aaina

bapu Trust for Research on Mind and Discourse

mental health advocacy newsletter
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Editorial

There is a rush by many state governments to look at the TN Rules, 2002 as a way out of the present impasse created by the Mental Health Act. Every body who has had to use the MHA has faced difficulties, which are now being publicly acknowledged in many policy circles. The policy maker has to acknowledge the fact that needed community services, which are already too meager, may be shut down if the MHA is strictly enforced. Many institutions are run by social workers and counsellors, and not psychiatrists, which is against the MHA norms. NGOs and others involved in community work also question why psychiatrists should be involved in rehabilitation and recovery work.

If any facility or service program is started under the MHA, it can only end up being a psychiatric program. Such programs run the risk of becoming mental institutions, which in many years of the Indian experience, have served as places of psychiatric neglect and abuse, and in general, a dumping ground for unwanted relatives. Psychiatrists and psychiatric administrators have had a chance over many years to bring good quality mental health care to those in these institutions. Several quality assurance conferences and reports have been brought out in the last decade by the medical profession. However, the condition in such places till today in most of India shows gross medical negligence and great human deprivation and degradation. When psychiatrists have been singularly inept at bringing any notion of "care" to people in psychiatric institutions, the MHA stands discredited for giving this responsibility whole sale to them. Compliance with MHA poses human rights risks to the users of psychiatric services.

However, is TN Rules, 2002, a solution? It may relieve some of the administrative bottle necks in mental health services. It gives scope for a larger number of people to bring people into the rehabilitation regime. But it does not ensure the dignity and autonomy of users of psychiatry. This issue of *aaina* carries a report on the TN Rules, stressing the need for further debate.

continued on page 2

Contents

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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, especially of the poor and the homeless.

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

editorial...continued from page 2

Meanwhile, over the last 5 years or so, research data is accumulating on the iatrogenic effects of the much touted atypical antipsychotics. It will be too mild and misleading to talk about these effects as "side effects", rather, these medicines cause chronic diseases, such as diabetes. This *aaina* issue covers some research on this topic.

While the pro-adoption lobby talks about awareness, law reform, etc. here in this issue of *aaina*, is the sobering "other side", the story of a man haunted by the memory and loss of a lost mother, who he is sure, was deprived of her dignity and autonomy in the process of adoption.

Meanwhile, there is another UN Convention Ad Hoc Committee meeting coming up in July this year. Also, consumers of mental health services around the world are meeting at the World Association of Psychosocial Rehabilitation (WAPR), in Milan in the month of June, this year.

Aaina thanks Mr. Anand Pawar, *Communication Support*, Pune, for dedicated time given to the layout and production of *Aaina* for the last four years.

Living With HIV/AIDS: How Do Widowed Women Cope?

Mrudula A.
U. Vindhya

HIV/AIDS: An Overview

The buzzword since the last decade has been HIV/AIDS, bringing to mind images of a grotesquely manifested disease which inflicts "them" and not us. It was considered the problem of a highly select group of individuals – those with high-risk behavior – sex workers, injecting drug users, and professional blood donors. The general masses were thought to lead a "morally pure" life and hence not likely to acquire the dreaded virus (Bharat, 2000). Despite the disease exacting a huge toll on people in their most productive years with adverse impacts on life expectancy, productivity of labor force and household incomes (Mahal, 2004), it has remained shrouded in the mists of ignorance and stigma.

With initial "denial" giving way to a "reluctant acceptance" of the epidemic as a real health problem (Bharat, 2000), surveillance data now reveals that HIV is present in almost all parts of the country. The National AIDS Control Organization (NACO) reports that the epidemic is no longer confined to commercial sex workers and injecting drug users, but has spread from urban to rural areas and from individuals practicing risk behavior to the general population (NACO, 2003).

Factors such as labor migration, mobility in search of employment from economically backward to more advanced regions, low literacy levels leading to low awareness among the potentially high risk groups, gender disparity, sexually transmitted infections and reproductive tract infections among both men and women have provided the thrust for the rapid spread of the epidemic across the country (Gangakhedkar et al., 1997; NACO, 1997-98). In India, sexual contact constitutes the main source of infection in AIDS cases, followed by contaminated blood transfusions. About 89% of the reported cases are occurring in the sexually active and economically productive age group of 18-59 years.

