cross examination was the most difficult part. Her memory of early years – marriage, honeymoon, pregnancy and other events – was very vague. We had to reconstruct every detail with the help of her parents and in the process foreground some facts but hide others. It was important to camouflage the fact that she had discontinued her education several times. We advised her to depose that she had discontinued as she was forced to take up domestic chores to prepare for her marriage. Though it is common for girls to discontinue their education, in Gauri's case one had to be cautious as such a fact could be read as a result of her illness. Similarly she was asked to make lists of her jewelry and sets of clothes, her chores in the household and relevant dates and places. She was taught to deny all knowledge about consultations with her doctors and the contents of the prescriptions. Here we were really walking on thin ice.

In a cross-examination, crucial counter-evidence is collected when the witness forgets, fumbles and slips on the facts. The purpose of a cross-examination is to intimidate the witness so that she lapses into confusion. I was not sure if Gauri could handle the extreme tension of a cross-examination. Gauri was cross-examined in two sessions of three hours each. She was confronted not only by the prescriptions but also with her diary and every scrap of paper that she had left behind. Apparently, Gauri had forgotten all about these papers in which she made notes on her illness, medications and queries to the doctors. When confronted with these papers for the first time, she was so petrified that she admitted some and denied some. But thankfully, she survived the intense cross examination with minimal damage. Her parents also deposed well in her support.

In his defense the husband examined himself as a witness. In his cross examination we elicited from him that that he pleaded no specific instances of Gauri exhibiting abnormal behavior; that the prescriptions carried no diagnosis, that the medicines could very well be prescribed for general health. He also admitted that he made no efforts to get his wife treated which was crucial evidence in our favour.

The Unexpected Turn

As is common to custody cases, the child was interviewed by the Judge. We did our best to coach the child, but were very unsure. To our pleasant surprise, the child spoke fondly about her mother and preferred to live with her. Apparently, the child had developed a certain intimacy with his mother during the trial period. We filed her progress reports to show that she was attending school regularly and also doing well in her studies.

Following this, the husband declared that he had closed his evidence. This turned into the astonishing conclusion to the trial. He did not examine his parents, friends nor did he examine the three psychiatrists who had issued the medical prescriptions. The case in other words had abruptly come to an end. Without the evidence of the doctors, the prescriptions carried no evidentiary value. The absence of corroborating evidence for the husband considerably weakened his case. In these circumstances the issue of Gauri's medical examination did not arise. Not revealing the fact that Gauri was ill and on medication throughout her marriage had worked to her advantage. We argued that the husband had leveled vague, uncorroborated and unsubstantiated allegations against Gauri and failed to prove her illness or her incapacity to be a mother.

In the face of the bleak evidence presented by the husband, we expected the Judge to give us a favourable order. But the Judgement was half hearted. The Judge gave Gauri the right to reside with her child only temporarily. Reading between the lines of the judgment, it was clear that the Judge was influenced by the unproved medical prescriptions. Even though there was no remark on her illness or the question of her capacity, the Judge used the husband's status as the natural guardian to deprive Gauri of the custody.

Questions and Dilemmas

This trial can be analysed in many registers. Here, I wish to raise some questions about the quality of women's engagement with the law. Gauri was ill at her marital home but recovered considerably when she moved out of that context. Her illness evidently was contextual, temporary and curable. The Supreme Court has held that a mere diagnosis of mental illness is not enough; only the degree of incapacitation is relevant in deciding such cases. Despite such precedents, legal practice often operates by setting up rigid categories of illness or health, especially in cases of mental illness. Gauri's mere admission that she consulted a psychiatrist in the early years of her marriage cast a shadow on her claim for custody. Her illness, however inadequately proved by the husband, influenced the Judge against her capacity. What was primarily on trial was the belief that a mentally ill woman was 'mad and incapable' and a burden and risk to family life. In the trial, pitted against one another were the 'fragility' of the child and the 'unpredictability' of the mother, both being essentialised unproblematically. Nowhere was there a possibility of arguing that the child staying with the mother can be important for the latter's health and wellness. It was only the "best interests of the child" that had to be argued and decided while the harassment and illness of the mother was only incidental. The function of the law was clear: except adjudicating rights claims it will not undertake any further responsibility of the wellbeing of its subjects.

Any trial demands intensive preparation and witnesses are generally very stressed about their performance in the witness box. Here, the stress was multifold. Gauri was not always well and we worried that the tension would trigger her illness. The trial demanded a high degree of clarity and consistency of performance over an extended period of three years. Gauri partly succeeded because she worked hard, managed her illness, was alert to potential confusions, and displayed a rare courage to fight the confidence of her able-bodied husband. There was always a lurking fear that she could lose the case and be forced to hand over the child to her husband. The legal battle works only as a win-lose formula. Inability to produce the right kind of evidence is read primarily as the untruthfulness and dishonesty of the claim that one is making. What would 'losing a case' mean for a woman like Gauri who was already victimised and castigated for her illness? Would not the 'verdict' of the legal procedure further damage her sense of self and well-being?

It is important to be aware that in appealing to the law one is consenting to the procedures which often produce enormous anxiety and helplessness. This gets exacerbated because the 'family' is viewed as a non-contractual domain and hoarding of evidence in the form of documents and witnesses is often seen as antithetical to the essence of this institution. Further, upon the breakdown of a marriage, women are rarely in hold of the right kind of such resources. Mental illness significantly adds to the existing list of limitations that women face in the courts. Yet a sizeable number of women appeal to the courts seeking justice to the cruelty and injustice that they face in their relationships, partly aware and unaware, of the hardships of this project. Many upon entering the precincts of the court hall either withdraw or 'compromise' their cases. A few, however, go through the entire trial. It is in this category of contested cases that crucial case law is produced that attempts to challenge inflexible notions of able and disabled bodies and their respective capacities and incapacities.

Involuntary Rehabilitation: Evidence of the Use of Force by Rehabilitation Centres in India

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As an American India Foundation Service Corps Fellow at the Centre for Advocacy in Mental Health (CAMH), I visited forty-four mental health facilities in Karnataka, Maharashtra, Tamil Nadu, and the Delhi Region. The goal of this study was to determine whether law and public policy inhibit the provision of community-based services in India, and if they do, to recommend ways to overcome or eliminate these barriers. This goal was achieved by analyzing mental health facilities and the laws governing their operations. To understand the functioning of these facilities, I documented the following aspects of their operations: infrastructure; admission/discharge procedures; relationships with governmental authorities; ward access policies; and inpatient/outpatient services. I then examined this data to determine whether there are any legal or public policy barriers that interfere with the provision of community-based mental health services. Insights were drawn, where appropriate, from the Convention on the Rights of Persons with Disabilities and laws regulating mental health services in other countries. This study concludes that there are currently a number of significant barriers to the provision of community-based mental health services in India.

The entire study, including findings, analysis, conclusions, and recommendations, is available on CAMH's website at http://www.camhindia.org/ghpurc.html.

One subject the study examines is the use of force by rehabilitation centres in India. Both the physical infrastructure and the admissions policies of some rehabilitation centres provide evidence of force or involuntary treatment.

The infrastructure of force is apparent at a significant number of rehabilitation centres. Of the mental health facilities that I visited, twenty-eight are run by nineteen separate rehabilitation centres. Eight of these nineteen rehabilitation centres have at least one facility that is essentially indistinguishable from the residences that surround it. These facilities are generally of the same scale as their neighbors and they do not have any physical characteristics – other than, in some cases, a sign – that mark the building as a mental health facility.

A surprising number of rehabilitation centres, however, have characteristics that are associated with involuntary institutions. For example, five facilities are surrounded by fences that are topped with barbed wire. Similarly, seven rehabilitation centres have facilities where locking mechanisms are used to prevent residents from exiting the facility or a portion thereof. I would therefore describe a significant portion of the rehabilitation centres that I visited as locked or closed facilities.

Evidence of the involuntary nature of some rehabilitation centres is also clear from their admission policies. Although the admission procedures at rehabilitation centres varies greatly, one commonality is that, for the overwhelming majority of rehabilitation centres, psychiatrists and the families of applicants play key roles. For fourteen providers, a psychiatrist plays a central role in the referral process. Thirteen providers stated that residents are brought to their facility by family members.

Eleven of the nineteen rehabilitation centres utilize an application form in their admission procedure. The application forms generally ask for information regarding the applicant's personal and medical history. One interesting variable is who is required to sign the application forms. Only six of the eleven applications include space for the signature of the prospective resident. Of the application forms that are required to be signed by the prospective resident, half of them also include space for the signature of a guardian or family member. All five of the applications that do not include space for the resident's signature require a family member to sign the application form. Six application forms include space for the signature or endorsement of a psychiatrist.

The description of the admission procedure for one rehabilitation centre highlights how a prospective resident's family is often placed at the center of the admission procedure: the *family* contacts the provider by telephone or email; the *family* visits the campus; the *family* provides the rehabilitation centre with medical reports if the reports are available; the *family* meets with staff and the treating psychiatrist to discuss the period of stay and the *family*'s expectations; and the *family* fills out the application form. This raises the question of what happens when the family's interests are contrary to, or not fully aligned with, the prospective resident's interests. It would seem to be important to, at the very least, have guidelines in place that protect the best interests of the prospective resident.

More generally, the emphasis on the opinion and approval of the prospective resident's family and psychiatrist raises questions about the voluntariness of treatment. This is an important question for practical as well as legal reasons.

As Helen Killaspy et al. have written in *What do Mental Health Rehabilitation Services do and What are they for? A National Survey in England*, "[r]ehabilitation psychiatry is practically an 'evidence free' zone in modern psychiatry." It would seem, however, that rehabilitation would be less likely to be successful when it is not voluntary. In particular, it is difficult to reconcile involuntary treatment with the goal of "promoting independence and autonomy." One provider emphasized that a major factor in its admission decisions is whether the prospective resident is motivated to participate in the rehabilitation programme.

The use of force is highlighted by the practices of the five rehabilitation centres that find some or all of their residents on the street. Two of these five providers described their admission procedures in detail. One stated that staff members sometimes have to use "mild force" to lift the person and put him or her into a vehicle. If the individual is going to be admitted to the rehabilitation centre, a Magistrate is involved in the admission process. If more than one admission has to be processed, the Magistrate will come to the facility to issue reception orders. Otherwise, the facility brings the patient to the Magistrate. It is generally a three-day procedure to produce a person before the Magistrate and receive a reception order. During that time, the "rescued" individual is kept in an isolation room unless he or she is calm.

Another rehabilitation centre that finds residents on the street stated that the person is "caught" and put in a jeep. Then the person is brought to the rehabilitation centre and cleaned. Next, a psychiatrist is called and told the person's symptoms. If the person is violent, a night duty nurse watches the person overnight.

One of these providers has developed a relationship with a government mental hospital. After the provider "rescues" an individual, the individual is brought to the police station where a memo is written to allow temporary shelter at the provider's facility. At the facility, a medical certificate is completed by three or four doctors and a complaint is filed with the police department requesting assistance. A "First Information Report" is used to file the complaint because there is no other legal form available. The Joint Commissioner then reviews the paperwork, and the Commissioner signs a reception order. The person is then taken to a government hospital for admission. Approximately thirty people a month are being admitted to the government hospital through this program.

Several aspects of these "rescue" procedures are disturbing. First, even though such acts are presumably done with the best of intentions, the use of force to "catch" a person on the street is an incredible assertion of power. These rehabilitation centres appear to be invoking an authority that is generally reserved for the state. At one rehabilitation centre, this blurring of the edges between private and governmental power is highlighted by the Magistrate's visits and the close relationship the facility has with a government hospital.

Second, after it "rescues" a person, one of the rehabilitation centres files a "First Information Report" (FIR). According to the Commonwealth Human Rights Initiative, an FIR is "a written document prepared by the police when they receive information about the commission of a [crime]." The use of an FIR potentially criminalizes being an individual with a mental health problem, and it brings mental illness out of the realm of health law and into the realm of criminal law.

Third, the "rescued" individuals are being deprived of liberty without the benefit of legal counsel. Section 91 of the Mental Health Act (MHA) provides for the free legal representation of a "mentally ill person" "in any proceeding under this Act before a District Court or a Magistrate." However, based on the above-stated descriptions of admission procedures, it does not appear that "rescued" individuals are being provided with legal assistance when they are produced before a Magistrate for the issuance of a reception order. This is an important topic for future research. As Professor Michael L. Perlin has written in a recent article entitled *International Human Rights Law and Comparative Disability Law: The Universal Factors*, "[t]he development of mental disability law in the United States tracks – inexorably and almost absolutely – the availability of appointed counsel to persons facing commitment to psychiatric institutions, to those being treated in such institutions, and to those seeking release from such institutions."

Fourth, the use of force by rehabilitation centres violates the Convention on the Rights of Persons with Disabilities (CRPD). Professor Amita Dhanda has concluded that, although the CRPD text “neither expressly prohibits nor permits forced intervention,” the ambiguity should be construed in light of the complete document’s emphasis on the dignity and autonomy of persons with disabilities. It is clear, however, at the very least, that the CRPD prohibits forced interventions with regard to rehabilitation: Article 26 specifically states that “habilitation and rehabilitation services” must be “voluntary.”

More generally, the CRPD emphasizes that a person with a disability has legal capacity. The CRPD requires that, if and when it is necessary for a person with a disability to be given support in exercising his or her autonomy, this support is subject to stringent limitations in scope and duration. Pursuant to Article 12(4), the safeguards must ensure that any measures relating to the exercise of legal capacity “respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.”

As opposed to the CRPD, much of the MHA seems to assume that a person with a mental health problem does not have legal capacity. For example, pursuant to Section 19 of the MHA, a relative or friend of a person with a mental health problem can apply to have the person admitted to a psychiatric hospital or psychiatric nursing home. This “admission under special circumstances” provision gives extraordinary power to other individuals to act on behalf of a person with a purported mental health problem. For example, for an admission pursuant to this section of the MHA, there is no provision for a hearing unless and until the person who has been committed applies to the Magistrate for discharge.

Although involuntary treatment would seem to be out of place in rehabilitation centres, India is not the only country where it occurs. For example, according to Killaspy’s national survey of mental health rehabilitation services in England, eighty-nine percent of short-term rehabilitation services accept patients detained under Great Britain’s Mental Health Act.

India’s ratification of the CRPD means that change will have to happen relatively quickly. Pursuant to Article 33, India is required to “maintain, strengthen, designate or establish . . . a framework . . . to promote, protect and monitor implementation of the [CRPD].” Within two years after the CRPD comes into effect, India will have to submit “a comprehensive report on measures taken to give effect to its obligations under the [CRPD] and on the progress made in that regard . . .” Given the evidence of the use of force by rehabilitation centres, there is much work that remains to be done.

Useful Resources

Search your soul: There is courage within

Gitika Talwar
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As part of my Clinical Psychology coursework I was required to read a book called ‘*Soul Searching: Why Psychotherapy must promote moral responsibility*’. I baulked at the title. Mostly expecting sentimental mumbo jumbo. Till I read it.

There is a reason they tell you to never judge a book by its cover.

Dr. William J. Doherty, besides being the author of this book is a remarkably gritty therapist for daring to say that therapists have a far greater responsibility to their clients than they previously realized. The details of his argument, I leave for another time. However, for right now I want to dwell on Dr.Doherty’s remarkable views on forced treatment. I like the fact that he chose to speak about ‘forced treatment’ in a chapter titled ‘Courage’. Throughout the chapter, Doherty attempts to lay the groundwork for his belief that there is something wrong “*both clinically and ethically in not taking responsibility for how our own insecurities influence our clinical decisions.”*

Doherty is clear and upfront in saying that there are clients, such as highly suicidal clients, who will fare better if they are in the hospital than outside. It however rues the fact that numerous hospitalization decisions are made out of a sense of anxiety. He acknowledges the deep seated fear that many therapists have – that they cannot bear the thought of their client committing suicide. However, he places his loyalty to clients on a higher pedestal than loyalty to the fear of consequences of suicide.

Doherty further surports the strong-willed statements he made regarding voluntary hospitalization by providing readers an example of a past client of his who had a history of depression and had begun speaking about suicide rather often.

Throughout the book, the individual autonomy framework has been expanded to include the community and family that the client is part of because of Doherty's argument that focusing primarily on the client at the exclusion of family and community makes it less likely that clients will think about the consequence of their actions (or inactions) on others, and that it is unnatural to expect people to become pure individualists at the cost of the community they belong to. Emerging from the same framework, Doherty asks his client (who is threatening suicide) to talk about the impact his death is likely to have on the different members of his family and following this conversation, he asserts that suicide is not an option. Doherty noticed that his client seemed to like the phrase "not an option", perhaps because it reminded him that suicide was a choice in his hands just like many other choices and they had to seek out those other choices (choices to live) before he chose to die. Just the way a therapist has to seek choices that promote autonomy rather than the ones that only promote self-satisfaction.

It is important to remember that nobody is "forced to hospitalize", we "choose" to hospitalize. Like all therapeutic choices, we need to ensure that our choices were aided by therapeutic goals and not by fear. It is also important to remember that promoting life is a therapeutic goal that has to be achieved in collaboration. Force is antithetical to life.

Doherty and his client agreed to a verbal pact – that the client would tell Doherty when he was thinking about suicide and Doherty would ask the client for permission before choosing hospitalization. The client did keep good on his promise and placed an extremely agitated call to Doherty, saying he had taken a lethal dose of his antidepressant medication and had called just to act on his promise. Doherty was definitely agitated and felt like it took all his courage to not call for an ambulance right away but he knew he had to keep his end of the promise. Calling this ambulance may have enhanced his credibility among his colleagues but for the client, Doherty would lose credibility forever.

Doherty continued to speak to his client, eventually telling him that he had the right to decide his own fate but that Doherty was unsure if he was in the frame of mind to make a decision. Doherty reminded the client of the fact that life-altering changes are not to be made when one is depressed or when one is extremely happy. A simple assertion by the therapist that cut past the noise about morality and instead just asked the client to think about suicide as a decision, which he had to choose to act upon or not. The client argued on behalf of suicide, saying that life would never really get better. Doherty acknowledged that the client could be right but he wanted to speak more about it and could not allow the client to make a decision in this frame of mind. He asked for permission to call the hospital and this time the client said yes.

Doherty looks back at this decision and realizes that he had lost precious "rescue" time when he thinks of the fact that the client had taken a lethal dose and the dose was taking effect as they spoke, but he chose to support the client's autonomy. He was glad that the client eventually agreed to call the ambulance and Doherty was glad that he did not have to stand before a court to explain why he chose autonomy over life. There is a fine balance between supporting autonomy and possible death, and shunning autonomy to choose life. Courage as a virtue, coupled with good judgment helped Doherty to sail through a very stormy sea.

He writes very movingly about the need for therapists to be honest about their failure of nerve, about their fear of being held responsible for death, so that there can be more space for conversation about how to promote life. He cautions about how 'failure of nerve' rarely lets us see clients outside our 'invisible veil of distortions.'

Doherty's argument made me think more actively about decisions that clients want to make, such as suicide, and how we need to be able to encourage a more coherent decision making than crumble under the fear of asking uncomfortable questions or making uncomfortable decisions (ones that contradict what we were taught). Also, that we need to have the courage to confront our inner lives while we work with our clients and help them confront theirs. I like the parallels that Doherty draws between surgeons and therapists – just as surgeons have to act with special courage during emergency operations, therapists are called to be brave about their inner lives and act with morality in tough situations.

I like how Doherty concludes his chapter on 'Courage' - '*Firmness of spirit is an acquired virtue that as therapists we are called to embrace and cultivate throughout our careers, for the good of our clients and the community, and for the enrichment of our own humanity.'*

Kudos to that.

Mental Health Law: On Road to Freedom

Amita Dhanda*

The decision by Mr. Pankaj Shah, Metropolitan Magistrate, Bandra, that Mr. Faisal Khan, Amir Khan's brother, need not be in anybody's custody and can live anywhere he wants is a clarion call for the rights of persons living with mental illness. The significance of the decision is that it speaks for the autonomy and freedom of a person even whilst acknowledging that he is living with mental illness.

The Mental Health Act of 1987 allows the friends and family of a person diagnosed with mental illness to seek his or her involuntary institutionalization, provided the afflicted person is a danger to self or others; or is suffering from severe mental disorder which merits institutionalization. Thus the law does not deprive liberty and autonomy on a finding of mental disorder alone. Such a consequence occurs only after these additional grounds are fulfilled. Unfortunately in a large volume of judicial decisions in the mental health arena, courts have issued orders of *institutionalization* upon a finding of mental illness alone. This is especially the case when the decisions are made by the first courts; though appellate courts have *been equally* culpable. This situation has continued, despite some crucial rulings of the Indian Supreme Court, which emphasized that whilst mental illness was a threshold condition, the *civil rights disqualifications* would come into force only after the additional requirements have been fulfilled. The decision of the Bandra Metropolitan Magistrate seems to be an example of one of the few cases where the directive of the Supreme Court has been understood both in letter and spirit. The judge was assisted in his decision by the fact that the JJ Hospital authorities made a distinction in their opinion between a diagnosis of mental illness and a finding that a person is unable to live on his own due to mental illness. The significance of the decision is that it accepts that incapacity to care for self is not a necessary or inevitable consequence of a diagnosis of mental illness.