The stigma attached to STDs and in particular to HIV/AIDS has devastating effects as discrimination against PLHAs (People Living with HIV/AIDS) denies them access to treatment, services and support and incomplete redressal of the pandemic (NACO, 2003). AIDS is seen as a "dirty" disease and associated with promiscuity, homosexuality and prostitution. In some developing countries, AIDS is also seen as a "woman's disease" because of its perception as a sexually transmitted disease and its association with prostitutes (Songwathana & Manderson, 1998).

The gender implications of HIV/AIDS is becoming increasingly important with rising HIV incidence among women – in view of the fact that heterosexual activity now constitutes the main mode of transmission of HIV. One in every four cases reported is a woman (NACO, 1997-98) and more and more women attending antenatal clinics are testing HIV positive (NACO, 2003). Women account for nearly half of the infected persons (UNAIDS, 1996; WHO, 2000) and the rates of infection have been increasing at much higher rates for women (Centre for Disease Control [CDC], 1993). The epidemic has hit women hard, yet, the HIV-related needs of women continue to receive minimal attention (Amaro, Raj & Reed, 2001).

Women have historically been under-represented in medical research, and as a continuing trend, have also been ignored in the development of appropriate diagnoses, treatment and prevention of HIV/AIDS (Corea, 1992). Coupled with this, the financial or material dependence on men (WHO, 2000), women's status in society, her lack of autonomy in her sexual relationship (Amaro, 1995), lack of access to education and information, poverty and sexual exploitation have all added to the special vulnerability of women to HIV/AIDS in countries like India where risk-taking among men is common (Aggleton & Rivers, 1999).

The early exclusion of women in clinical research (Fox-Tierney et al., 1999) and unequal gender relations contributed to a male-centered case definition of AIDS (Berer, 1993; Cohan & Atwood, 1994; Strebel, 1995). It is only in recent years that new research has begun to gain a more contextual understanding of women's HIV risks (Amaro & Raj, 2000).

However, despite increased recognition of the HIV epidemic among women, HIV-positive women's needs are still not being met completely. Women remain at high risk for HIV as a result of multiple types of discrimination, poverty, women's overall lower status in society and a medical field dominated by a male-centered approach (WHO, 2000). Due to this inherent difference in the social value ascribed to them, women tend to get marginalized from all aspects of social well being, and this distinction is clearly apparent in the realm of health (Datta, 2003). Women get doubly marginalized by virtue of being poor and of being women (Vijayanthi, 2002).

Literature in developed countries points to the role of psychosocial factors in adjustment and coping with chronic illness. Coping strategies such as creating a meaningful life pattern, connectedness and self-care have been identified as having an impact on the coping ability of people living with HIV/AIDS (Mellors, Erlen, Coontz & Lucke, 2001). High levels of social support, spiritual perspective, interpersonal conflict and perceived stress intensity are predictors of mastery over stress in HIV-positive women (Gray & Carson, 2002).

The plight of women who have been widowed due to HIV/AIDS and are infected themselves, has not received any attention so far. Their situation is further complicated, as they are widows, *and* infected with HIV/AIDS. This study therefore made an attempt to explore the dynamics of how this group of women, who are disadvantaged in all aspects of life, cope with their lives and their illness.

❖ The Twenty Women

Twenty women who had been widowed due to HIV/AIDS were interviewed and their general health assessed with the help of the General Health Questionnaire (GHQ). These women visit a local Non-Governmental Organization for medical and moral support.

❖ Sociodemographic Profile

The women revealed information about their family, marriage and lifestyle, relationship with husband, in-laws and parents, knowledge and awareness of HIV/AIDS, stigma, diet and exercise, children, education, income and occupation in an in-depth interview. The common characteristics of the women that emerged were as follows:

› The women were all widowed as their husbands died of HIV/AIDS after infecting them.

› The women were all in the age range of 18-45 years, and their mean age was 26.9 years.

› The women interviewed either had no formal education or had received primary schooling.

› Income levels of the group were low, with incomes ranging from having no income (n=6) to earning less than Rs.500 (n=7).

› All the women belonged to the lower socioeconomic class.

› Except for three women, all had 1-3 children, none of whom were infected.

› Most of the women (n=15) hailed from urban slums in the city that had been identified as high-risk areas by the NGO.

› A majority of the women lived in nuclear families, while some had a parent(s) living with them.

› The women had been diagnosed asHIV-positive between 6 months and 7 years prior to the date of the interview with them.