It needs to be appreciated that the Court's refusal to order forced treatment is not an embargo on obtaining treatment, insofar as both law and medical practice allow persons living with mental illness to voluntarily seek treatment. In closing the door to coercion, Magistrate Shah has extended an invitation to the healing professions to sharpen their skills of persuasion. Psychiatry and psychiatrists are geared to offer relief and assistance to persons battling with psychological conditions. Ordinarily, the logical consequence of the availability of such assistance would be that the persons needing such treatment would seek it on their own: They do not need to be forced and coerced into obtaining the same. The incapacity of the victim is offered as the standard defense against this criticism. It is contended that psychiatrists are forced to practice coercion because afflicted persons lack insight and hence do not know what is good for them. Without entering into disputes on the truth or falsehood of this justification, it is necessary to note that psychological sciences have made no effort to surmount this obstacle of patient recalcitrance through expertise. Instead they have opted for convenience and steamrolled patients into submission with the force of the law.

Indian families, as families anywhere, are as much sites of aggression and dispute as of comity and protection. This aggression, dissent, or deviance gets further complicated when implicated with a psychiatric diagnosis. A medical explanation for an interpersonal or psychosocial problem can only further complicate matters as it deflects attention from the root problem. It is important that both law and psychiatry recognize this reality and resist falling into the trap of proffering facile medical explanations for interpersonal difficulties, especially as these explanations carry within them the danger of disempowering the afflicted person and demonizing the family.

Taare Zameen Par struck a chord in the hearts of so many because it raised a voice against the totalitarianism of the education system. Such straight jacketing of individuals by labels is not confined to the educational system alone. Similar and deeper queries can be raised on the mental health system. The metropolitan magistrate, Bandra, has provided this space for reflexive understanding. This process is further strengthened by the fact that the newly adopted UN Convention on the Rights of Persons with Disabilities recognizes the full legal capacity of persons with mental disabilities to live their lives according to their own lights. This Disabilities Rights Convention, which India has both signed and ratified, recognizes that persons with disabilities have the right to obtain support with respect and dignity instead of it being forcibly rammed down their throat by the force of the law. The Faisal Khan decision in respecting the preference of Mr Faisal Khan to live alone and to self manage his own treatment has further pushed Indian Mental Health Law in this forward looking direction.

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Advance Directives: An Effort to Oust Force

Amita Dhanda

We are presently engaging with the issue of forced intervention in mental health and why such interventions are counter-indicative to both the health and the liberty of persons living with mental illness. Whilst danger to self and others is put forth as one explanation for the use of forced intervention, the loss of ability to make decisions is put forth as the other explanation. Any person can, by a Mental Health Advance Directive state how they want their care and treatment to be organized, in case they lose the ability to make or express such decisions. This directive can state both what the executing persons want or do not want. If they so desire, and primarily to ensure that, the wishes recorded in the directive are duly executed, the executing persons can nominate one or more persons as their agents to ensure that their treatment happens in accordance with their directive. The executor of the Directive can anticipate as many questions on which decisions may be required and give instructions for the same. The executor can also decide how much finality they wish to confer on the Directive and in what circumstances would they wish to change it.

It is pertinent to note that whilst any person can execute and register a mental health advance directive, the need to execute such directives is primarily impressed on persons living with mental illness. And this is the case even when for example the reasoning given by the legislature of the State of Michigan for observing May 2006 as Advance Directive month could be equally appropriately be extended to Mental Health Advance Directives. The House Resolution stated that Advance Directives were required because "each of us values dignity, independence and self determination. There are many circumstances in which we may lose the ability to express our decisions about our medical and personal care". If persons sign an advance directive then such decisions can be made in accordance with their will without "the need for guardianship, a legal proceeding by which an individual loses many basic rights". The House thus adopted the aforementioned Resolution in order to overcome the informational and emotional barriers to the signing of advance directives.

The Bazelon Centre of Mental Health has hosted a template for a Psychiatric Advance Directive on its website. This Directive has been formulated to enable persons living with mental illness to ensure that their treatment is carried out in accordance with their wishes, without questioning or problematizing the legal attribution of incapacity to persons living with mental illness. I accept that all persons including persons living with mental illness can lose the ability to make decisions with regard to their treatment and care; and persons living with mental illness like all other persons need to take steps to protect their dignity, independence and self determination. However such steps are not especially required by persons living with mental illness and the standard form for a Mental Health Advance Directive should be constructed in acknowledgement of the fact. I have therefore reworked the template formulated by the Bazelon Centre as a form which, can be used by persons who so desire, to Advance Direct their mental health treatment. This form has no legal status in India today, insofar as there is no legislation by which advance directives have been recognized or a procedure for their registration specified. However section 18 (f) of the Registration Act 1908 gives the all inclusive residuary option to register any document. This section can be employed to register advance directives. In availing of the registration option, executors of advance directives would stamp their will with the solemnity and formality of law, whilst retaining the autonomy to organize their own affairs.

Template of an Advanced Directive:

I] **PHYSICIANS AND OTHERS PLEASE NOTE:**

I have an advance directive for mental health decision-making, a legal document stating my preferences as to mental health care and treatment has been duly registered. A copy may be found at:

____.

If I am unable to make or express my decision with regard to my care and treatment, please obtain this document and respect the choices I have registered in it.

My name: __________________________________

My PAN : __________________________________

I have appointed as my agent for mental health decision-making ________________________ , who can be reached at __________(day) or __________ (evening). This person has been authorized and informed of my will and preference and shall express and make decisions about my mental health treatment in the event that I am unable to make or express such decisions.

II] **Appointment of Agent For Mental Health Care**

Make sure you give your agent a copy of all sections of this document.

Statement of Intent to Appoint an Agent:

I, (your name)__________________, being of sound mind, authorize a health care agent to make certain decisions on my behalf regarding my mental health treatment when I lose the ability to do so. I intend that those decisions should be made in accordance with my expressed wishes as set forth in this document. If I have not expressed a choice in this document, I authorize my agent to make the decision that my agent determines is the decision I would make if I had the ability to do so.

1. Designation of Mental Health Care Agent

A. I hereby designate and appoint the following person as my agent to make mental health care decisions for me as authorized in this document. This person is to be notified immediately of my admission to a psychiatric facility.

Note: Make sure to list this person in Part IV of your advance directive.

Name: ____

Address: ____

Day Phone Number ______________ Night Phone __________________

B. Agent's Acceptance: I hereby accept the designation as agent for

(your name) ____

(your agent's signature)______________________________________

Designation of Alternate Mental Health Care Agent

If the person named above is unavailable or unable to serve as my agent, I hereby appoint and desire immediate notification of my alternate agent as follows:

Name: ____

Address: ____

Day Phone Number ________________ Night Phone ____________________

Note: Make sure to list this person in Part IV *of your advance directive.*

Alternate Agent's Acceptance: I hereby accept the designation as alternate agent for

(your name)____

(Your agent's signature)______________________________________

The following paragraphs will apply when you appoint an agent.

2. Authority Granted to My Agent

Initial if you agree with a statement; leave blank if you do not.

A. ________ If I lose the ability to give consent to mental health care treatment, I hereby grant to my agent the power and authority to make mental health care decisions for me, including the right to consent, refuse consent, or withdraw consent to any mental health care, treatment, service or procedure, in accordance with the instructions and/or limitations I have set forth in this advance directive. If I have not expressed a choice in this advance directive, I authorize my agent to make the decision that my agent determines is the decision I would make if I were competent to do so.

B._________ Having named an agent to act on my behalf, I do, however, wish to be able to discharge or change the person who is to be my agent if that agent is instrumental in the process of initiating or extending any period of psychiatric treatment against my will. This advance directive would be the basis of my asserting my ability to revoke or change agents in this circumstance in assertion of my dignity and self-determination. Even if I choose to discharge or replace my agent, all other provisions of this advance directive shall remain in effect and shall only be revocable or changeable by me at a time when I have the ability to make informed health care decisions.

III] **Statement Of My Desires, Instructions, Special Provisions And Limitations Regarding My Mental Health Treatment And Care**

In this part, you state how you wish to be treated (such as which hospital you wish to be taken to, which medications you prefer) if you become incapacitated or unable to express your own wishes. If you want a paragraph to apply, put your initials after the paragraph letter. If you do not want the paragraph to apply to you, leave the line blank.

1. My Choice of Treatment Facility and Preferences for Alternatives to Hospitalization If 24-Hour Care Is Deemed Medically Necessary for My Safety and Well-Being

A. _____ In the event my psychiatric condition is serious enough to require 24-hour care and I have no physical conditions that require immediate access to emergency medical care, I would prefer to receive this care in programs/facilities designed as alternatives to psychiatric hospitalizations.

A1. _____ I would prefer to receive 24-hour care at the following programs/facilities: ______________________________ ______________________________ ______________________________	B._____ In the event I am to be admitted to a hospital for 24-hour care, I would prefer to receive care at the following hospitals: ______________________________ ______________________________ ______________________________

C. _____ I do ***not*** wish to be committed to the following hospitals or programs/facilities for psychiatric care for the reasons I have listed:

Facility's Name:____________________ Reason: ______________________________

Facility's Name:____________________ Reason: ______________________________

Facility's Name:____________________ Reason: ______________________________

3. My Preferences About the Physicians Who Will Treat Me if I Am Hospitalized.

Put your initials after the letter and complete if you wish either or both paragraphs to apply.

A. __________My choice of treating physician is: Dr. ______________________ Phone number ______________ OR Dr. ______________________ Phone number ______________ OR Dr. ______________________ Phone number ______________	B. __________I do not wish to be treated by the following, for the reasons stated: Dr. __________________________ Reason: ______________________________ Dr. __________________________ Reason: ______________________________ Dr. __________________________ Reason: ______________________________

4. My Preferences Regarding Medications for Psychiatric Treatment

In this section, you may choose any of the paragraphs A-G that you wish to apply. Be sure to initial those you choose.

If it is determined that I am not legally competent to consent to or to refuse medications relating to my mental health treatment, my wishes are as follows:

A. _____ I consent to the medications agreed to by my agent, after consultation with my treating physician and any other individuals my agent may think appropriate, with the reservations, if any, described in (D) below.

B._____ I consent to and authorize my agent to consent to the administration of:

Medication Name	**Not to exceed the following dosage:**	**OR**	**In such dosage(s) as determined by**
____________________________	______________________________________		Dr.______________________________
____________________________	______________________________________		Dr.______________________________
____________________________	______________________________________		Dr.______________________________
____________________________	______________________________________		Dr.______________________________

C._____ I consent to the medications deemed appropriate by Dr.__________________________, whose address and phone number are:
____

D. _____ I specifically do ***not*** consent and I do ***not*** authorize my agent to consent to the administration of the following medications or their respective brand-name, trade-name or generic equivalents:

Name of Drug	**Reason for Refusal**

E._____ I am willing to take the medications excluded in (D) above if my only reason for excluding them is their side effects and the dosage can be adjusted to eliminate those side effects.

F. ____ I am concerned about the side effects of medications and do ***not*** consent or authorize my agent to consent to any medication that has any of the side effects I have checked below at a 1% or greater level of incidence (*check all that apply*).

_____ Tardive dyskinesia
_____ Tremors
_____ Loss of sensation
_____ Nausea/vomiting
_____ Motor restlessness
_____ Neuroleptic Malignant Syndro
_____ Seizures
_____ Muscle/skeletal rigidity
_____ Other _______________

G._____ I have the following other preferences about psychiatric medications:
____
____

5. My Preferences Regarding Electroconvulsive Therapy (ECT or Shock Treatment)

If it is determined that I am not legally capable of consenting to or refusing electroconvulsive therapy, my wishes regarding electroconvulsive therapy are as follows:

Initial A or B; if you check B, you must also initial B1, B2 or B3:

A._____ I do ***not*** consent to administration of electroconvulsive therapy.

B._____ I consent, and authorize my agent to consent, to the administration of electroconvulsive therapy, but only:

B1. _____with the number of treatments that the attending psychiatrist deems appropriate;

OR

B2. _____ with the number of treatments that Dr. __________________________ deems appropriate. Phone number and address of doctor:
____
____

OR

B3. _____for no more than the following number of ECT treatments: ____________

C. _____ Other instructions and wishes regarding the administration of electroconvulsive therapy:
____
____
____
____
____
____
____
____

6. Consent for Experimental Studies or Drug Trials

Initial one of the following paragraphs.

A. _____ I do ***not*** wish to participate in experimental drug studies or drug trials.

B. _____ I hereby consent to my participation in experimental drug studies or drug trials.

C. _____ I authorize my agent to consent to my participation in experimental drug studies if my agent, after consultation with my treating physician and any other individuals my agent may think appropriate, determines that the potential benefits to me outweigh the possible risks of my participation and that other, non-experimental interventions are not likely to provide effective treatment.

V Statement Of My Preferences Regarding Notification Of Others, Visitors, And Custody Of My Child(ren)

1. Who Should Be Notified Immediately of My Admission to a Psychiatric Facility

If I am unable to do so, I desire staff to notify the following individuals immediately that I have been admitted to a psychiatric facility:

Name:______________________________________
Relationship: ________________________________
Address: ____________________________________
____
Phone (Day):_________________________
Phone (Eve.): ________________________
It is also my desire that this person be
permitted to visit me: Yes_____ No _____

Name:______________________________________
Relationship: ________________________________
Address: ____________________________________
____
Phone (Day):_________________________
Phone (Eve.): ________________________
It is also my desire that this person be
permitted to visit me: Yes_____ No _____

Name:______________________________________
Relationship: ________________________________
Address: ____________________________________
____
Phone (Day):_________________________
Phone (Eve.): ________________________
It is also my desire that this person be
permitted to visit me: Yes_____ No _____

Name:______________________________________
Relationship: ________________________________
Address: ____________________________________
____
Phone (Day):_________________________
Phone (Eve.): ________________________
It is also my desire that this person be
permitted to visit me: Yes_____ No _____

2. Who Should Be Prohibited from Visiting Me

I do not wish the following people to visit me while I am receiving care in a psychiatric facility:

Name	Relationship	Name	Relationship

3. My Preferences for Care & Temporary Custody of My Children

In the event that I am unable to care for my child(ren), I want the following person as my first choice to care for and have temporary custody of my child(ren):

Name:_________________Relationship: ____________________Address: ____

City, State, Zip:_______________________________________Phone number: (Day) ___________________(Evening)________________

In the event that the person named above is unable to care for and have temporary custody of my child(ren), I desire one of the following people to serve in that capacity.

My Second Choice
Name: ____
Relationship: ___________________________________
Address: ______________________________________
Phone (Day):___________________________________
Phone (Eve.): __________________________________

My Third Choice
Name: ____
Relationship: ___________________________________
Address: ______________________________________
Phone (Day):___________________________________
Phone (Eve.): __________________________________

Part VI Statement Of My Preferences Regarding Revocation Or Termination of This Advance Directive

Initial all paragraphs that you wish to apply to you.

1. Revocation of My Psychiatric Advance Directive

___________My wish is that this mental health directive may be revoked, suspended or terminated by me at any time...

2. Other Instructions About Mental Health Care

(Use this space to add any other instructions that you wish to have followed. If you need to, add pages, numbering them as part of this section.)

____
____
____

3. Duration of Mental Health Care Directive

Initial A or B.

A._____It is my intention that this advance directive will remain in effect for an indefinite period of time. OR

B._____It is my intention that this advance directive will automatically expire two years from the date it was executed.

VII Advance Directive of (your name) ____________________________ for Mental Health Care Decision making

Signature Page

By signing here I indicate that I understand the purpose and effect of this document.

Your Signature	***Date***

The directive above was signed and declared by the "Declarant," (*your name*)____ , to be his/her mental health care advance directive, in our presence who, at his/her request, have signed names below as witness. We declare that, at the time of the execution of this instrument, the Declarant, according to our best knowledge and belief, was under no constraint or undue influence. We further declare that none of us is: 1) a physician; 2) the Declarant's physician or an employee of the Declarant's physician; 3) an employee or a patient of any residential health care facility in which the Declarant is a patient; 4) designated as agent or alternate under this document; or 5) a beneficiary or creditor of the estate of the Declarant.

Dated at ____ (*state, city*),

this ___________________ day of ___________________, 19____.

Witness Signatures

Witness 1: _______________________________________	**Witness 2:** _______________________________________
*Signature of Witness 1*________________________________	*Signature of Witness 2* ______________________________
Name of Witness 1 (printed) _________________________	*Name of Witness 2 (printed)* _________________________
Home address of Witness 1 ___________________________	*Home address of Witness 2* ___________________________
City, State, Zip Code of Witness 1 _________________	*City, State, Zip Code of Witness 2* _____________________

(for use by the notary):

State of_________________, County of ___________________________

Subscribed and sworn to or affirmed before me by the Declarant,

____,

and (*names of witnesses*)

____ and

____,

witnesses, as the voluntary act and deed of the Declarant, this ___________ day of ___________, _____________.

My commission expires:

____

____

Notary Public

Record of Psychiatric Advance Directive

Keep this form and give a copy to your agent, if you have appointed one.

My name	My health care agent's name
My address	My health care agent's address
My date of birth	My health care agent's telephone number(s)

I have given copies of this form to:

Name	Address or phone
Name	Address or phone
Name	Address or phone
Name	Address or phone
Name	Address or phone
Name	Address or phone

Forcing mentally ill women into giving their child in adoption

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On the 3rd October 2007, in the Bombay High Court, there was petition [No 89] about foreign adoption by a mentally ill woman from Bombay who had delivered a child. The child was kept at an adoption centre for care and treatment. But the adoption centre had directly filed a petition to the high court, that mother of child was mentally ill and that she was not capable of taking care of the child; and so, for the child's better future it is good if the child is given for adoption. But the High Court gave a very good and sensitive decision that child can not be adopted because the woman can take a decision about her child and this case was dismissed on the ground that, mental illness is curable and only abandoned children or parents who are not capable of taking care of children can be put up for adoption.

But there are many mentally ill women who are vulnerable, and they can be in a position where her parental rights can be violated. And if she became pregnant, due to any reason she can be in a position to have no right over her child.

Motherhood is one of the beautiful and happiest moments of any woman's life but it is not so for many a woman, if she is unwed or if the child is born out of wedlock. There is much social stigma attached to these.

Mental Health Act, 1987, Chapter 5 Section 52 clearly says that if a person is mentally ill, the person is incapable of taking care of himself or of managing property; or incapable of managing his property only. And S 53 says to appoint a guardian to take care of him; S 54 says to manage his property.

According to S 53, the guardian of the mentally ill person is not the guardian of mentally ill persons' child or children. But it is assumed that the guardian has the right to take a decision on behalf of the children of a mentally ill person, which is not true. In many cases of mentally ill women, if they are became pregnant due to any reason or child born out of wedlock, many times the family takes the decision that child should go for adoption or the family forces the woman to surrender her child.

Women are not counseled on this topic. It is believed that it is better for the child's future if he / she can go for adoption; and that she will be selfish if she wants to keep her child with her. The women are not told about their rights, they are not told about other options. And most importantly, after relinquishing her child she will not have any further contact with her child, ever.

We need to keep these in mind, when we say that it is for the child's better future it is good to go for adoption. We also need to think about this fact that, in India all adoptions are confidential or close adoptions. And a biological mother has simply NO opportunity to know where her child is, after she has signed the relinquishment document. So after relinquishing / surrendering the child, women and child will lose all contact with each other.

The other most important thing is that, the Mental Health Act doesn't say anything about what should be done for mentally ill women's children and if the woman had a child without marriage. There are many wandering mentally ill women who became pregnant, and they are in the mental hospital and their children are at some children's shelter home. In many cases, the women want to keep their child with her, which is her right. The authorities give the child away in adoption without consent.

There is debate on this issue that women, if mentally ill, is not able to take care of herself, then how she can take care of her child? Many times it is said that mentally ill women become violent, and so they can harm their children. Here we are talking about a very sensitive issue of mother and child. It is every mother right to take care of her child and raise her child. When she is not in the position to take of her child, she can stay at the institution which should take care of both the woman and the child.

Of course, we need to know that, mental illness is curable, and with proper treatment it can be cured. But here the issue is not only of care, treatment and shelter for child. We need to think about mother and child's emotional states. Every mother and child has the right to know about each other and live together. That is very natural. How can the mother and child live the rest of life knowing that they have lost each other forever, how can they deal with their loss, grief, sorrow, and a very natural desire to meet each other. Can giving a child for adoption by force solve these rights issues……..?