The socio-demographic pattern that emerged indicates that the entire sample belonged to the lower socioeconomic class. Occupation wise analysis revealed that a major portion of the women consisted of unskilled and semi-skilled workers, and housewives constituted 35 per cent of the total sample.

❖ Psychological Health Profile

An analysis of the GHQ revealed that:

- All the women had depressive symptoms
- Anxiety and insomnia were commonly reported
- All the women had contemplated suicide after they had been diagnosed as HIV-positive
- No social dysfunction was reported by the women.

❖ How Do They Cope?

Their Marital Life

The women in the sample reported that they had only one sex partner (their husband), pointing out to the disheartening fact that they were all infected through their husbands. Some of the women reported being forced to engage in sexual relations by their husband, knowing that he was HIV-positive, without heeding the doctor's warning to abstain from unsafe sex. The women revealed that the husbands had asserted that it was their right to engage in sex and that they had succumbed since they too endorsed such a right. This finding reaffirms that patriarchy and an association of masculinity with sexual domination and control play a major role in undermining women's choices. It also points to the internalization of such an ideology by the dominated and subordinate group.

When questioned about the quality of their marital relationship, the narratives revealed two opposing characteristics of their husbands. A majority of the women (n=14) reported alcohol consumption in varying degrees by their husbands. Of these, eleven of them revealed that they were abused when their husbands were in an inebriated state. Surprisingly, going against Indian women's strong belief of the 'God-like' status of their husbands, seven of these women reported feeling relief at the death of their husbands. Some of the women expressed that they had a good marital relationship with no abuse, and were taken care of by their husbands. However, only a few of this happily married group expressed sorrow at the death of their husband. Two of the women reported that they were kept in the dark about the HIV-positive status of their husbands before marriage.

These women felt cheated out of their right to live happily. This reflects, once again, the general disregard for women's rights and choices.

Social Support Network

Social support has been shown to contribute to a person's psychological and physical well-being (Cohen & Wills, 1985). The collectivist society in India provides for a vast network of social support not only from the immediate family, but also from the extended network of relatives, friends and neighbors. The in-depth interviews revealed that these widows enjoyed some form of support from their natal family, whether financially, emotionally or mere moral support. Almost all of them complained that their in-laws had abandoned them as soon as their husbands passed away, and after their HIV-positive status was confirmed.

Responsibility towards Children

One of the great challenges faced by HIV-positive women is that young women typically perform multiple roles (spouse, mother, daughter, employee), many of which include care giving (Ciambrone, 2003). What we found was that the burden of care giving acted as an effective strategy for coping with the illness. Amidst the sense of hopelessness, despair and helplessness, it was the burden of having to care for their children and their commitment to responsibility for their children's future that provided them with a reason to live. All of them cited that their children and their future was what kept motivating them to somehow live with the situation. The future of their children was a great source of concern, and this responsibility motivated the women to think positively and plan for the future of their children. The children's future served as a goal or focus for the women's energies and will to live.

Responsibility towards Self

Hailing from the lower socio-economic strata, and being widowed, being occupied to earn their livelihood was more a necessity than an option. The women received meager to no financial support from parents and in-laws. Self-care was another important factor which enabled the women to exercise control over their illness, and consequently over their lives. All of them reported conforming to the diet and exercise regimes advised by the counsellor. Most of them relied on the free vitamin supplements and health enhancing products that were distributed by the NGO. Personal hygiene also received priority.

Spirituality

When discussing their illness, the importance these women place on a strong spiritual life is clearly evident (Woodward & Sowell, 2001). Most of the women had a firm belief that God (in particular, all of them mentioned faith in Christianity) would guide them and give them the strength required to carry on in the face of adversity. An interesting finding was that none of the women denied their HIV-positive status. An active acceptance was evident, with the women integrating HIV into their lives.

Thus, caring for children, social support, keeping themselves occupied, religious/spiritual beliefs, and active acceptance of their health status were the important coping mechanisms adopted by the women.

Awareness about HIV/AIDS

The interview data revealed startling information that these women had no awareness of the disease, despite the massive campaign launched by the State and the Central governments. Being illiterate and poor, they paid no heed to the information being broadcast through both the print and electronic media. Despite the claims of organizations, both governmental and non-governmental, that there is an in increase in public awareness of HIV transmission, the truth is that this campaign does not seem to have reached the people at the grass-roots level. Thus, there does not seem to be any corresponding change in HIV/AIDS-related high-risk behavior.