Freedom makes a lot of difference... for the better

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Freedom in the mental health scenario is hidden or an unseen factor as far as I am concerned. I strongly emphasize on that because I am psychologically strong. When I am in a crisis situation I can think about basic principles of the facts there and I can see others' problems and their roles. It helps me to see the naked truth about the situation. Most of the time due to normal/abnormal terms, professionals give some space to function but they always try to make corrections in behaviour in comparatively fast methods so that it is acceptable by the society easily. In the real sense they should think about what in the reason behind this behaviour.

To achieve emotional stability, I have experimented on myself several times and I have also been successful at it. But I never wanted to do that in the conventional way. My parents pushed very hard for me to go the conventional way. Because of that I started looking at everything in a very negative manner. I couldn't just do what was the demand of the hour. My parents had made me into a newspaper of the living room. Anybody came, read and gave their unnecessary free advice. That probably came out of their hopelessness.

From time to time, my parents kept looking for flaws in me, nagging me about it and wasted a lot of time on that. Because of which I failed to bring out my inner strength and resilience. As a result I became more introvert. I didn't feel the need to indulge in emotional sharing with anyone under any circumstances. I worked by myself on my shortcomings without involving anyone else in it and in turn the misunderstandings about me kept increasing. I ignored what others felt about me and kept myself pleased with what I felt about myself. I yearned for emotional happiness more than materialistic things because of which the differences just increased.

Except F M, each one who tried to understand me failed in that attempt. She familiarized me with each individual's responsibilities and duties through my perspective. She was aware that my dependency was not superficial and knew how much freedom I should be given. Each individual has her / his abilities and they keep changing but I was not interested in such a long list of responsibilities and this she understood very well. She understood my need to get involved in intellectual level work. These days what my parents expect out of me is at a moderate level but till the age of 27 ½ I had a strong feeling that I wasn't born to just fulfill my parent's dreams.

F M had accepted my rash and slang manner of talking. Once, while we were in the process of building rapport, she asked me how I was feeling and asked me to share without any hesitation and I told her that "When a prostitute who has been asked to do several acts for hours together with so many people and then is asked what interests her. The way she feels at that moment is what I am feeling right now".

Her trust in me and the freedom she gave me, won me over. In the beginning whatever small mistakes I made, she was careful not to immediately pass comments on them but rather allow me to say. Whatever she said at the right times helped me clear my thought processes. While building rapport with me, she explained that psychiatrists/ psychologists have custom-built questions and there are several reasons for it and also have custom-built answers. She also explained that there are a lot of people here whom I need to give time to and she asked me whether I would be willing to use my potential there. She made it clear that she would not force her theoretical knowledge or practical experience on me and that my non-hesitant and to the point manner of speaking would not even allow it to be forced on me. In my interactions with my family in the past 20-22 years they has a controlling and skeptical attitude of '*handle with care*' – I did not see this in my interactions with her. I used to talk in-depth about my family as well as with moderate seriousness about my life but why it was not working was something she experienced and understood.

In my personal relationships I'm very comfortable, but when my family gets involved in it, it's very difficult to maintain a free and fair relationship. She tried to explain this in the beginning as a complex that I'm experiencing but later she, from her experience, accepted what I had to say. She guided / encouraged me to mould myself about how I can survive in a contaminated atmosphere.

The therapeutic relationship that develops during counseling is very helpful. But it doesn't give you a lot of life answers. But it definitely helped me start that journey and mould myself to survive.

Treated but not healed

-Excerpts on Forced Treatment

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I recently met a person, Chandra Fowler, working in an organization which supports user / survivor work in the UK. We talked about how the systems in the UK are different from here in India. What struck me most were the new legislations being implemented which are taking forced treatment, previously restricted to the institutions, into the community under the name of 'Compulsory Community Treatment'.

I started to question then, which system was better and more conducive to freedom. Does the more chaotic, unplanned, unregulated, existing Indian system give more freedom to a person with psychosocial disability or the over-structured and progressive system of the west?

The dilemma still persists but here I would like to explore and understand the circumstances in which forced treatment operates and what are the experiences of persons undergoing these inhuman means of forced 'treatment'. At the Center for Advocacy in Mental Health, Pune, I'm involved in an activity called the Archives, which creates a space for persons with mental illness or distress to share their stories. The Archives provides a space to share emotions, experiences, as well as creates a political space to narrate experiences with the mental health system.

The Archives have made evident the very stark experiences of persons with mental illness. These experiences are mainly in the context of the mental health system and the abuses faced by individuals who have accessed these systems. Freedom within a system means that the system presents choices before the individual so that they can take informed decisions about their lives. But this is not how things work out at all. The system generally equates mental illness with being unable to make your own life decisions. When an individual is fitted into certain diagnostic criteria, force is executed at various levels.

When it is first understood that an individual in the family is suffering from a mental illness, that individual's right over his/her life is taken away and persons with apparent complete capacity take all the further decisions. These decisions range from the nature of treatment to what they can and cannot do in their daily lives. The treatment is generally limited to medication to reduce intensity of the symptoms. This form of treatment gives little choice to the "patient" in terms of either time or options where they can discover their own method of healing.

When others choose treatment, it is usually based on what is most convenient to them rather than what is appropriate and sensitive to the one in distress. Here, it is assumed that medication necessarily improves the outcome without actually exploring other less intrusive and less painful options.

When treatment is forced it defeats it own purpose of being a path of healing and recovery. An environment is conducive to healing when the space is safe, secure, provides atmosphere of freedom and dignity and gives the individual the right to choose for her/himself.

At times some "experts" can also have the authority to choose a treatment modality for a "patient". When this expert terms an individual as a patient, the individual's right to choose the treatment for himself or herself is taken away. What will be done with the body or mind is no more that individual's prerogative.

The nature of the doctor-patient relationship inherently survives on hierarchy. The individual is automatically denied any rights regarding her/his course of treatment due to the very nature of this relationship. The hierarchy automatically transfers the power to one faction of that relationship leaving the other group vulnerable and subject to oppression.

Often one is told that an individual with mental illness does not have insight and is not capable of taking any decisions regarding her/his own life. There is a general disbelief in an individual's judgment about the choices s/he would make for her/himself. This automatically leads the state or any authorities to believe that they have the right to decide for this person regarding any further interventions. This disbelief in an individual with mental illness is manifested through restricting a person by chaining her/him or by putting them in an institution.

There is a "fear" that mentally ill people are dangerous and it is for the good of the society at large that they are being restrained. What this does is that it only makes the society more unjust and inhuman but automatically takes away the responsibility of the society towards that individual. The society does not have to deal with anymore disturbance and differences. The society is sold on the idea that restraining someone with mental illness is for the good of the society. The only response society tends to have to violence is more violence and restraint. When on the other hand more just, sensitive and non-violent options need to be explored and implemented.

My file had instructions that I should be given Serenace injection every morning and evening. I was agitated. I thought I should do *Brahmari Pranayam*, which is an alternative method of controlling your anger. I didn't want ECT or Serenace injection for bringing down my anger. I did my *Brahmari Pranayam* 151 times and my anger literally dropped down like mercury. Yet the *aayahs* came and gave me an injection. I didn't like that. They should have asked me. I was quiet; I was smiling. So they should not have given me that injection. I think that was real injustice. They should've asked me if I was still feeling agitated or whether I think I need the injection, because the patient does have the right.

The other justification for forced treatment is violence. But I believe that it is necessary to understand the context in which violence operates. Very often violence within institutions is seen as a way of showing the non-compliance on behalf of the individual. But why is there non-compliance, if at all? The system needs to understand the reason for non-compliance before finding the 'solution – the only solution being forced treatment' for it. Is there non-compliance because the individual who is a victim of the system is not given a choice regarding his / her own life? Has the system ever looked at violence as a cry for help? The system is blind towards these issues and perceives only the violence, which further leads to more coercion and then more violence.

In the mental hospital, once when I was violent but I didn't beat anybody, I was just angry. This nurse, not a psychiatric nurse, but the one who observes the patients and gives medication and injection, called a patient who was very hefty and very strong pounced on me and dropped me down, she fell on me and she pierced her fingers into my eyes. After that I was kept in a lock up. Then I was transferred to the observation ward and kept there for a long time. I don't exactly remember but they used to keep me for a long time in the lock up in a room. In one single room I used to be kept in a lock up.

My violence had increased when I was undergoing the treatment of a private psychiatrist. In my case, all my violence, my anger, everything increased under his treatment and I can't forgive him for that. I told myself that if anything happens to my parents I'll go and tell him that you have killed my parents. I'm going to tell him that. I may have beaten them but you have killed them. That time my violence had increased so much. Every hour I was given a Serenace injection! Can you believe that? The violence is because of that. They used to tie me up to the bed. Ultimately he said that now she needs to be sent to the mental hospital. I didn't ask him why he was tying me up. I didn't have a mouth to open. That time I was helpless. They were doing it to me. How could I ask them why are you tying me up? But I used to reject. Wherever I go I have my paint box with me. I rejected it so badly that I broke it open and I made a painting. It was a flower vase. I didn't like the way he was tying me up all the time. He used to always give me injections and medicines and tie me up. He said you admit her here and we'll handle her here.

If anyone is restrained (I refer to restraint and struggle metaphorically as well and not just physical restraint) it automatically leads to a struggle for freedom. This is true for everyone. We see this kind of struggle by so many people around us all the time. But just because they don't have the label of mental illness we don't restraint them further but in fact support them in their struggle for freedom. Then why not someone with mental illness?

I was also taken to private psychiatrists. I've also been admitted to a hospital. The psychiatrist used to tie me up there. That is a general hospital OPD but he used to tie me up to the bed. I used to struggle and struggle and struggle and break up all those bandages. Where I won't be able to see myself like the legs and the waist, he used to tie me up everywhere. I used to struggle and struggle. I wanted my freedom and I used to break open. When I used to get violent, they didn't know from where I used to get the strength to be so violent.

The doctor himself got nervous that he had kept me in a lockup for such a long time. He was very strict and he said that she has to be controlled like this. I used to be kept for months like that. The Superintendent used to write letters some times. She used to tell the counselors and write in my file that my parents should come and meet me every fifteen days. Even if I was 15 days in the lockup and if my parents came to meet me, I used to feel good about it. When I said that I want to meet my mother, that doctor didn't turn up the next day. He got nervous because he was so strict with me and my parents can also react.

Once when I got violent at a doctor, he pulled my hair. I was there and I was painting. The nurse said that she has to sleep but she is not sleeping. It was written in the files that if she doesn't sleep, give her an injection. I was given an injection. I don't remember the exact series of events. He had made a pass at a pretty girl in the OPD. I had not liked the conduct. If it were any other doctor who had given me an injection, I would not have beaten him. But I didn't like his conduct of making a pass at a pretty girl in the OPD. I beat him up because I remembered that incident. That's why I got angry with him giving me the injection and I beat him. So he pulled my hair. A doctor getting angry on a patient and reacting in that fashion!

Force is something that is not experienced only in the context of the hospitals or service delivery system. At times, the family of the person with illness is also involved in harnessing force as a factor in the treatment procedure. As you will see in the following narrative, often, the family starts taking decisions on behalf of the person and that too without informing them about it or giving them a choice about their own life. This not only causes more stress to the individual but also is a violation of the right of the person to know and take decisions for their own life. According to the Convention of the Rights of Persons with Disabilities (CRPD), a new concept of supportive decision-making rather than substituted decision-making has been introduced. Supportive decision-making takes into consideration the fact that there is only a miniscule number of people that need 100% support otherwise people are entirely capable of looking after themselves and making their own decisions.

My children were taken out and my husband also left with them. I don't remember what he said to me and why he is taking them. But my elder son told me that, *"Mama, he told us that he is giving us chocolates and so he took us down."* The bell rang after that and I opened the door. There was a man, quite decent looking, a female wearing a white sari looking like a hospital nurse and another man in hospital uniform. I never doubted anything. This man told me that I have come to this building to give mosquito vaccines and I have come to vaccinate. At that time I don't know if he hypnotized me or what. I argued with him but I don't even remember what I argued about. I am a naturopath and I was hesitant about giving my children also vaccinations. I was questioning about a hundred things but somehow I called them inside and they sat down. I was arguing with them for about 20 minutes. They said that this is important and we're giving it to each and every person in the building. I argued with them for sometime, picked up my shoes, shut the door and walked out with them. Before that he injected me without asking a single question. I was reluctant but I saw that lady and I trusted them and felt safe because there was a woman. It wasn't something I feared and allowed him to inject me. He gave me something on my hand and immediately I took my shoes and within a minute I walked out with them and fell on that lady's shoulder in the lift. That's all that I remember. I don't remember anything after that. After that what I remember is that

I was in the hospital just as a prisoner. The hospital has wired windows and nobody can say that I'm jumping off and go. These people used to just give me tablets. I was never sick in my life and I never used to have tablets on a regular basis. I used to hate it. They used to watch me and they used to say that you have to have this. I was just having my tablets and eating my food and sleeping .. getting up… sleeping .. getting up… having a bath… After some time I realized that my fingers didn't work properly and trembled. I was feeling very weak and working was becoming very difficult for me. I did not know what was happening to me and nobody was visiting me at all. I think I used to ask questions. Then I remember that many times in the hospital, I think it was on every second day basis, I was unconscious. I did not know what was happening.

Forced treatment is not only about forcefully receiving treatment but it also means denying someone a treatment modality that they want and may benefit from. Denial of treatment not only leads to exacerbation of the problem but also leads to stagnation in the condition of the individual rather than an effort in the direction of healing.

The observation ward has cells. There are about six to seven cells attached to it. They don't give the injections and then the patient gets violent and so he is kept in the observation ward. He gets more violent because he is kept in a lock up. The injections are not given. That's another thing. They just tick mark that they have given it. Some people are not sincere.

Everybody goes home after half day. Psychiatrists also go home. In the afternoon it is so boring in the hospital because there is nobody there. Doctors also leave by 2. All of them have private practices. There is nobody to provide any activities. Occupational therapists, psychiatric social workers also go off at 2. Through out the day we do nothing. We used to just roam around the hospital or sleep. There are very bad conditions.

As to my knowledge I haven't seen anybody there sitting and counseling patients. If anybody wanted to talk they used to. But then it wasn't exactly like counseling.

There wasn't enough space for everyone in occupational therapy. There is one room and some people come and make bags, some people do embroidery, and then these occupational therapists just observe the patients and probably in the file mark that she is doing well or whatever. Then they weigh the material and decide what remuneration she should get out of that. They see all that.

There is a thin line between not denying treatment and forced treatment. One needs to understand the nuances of the issue like freedom, rights, sensitivity, and choice before falling back on any form of treatment. Also, what needs to be explored are the alternatives to forced treatment. While working on the Archives what has come through strongly is the dire need for a change in the way the system functions, abolishing some of the old and barbaric forms of treatment and looking for user led treatment options which give dignity, respect and freedom of choice to the individual.

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"Oral histories archive" is a collection of mental health experiences of people. This is based on our belief that people who have undergone mental distress have memories, histories, personal experiences and a coherent story to share.

We invite you to connect with us and share your experiences, your story, creative writings, poems, photographs, music, arts and artefacts with us. We are also interested in the political materials you may have published, such as posters, fliers, campaign letters, etc. Users have also willingly contributed their correspondence with their therapist or doctor. We share this invaluable collection with the community through our library and documentation center.

We hope that the stories will mobilize user / survivors in India and the south Asian region, and will bring us courage and self-confidence in speaking for ourselves.

For further information regarding the Archives, please contact Maitreyee / Puja / Seema at the Center for Advocacy in Mental Health, Pune.

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International Ashoka Fellows Exchange Program

Visit by Mr Gábor Gombos, Mental health & Human Rights scholar and activist from Hungary, June 2008 - November, 2008

The Bapu Trust for Research on Mind & Discourse is facilitating a 6 month visit by Mr Gábor Gombos, from Hungary. Gábor Gombos, a former theoretical physicist and survivor of psychiatry, has become a world-renowned advocate for the rights of persons with psycho-social disabilities. For over a decade, and until 2006, he chaired Hungary's only network of user organisations (Hungarian Mental Health Interest Forum). During this time he liased with self-advocacy groups and local user NGOs with the relevant authorities, including local municipalities, members of the Parliament and the national govenment. The Forum had gained official recognition by the legislature and local and central policy makers while maintaining its grassroots character. Gábor focussed his efforts to train self-advocates and local advocacy groups. He and the Forum has extensively contributed to recent legislative reforms in Hungary, including the legal ban on the cage beds that had been widely used in psychiatric facilities to restrain people. He also contributed to relevant amendments to the social care act and to the development of standards for alternative, non-coercive, community-based services for persons with psychosocial disabilities.

The Mental Disability Advocacy Center in Hungary advances the human rights of children and adults with actual or perceived intellectual or psycho-social (mental health) disabilities. Focusing on Europe and central Asia, they use a combination of law and advocacy to promote equality and social integration. Gábor is Senior Advocacy Officer at MDAC, leading their intergovernmental and national level advocacy. In this role he has extensively advised intergovernmental bodies, such as the Council of Europe, the European Commission and the United Nations on disability rights issues and has participated as a delegate of the civil society in the work of the UN Ad Hoc Committee which drafted the new Convention on the Rights of Persons with Disabilities. Gábor was profiled in the project, Speak Truth to Power as one of the 51 select leading human rights defenders around the globe. He is a Fellow of Ashoka: the Global Association of Leading Social Entrepreneurs.

Internationally, Gábor acted as chair of the European Network of (ex-) Users and Survivors of Psychiatry, a European umbrella of national NGOs of persons with psychosocial disabilities until 2004. Currently he serves as deputy chair and regional board member for Central Europe. Between 2001 and 2003 he extensively worked as a consultant in Kosovo to help self-advocacy initiatives.

Need for this exchange

Persons living with a mental illness can be the best advocates for themselves as well as for their peers. This potential is hindered by many obstacles, each of them rooted in the stigma associated with disabilites in general and with psychosocial disabilities in particular. Discrimination against persons living with a mental illness affect every aspect of private and public life. Having a psychosocial disability or even a family member with such a disability is a taboo in many societies including India. In most societies persons with psychosocial disabilites belong to the most marginalised, disenfrenchised, disempowered groups of people, who are kept invisible, whose voice is not heard and not listened to.

While in India important steps have been made by a number of disability rights activists, human rights defenders and academics working in the field, the movement of self-advocates, advocates who are persons living with mental illness themselves, has not yet started. India has much potential to approach psychosocial disability in an innovative way, partly based on its traditional healing, spiritual sensitivity, and the like.

The objectives of the international exchange:

Gábor Gombos' work in India has the following objectives:

- ➲ To create a non-combative, safe environment where public discourse on the need for and viability of self-advocacy of persons living with a mental illness is encouraged.
- ➲ To facilitate such a discourse in different settings and with different stakeholders.
- ➲ To engage as much as possible in this short period of time, with the in-country processes of CRPD implementation with respect to various Acts and laws.

- ➲ To develop and test training and audio visual materials that can be used by Bapu Trust to train supporters and future self-advocates.
- ➲ To inform stakeholders on the issues by doing the activities, including speaking arrangements, lectures, media appearances and the like. All these objectives are planned to be realised through a collaborative and participatory process.

Plans for Gábor's visit

Gábor aims to work with a wide diversity of constituencies in the mental health sector while he is here. We are looking for collaborations where Gabor can actively interact with groups of users and survivors of psychiatry, and other mental health sector leaders. He will develop and conduct workshops on Self advocacy for persons with psychosocial disabilities, for various mental health constituencies. Training programs for care givers using the Self Advocacy model is also being considered. The Bapu Trust is also happy to receive collaborative proposals for public lectures and seminars from research and training institutions, particularly relating to the CRPD, on which he has expertise. Strategic or policy level meetings, consultations in different parts of the country with legal, research and human rights institutions would also benefit from his contributions.

Organisational support for the Exchange:

Bapu Trust for Research on Mind & Discourse, India.

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...that is why they sent her there

Radhika Sharma

Imagine you leave home in the morning to visit a court, where you are contesting a civil case, and you land up in a mental hospital later, that very day due to some occurrences at the court, instead of returning home- Weird? Why am I asking you to imagine something like this, will be your question… right?

I would have probably found this question equally weird, was I not a witness to an incident of this sort. I remember being so scared that Malvika [(name changed), (the woman who experienced forced institutionalization)] will be stripped off her most basic rights on being institutionalized, angry as to how could a "Justice dispensing system" be so unjust to an individual and family, helpless where my belief in rights and dignity and strategies to restore the same was yielding no results. Eyes still moisten up and head spins round when I recall that day. It happened over 10 months back but this is the reaction that the gross memories still evoke in me.

To lay context of how I got involved in this is that I work with an organization that carries out psychotherapeutic interventions at one of the courts in Mumbai. This incident took place in the same court. I was called by the court to manage an "emergency situation"- the situation being that a woman had become aggressive and was verbally as well as physically abusing the police, arguing and shouting at the Judge etc. She was "not listening to" anyone attempting to pacify her, be it the court staff or other litigants of the court. There was no one from the woman's family accompanying her, on the court premises that day. The woman had a divorce case filed (by the husband) in the court, but that day was not her court date. When I reached there, she was being taken away by the police.

I later found out that her name was Malvika. Stories of Malvika being affected by mental illness were coming in abundance. In fact one staff member termed her mother "half mad" as they had been telling Malvika's mother for long to get her treated with psychiatric medication; But the mother always denied the option saying that nothing was wrong with her daughter.

The Judge asked me to follow up the case by attending to the client, to help her calm down and to accompany her to the Magistrate's court, and to see to it that she was admitted to the Mental hospital. "Mental Hospital"??!!! I said to myself. My body and mind began sending so many warning signals to each other as soon as I heard of it. Trying to not make my internal alarm so evident and not sound ridiculous over the institutional mathematic that the court had worked out, I explored with him the possibility of the court officials accompanying her to a psychiatric OPD or ward. I added- "It is not custodial and she could be discharged from there once she was feeling better." I told him that there were instances where people had found it difficult to come out from mental hospitals even after they were doing much better and languished there for long time. The Judge was quick to cut me short and to say that people (of course referring to me) held a lot of misconceptions regarding the mental hospital. He added that there were provisions made for such admissions under the Mental Health Act[1]. He said that this would ensure that she was getting treated properly there. He added that he was not looking at short-term and patch work treatment but rather a comprehensive treatment which he felt would best happen at the mental hospital itself.

I got my hands on the court order / (letter by the Judge, carrying the seal of the Court) addressed to the Chief Metropolitan Magistrate. The order briefed the magistrate about the incident that had taken place at the court. The Judge stated in the letter that he strongly believed that she required immediate medical help and probably required admission to the mental hospital also. Hence he was sending her to the magistrate so that he could pass the required order. He asked him to kindly do the needful and oblige. In the meanwhile Malvika was taken to the nearest police station- she was now in police custody- officially.

In the meanwhile, a court staff traced the client's details and got in touch with the mother and told her about what had happened. She asked them, not to take her daughter to any hospital and that she was on her way and would reach the court as soon as possible. After she reached the court, she was taken to the Judge, so that she could explain to him that she would take care of her daughter and did not wish a mental hospital admission. When the Judge was told about her, he refused to even look at her and said that he had nothing to do with what she had to say and that he did not want to talk to the mother. The mother, me and a court official went to the police station to meet Malvika.

From there on, she was taken to the Sessions court and presented there. Her younger brother, who had got to know about it while at work, also joined us there. When the magistrate spoke to her and asked her questions, she was already in a much better state and answered all the questions. The family also told him that she was already undergoing treatment with a psychiatrist who was associated to a government hospital. He asked them if there was any proof of her being on psychiatric medication. They said that they were not carrying any prescriptions at that time, since all this had happened all of a sudden. The magistrate passed a reception order, committing her to the mental hospital. While the Magistrate was dictating the order to the steno, the client could understand some things about it and it led to her getting into an argument with the magistrate. This led to another episode of aggressive behavior that took a lot of our collective energies to pacify her. It also led to Malvika verbally abusing the police constables and also getting equally abused by them.

Malvika was taken to the mental hospital at 11 p.m. after all these legal and administrative formalities were over.

At 11 p.m. while she was being taken inside the hospital, she kept pleading to the officials that she would "behave herself" from thereon. She also told me that the court had been so unjust to her (by not providing her with interim maintenance, not helping her with a job) for 4 years. When she misbehaved with them for once, she was sent away to the mental hospital. "Did I punish them for not giving me justice? But they have punished me straight away", she said.

Malvika stayed in the mental hospital for 14 days. Her mother would go and sit at the hospital gate every morning hoping to atleast catch a glimpse of her daughter if not meet her. However the walls of the institution were overwhelmingly big and robust, to let her in. She would talk to various employees, ask them for a way out of that place; send undergarments and sanitary napkins for Malvika (she had started menstruating the day she was institutionalized and of course needless to say that the mental hospital she was in, did not provide sanitary napkins and undergarments). Her brother, me and my colleague would talk to the medical officers there, the woman psychiatrist treating her, and the senior psychiatrist to explore some way out of this.

Finally with the family's consistent untiring efforts to get her out of there, on the 14th day after her institutionalization she walked out. She constantly kept telling and asking- "I don't want to come back here. Never. They will not put me in the hospital again, na?"

For the next one month Malvika was in a government hospital "under treatment and observation" since the court wanted to ensure that she was being treated "comprehensively". So another month of captivity, though not quite like the mental hospital.

Malvika is home now with her family, doing much better as home is where her heart is. But she has stopped coming to the court - I don't think I need to clarify why. Her interim maintenance has still not started. Her husband who has filed for a divorce was ready to pay alimony of 2 lakhs (before this incident). He now says he will pay only 50,000/- The court itself has done the honors of proving that his wife Malvika has mental illness, which has made seeking divorce for him very simple. Why would he pay Malvika 2 lakhs then?

I wonder at times, what Malvika could have been signifying by being aggressive on court campus. Later in one of my many conversations with her she told me that she had come to the court for creating a noise. Deliberately. She called it *"Hungama"* And she did just that. Her case had been in the court for the last 4 years and her interim maintenance had not started yet. How was she to support herself financially? She had been hunting desperately for a job (Malvika is a Ph D in Physics), but her identity of being mentally ill was most stark for everybody. So no job. She was labeled with mental illness, and that identity was big enough to hide behind itself all other virtues, reasoning and capacities that she had in abundance. Her biggest identity was that she was "mentally ill". Yes now I know! This is what went against her! Now I know. That is why they sent her there.

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[1] In fact, the Mental Health Act has absolutely no provision for referral from a civil court to the mental hospital. The Family Court Act also has no such provision for a mental hospital referral.

Drive love away

Replace a free and loving heart
with a gangrenous fortress:

The chill of loneliness,
frost bitten emotion,
time and experience settled
like ancient hard mold,
the egos darkness
scattering its demons
and contagions.

Tenaciously dream
lies of secure towers within,
weak defenses
guarded fiercely
by cataract eyes,
short-circuitd bodies
and snapping mouths.

Unleash
the dread and violence
of anger and anxiety
upon fuzzy targets
of your own delusions.

Drown
the warm smell of earth
in a reptile ridden moat
of predatory emotion
and anticipate the
perfumed odours of staled life.

Pack
the sunshine and bury it
in that opulent emptiness
of your remote heart
where carrions roam
feeding on your own and others death.

Drive love away
and wait to be overcome
in heart space fully alien
but religiously possessed
in willed hallucination
from your everyday death space.

Bhargavi V, 1991

Heres another

Heres another
dedicated to those
who turned away
when I lacked the finesse
to protest with love
and speak softly
of my need
to often wander
outside the sheltering
stifling?
penumbra within
which they sought
to contain me.
Catch the lightness
And warm hue
Of the space between
You and me
When you stretch
A tentacle of your self
To swiftly but firmly
Push me away
From your border,
And I understand,
Afresh,
My separateness.
Ah, ah,
A moment of grief
Of death and loss
And then, Aha!!
A new Me
Lonely
But not broken,
Even joyful.

Bhargavi 24/7/07

"...since human beings invent
symbols with infinite
inventiveness, the propensity
to harm people in the name of
helping them is one of
mankind's favourite
occupations."

Thomas Szasz

Soteria: An Alternative Mental Health Reform Movement [1]

In honor of Loren R. Mosher, Volkmar Aderhold, Peter Stastny and Peter Lehmann

The Soteria treatment model was introduced by the American psychiatrist Loren Mosher (1933-2004) in the early 1970s and named after the Greek goddess of safety and deliverance from harm. The aim was to investigate the effects of a supportive milieu ("being with") for individuals diagnosed with "schizophrenia," who were experiencing acute psychotic episodes for the first or second time in their lives.

An Understanding of Psychosis

Mosher had a life-long scepticism vis-à-vis all models of "schizophrenia," primarily because they would stand in the way of an open phenomenological view. He saw the phenomenon, which is usually called "psychosis," as a coping mechanism and a response to years of various traumatic events that caused the person to retreat from conventional reality. The experiential and behavioural attributes of "psychosis"—including irrationality, terror, and mystical experiences—were seen as extremes of basic human attributes. Accordingly, the initial Soteria experiments were set up in an open, fairly unstructured fashion, creating opportunities for profound as well as everyday experiences and mutual learning and support.

Any psychiatric drug was supposed to remain under the control of each resident. Dosages were adjusted according to self-observation and staff reports. After a two week trial period, a joint decision was taken whether it made sense to continue the "medication" or not (Mosher, et al., 1994, p. 17).

The Setting

Soteria offered a homelike environment in a 12-room house with a garden in a fairly poor neighbourhood of San José, California and intensive milieu therapy for six to seven individuals. About seven full-time staff members plus volunteers worked there, selected for their personal rather than formal qualifications, and characterized as psychologically strong, independent, mature, warm, and empathic. Soteria staff members did not espouse an orientation that emphasized psychopathology, deliberately avoided the use of psychiatric labels, and were significantly more intuitive, introverted, flexible, and tolerant of altered states of consciousness than the staff on general psychiatric inpatient units (Hirschfeld, et al., 1977; Mosher, et al., 1973). These personality traits seem to be highly relevant for success in this kind of work. Former residents became staff members on several occasions. Soteria employed a quarter-time psychiatrist, who visited the house once a week, and was available on call. Shifts up to 48 hours gave the opportunity of "being with" residents for extended periods of time and thereby going through complete biological/psychological cycles while avoiding disruptive separations due to staff rotations.

Procedures

Soteria was an open social system, which allowed easy access, departure and return, if needed. The staff's primary duty was to "be with" disorganized clients without the expectation that they needed to be doing something specific. If frightened, they could call for help. The average length of stay was 4-5 months, and full or partial recovery was generally achieved within 6-8 weeks.

Everyone shared the day-to-day running of the house to the extent they could. Roles were only minimally differentiated to encourage flexibility, with little emphasis on hierarchy, which meant a relatively informal daily schedule. Integration into the local community was paramount.

Instead of traditionally defined, formal in-house therapy, Soteria residents appreciated the offerings of yoga, massage, art, music, dance, sports, outings, gardening, shopping, cooking, etc.

Special meetings were scheduled to deal with interpersonal problems as they arose, and family mediation was provided as needed. Continuity of relationships after moving out of the house was greatly encouraged.

General guidelines for behaviour, interaction and expectation (adapted from Mosher & Hendrix, 2004):

- ➯ Do no harm.
- ➯ Treat everyone, and expect to be treated, with dignity and respect.

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(1) This is a very shortened version of the article, which was originally published in: Peter Stastny & Peter Lehmann (Eds.) (2007). *Alternatives beyond psychiatry* (pp. 146-160). Berlin / Eugene / Shrewsbury: Peter Lehmann Publishing. More about this book see www.peter-lehmann-publishing.com/comingoff

- Guarantee asylum, quiet, safety, support, protection, containment, interpersonal validation, food and shelter.
- Expect recovery from psychosis, which might include learning and growth through and from the experience.
- Provide positive explanations and optimism.
- Identify plausible explanations: emphasis on biography, life events, trigger factors instead of vulnerability; promoting experiences of success.
- Encourage residents to develop their own recovery plans; consider them the experts.
- Identify meaningful aspects of life beyond Soteria House.
- Do not assume responsibility for anything the clients might be capable of achieving—trust in self-help.
- Do not use the labels "schizophrenia" or "schizophrenic."
- Collaborate with residents, even if they do not take the prescribed psychiatric drugs.

Rules

Violence to self or others is forbidden, as are sexual relations among residents and between residents and team-members. Visitors are only allowed with prearrangement and agreement of the current residents of the house. Family members and friends are welcome, but it is preferred that they plan their visits ahead of time. No illegal drugs are allowed in the house. (In actuality, residents rarely used illegal drugs, certainly not in the house.)

Three Phases

1. Acute crisis: During this phase "being with" was employed as a practice of interpersonal phenomenology. The use of a special "soft" room was soon abandoned in favour of a fluid interpersonal way of "being with" in a variety of physical and social settings. As long as residents were not a threat to themselves or others, extremes of human behaviour were tolerated.

2. Restitution: During this phase, the resident was expected to get involved in daily routines, which corresponded to a role change by the staff from parent-substitute to a more symmetrical peer relationship. In order to normalize the experience of "psychosis," it was related to the person's biographical context, framed in positive terms, and described in everyday language. Developing relationships was of great importance to facilitate a process of emulation and identification among clients, and to enable the staff to recognize any precipitating events and the painful emotions that stem from them.

3. Orientation to the world outside: This phase included role diversification, growing competence and the development of new relationships inside and outside the house: cooperation, planning, accommodation. It was common to reach a consensus among the entire group regarding the timing of a resident's departure. The naturally developing social network of peers remained available after discharge to support recovery and to facilitate community integration, which included direct help with housing, education, work and social life. If necessary, former residents were always welcome back, as long as space at the house was available. Mosher believed that this network was of crucial importance for the long-term outcome of the Soteria work. The "Soteria community" remained active for at least ten years after the program was closed.

Dissemination and Replicability of the Soteria-Approach

Similar programs have been developed in Europe and North America, mostly in proximity to psychiatric hospitals. Initiatives to promote such programs are currently active around the world. The Soteria model has been marginalized in psychiatric discourse and largely ignored in the psychiatric literature due to the expectation that neuroleptics should be used selectively, for example " if there was no sufficient improvement after six weeks" (Mosher & Menn, 1978). Thereby the program constitutes a challenge to the medical model, and the wide acceptance of hospital treatment as the standard of care for acute psychosocial crises (Mosher & Hendrix, 2004, p. 282).

Nevertheless, during the past 20 years, the Soteria approach has become quite influential within the debate about the reform of therapeutic methods. To this day, the Soteria model remains particularly encouraging for the movement of (ex-) users and survivors of psychiatry and for mental health workers who feel allied with it since it represents a concrete alternative to traditional treatment and is not dominated by neuroleptic use. By demonstrating the self-healing potential of individuals experiencing acute psychoses, it constitutes a major attempt to create a system of appropriate and effective support for people in psychosocial distress.

Additionally, the Soteria model has contributed to the occasional development of acute inpatient units that employ so-called Soteria elements, such as a live-in kitchen, availability of multiple relationships, involvement of relatives with the possibility of overnight stays, an open door secured by a reception area, a "soft room" and psychotherapeutic support. Initially, the main focus was the reduction of coercive measures and the promotion of an open-door policy. Support for patients in the midst of psychosis by "being with" is not routinely provided. Neuroleptics are generally given in low doses, but rarely avoided altogether.

As an answer to the risk of dilution and alteration of the Soteria concept, Mosher and Ciompi have developed the following catalogue of elements that must be in place before a program can call itself "Soteria". While there may be reasons to modify these elements, the question as to who might have the right to do so while still using the Soteria moniker is sensitive and remains unresolved.

Since the founding of Soteria in 1971, there have been approximately 12 similar projects around the world, most of them in Europe.

Soteria: Critical Ingredients

1. *Facility*: Small, community based, open, voluntary, home-like, living no more than 10 persons including two staff (one man and one woman) on duty, preferably in 24 to 48 hour shifts to allow prolonged intensive one-to-one contact as needed.

2. *Social Environment*: Respectful, consistent, clear, and predictable with the ability to provide asylum, safety, protection, containment, control of stimulation, support and socialization as determined by individual needs. Over time it will come to be experienced as a surrogate family.

3. *Social Structure*: Preservation of personal power to maintain autonomy, mute the hierarchy, prevent the development of dependency and encourage reciprocal relationships. Minimal role differentiation (between staff and clients) to encourage flexibility of roles, relationships and responses. Daily running of house shared to the extent possible. "Usual" activities carried out to maintain attachments to ordinary life—e.g, cooking, cleaning, shopping, music, art, excursions etc.

4. *Staff*: May be mental health trained and user/survivor-trained professionals, specially trained and selected non-professionals, former clients, especially those who were treated in the program, or a combination of the three types. On the job training via supervision of work with clients, including family interventions, should be available to all staff as needed.

5. *Relationships*: These are central to the program's work. They are facilitated by staff being ideologically uncommitted (i.e., to approach psychosis with an open mind), conveying positive expectations of recovery, validating the person's subjective experience of psychosis as real by developing an understanding of it by "being with" and "doing with" the clients. No psychiatric jargon is used in interactions with clients.

6. *Therapy*: All activities viewed as potentially "therapeutic" but without formal therapy sessions with the exception of working with the families of those in residence. In-house problems dealt with immediately by convening those involved in problem-solving sessions.

7. *Psychiatric drugs*: No or low dose neuroleptic drug use to avoid their acute "dumbing down" effects and their suppression of affective expression. Also avoid risk of their long-term toxicities. Benzodiazepines may be used short term to restore sleep-wake cycles.

8. *Length of stay*: Sufficient time spent in the program for relationships to develop that allow precipitating events to be acknowledged; usually disavowed painful emotions to be experienced and expressed and put into perspective by fitting them into the continuity of the person's life.

9. *After-care*: Post-discharge relationships encouraged (with staff and peers) to allow easy return (if necessary) and foster development of peer-based problem solving community based social networks. The availability of these networks is critical to long-term outcome as they promote community integration of former clients and the program itself.

Soteria as an Ideological Movement and a Guiding Idea

No definitive instructions or algorithms for the treatment of psychosis were formulated the Soteria projects in California. It is not the psychosis—whatever this might be—that is being treated, but a human being in the midst of an altered experience who is being supported and accompanied, realizing that each individual is very different from the other, and consequently that there can be no "universal recipe" (Runte, 2001) and no universal diagnosis, or in the words of Mosher: "there is no cookbook." The uniqueness of each staff member is being recognized as well.

Referring to psychiatric drugs, Mosher and Hendrix summarized in 2004:

Today (2004) my position is that, since no real alternatives to antipsychotic drugs are currently available, to be totally against them is untenable. Thus, for seriously disturbed people, I occasionally recommend them—as part of collaborative planning with my client— but in the lowest dosage and in the shortest length of time possible. Instead of antipsychotics, however, I prefer to calm acute psychosis and restore sleep/wake cycles with an initial course of minor tranquilizers accompanied by in-home crisis intervention (Mosher & Hendrix, 2004, p. 303).

In sum, the Soteria idea has contributed to the fact that milieu- and interpersonal aspects of treatment, especially in German-speaking countries, are taken a bit more seriously.

In the past 15-20 years, we have been continually accompanied, overtly or not, by the Soteria model. It has become a measure of humane treatment methods, a humane approach towards patients, even a measure of the appropriate conduct of doctors (Marneros, 2001, p. 219).

Current Assessment and Outlook

The Soteria-model has provided a notable impulse for rethinking the therapeutic milieu within the acute care system, but has so far not been translated into actual services that would be available to a significant proportion of individuals who might benefit from them. In addition, several program models have emerged that have implemented some of the Soteria-elements within routine services.

Such a treatment model could become a rallying point for service users, friends and relatives. Professionals and family organizations still seem thwarted by the economic dependencies from the pharmaceutical industry that have invaded the entire medical system in an insidious fashion (Angell, 2004), as well as by one-sided beliefs determined by biological reductionism. There is a growing international movement to promote and disseminate Soteria (i.e., www.intar.org, www.soterianetwork.org) and similar alternative treatment programs, because it may offer an alternative treatment for people diagnosed with schizophrenia spectrum disorders (Calton, et al., 2007).

Thus, there is hope that the pioneering work of Mosher (who proved that humane, non-medical support is the best way to help people undergoing severe emotional distress), will continue to provide fuel to an alternative mental health reform movement until alternatives to biological psychiatry are available.

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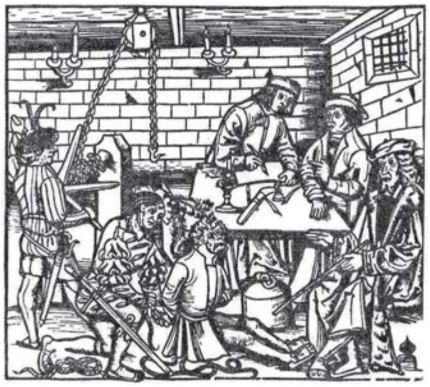

War Insurance Boycotter

Yoga Bare

We were handed shovels and instructed:
"This is your rehabilitation."
As we dug the trench
Coffins were unloaded from hearses.
I grew suspicious:
"Why?" I asked.
The foreman laughed:
"We have always done it this way."
I saw a cement slab with my name on it
And slammed down my shovel with a curse
I was hurried into a police wagon,
Lest others should hear my protest.
I was confined to a solitary cell.
I pounded frantically for fresh air to breathe.
Then my voice became silent;
My fingers were red with blood.
Mt ears quivered like leaves in a whirlwind,
My eyelids twitched against ugliness of my cell.
Finally the Doctor came and asked me my name;
"The surviving," I replied.

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