Conclusion

While psychosocial risk factors have been the focus of burgeoning research in HIV/AIDS literature of women, the protective factors have received far less attention. It has now been accepted that the epidemic in women is very different from that observed in men, and the need for different paradigms to understand HIV in women has been established. This paves the way for future qualitative and quantitative investigations of HIV in women.

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Life behind walls...

Human rights within institutions

In this booklet, we bring you stories of people, women and men, who are living invisible lives as "mad criminals", "wandering lunatics", and unrecoverable patients within institutional settings: jails, mental hospitals and beggars' homes. This booklet is dedicated to the men and women who have struggled bravely with the troubles and traumas of their lives. Some of them continue to survive the harsh institutional environments where they eventually found themselves in, without knowing why. Others perished leaving no living memory of their foot print upon this world.

This booklet has been drawn from extensive research and documentation of users and survivors of psychiatry living within custodial institutions: jails, mental hospitals and beggars' homes. We have used the story telling method, drawing from our case studies, our library and our archives. The booklet may be used for training of government officers in different departments, as well as NGO staff in some human rights and advocacy aspects plaguing institutional care. The booklet is firm in its advocacy for non-institutional, non-coercive care for persons with psychosocial disabilities.

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Who am I?

Arun Dohle

This question, in its deepest roots, bothers me now for quite some time. I, Arun Dohle, or better, Swanand (my name before Adoption?) was born to a young unwed mother in Sassoon hospital in Pune. Well I know that now! I also know that she was an inmate of Mahila Seva Gram. That is almost all I know about her.

My parents Michael and Trudi Dohle are my German adoptive parents. Who are my natural parents? I have come to the conclusion that I´m related to a 1973 guest-family in Pune, of my adoptive parents. I could confirm this with a DNA test.

Now I'm trying to find my mother, with a lot of energy since the last four years. Almost all my energy seems to be pulled into the big black hole. And I can´t get this out of my head and resume a normal life. It is quite a burden not only for me, but also for my wife and my children.

I was most probably kidnapped from my mother, as I feel (and know from the missing documents) she never gave her consent. I was taken away from her, against her will. I was taken away from my community, from my country, India. Just for the protection of my family's reputation.

Nevertheless I was very lucky to have such lovely adoptive parents. I got everything a child deserves. Love, a good education, freedom in the sense I would have never had, if I would have remained in India. I can say overall I had a nice childhood and youth.

But at what price? I grew up in an alien country, though I was very much wanted and generally accepted. Today I feel I don´t fit in either here or there. I lost the opportunity to learn Indian languages and will probably never be able to speak them accent free.

Of course the forced separation and the subsequent adoption must have been a deep traumatic experience for me as a baby. But now I face the second one, the rejection of my paternal family/orphanage and the absolute silence from them to tell me who MY mother is.

I started the search at the age of 14. At least I wanted to. But of course wasn´t able. So the first time I came to India was in 1993. At that time I had no real idea how to go about it. So I was blocked soon.

My career wasn´t easy. I started studying, but discontinued studies and started my own business as a financial consultant. I became quite successful. Something from inside pushed me to start a search again. I had always thought about the search and had gone through several difficult times including experimenting with drugs. Luckily I never got really addicted.

One of my therapists actually tried to make me understand that I shouldn´t look into the past but look into the future and work for it. When I did this, things became worse, and I could see it in my business turnover. I made the conscious decision to work hard for my career in the next seven years and forget about the search. Consequently my turnover as a financial consultant declined. It was my fault. I changed the therapist. The new therapist just sort of allowed me to follow my inner feeling and push for the search. So I started the endeavour.

I never thought it would be so difficult and I would face so many practical difficulties. People denied my right to know who is my mother.

Of course whether I search or not, my soul is somewhat restless. So better to follow the pull and push? Currently, I really don´t know. I m in such a mess. Hardly able to get the resources to do it. At the same time now I am the father of twin sons with my wonderful wife in Germany. I hoped becoming a father would improve things, but I was wrong. Seeing my wife how nicely she deals with the kids, made my longing even stronger.

Without the support of my adoptive parents, I would hardly be able to do things. A thirty one year old father again dependent on parental support? Not a nice feeling.

However, I know from various interactions with other adoptees, be it in home-country or inter-country, that after the search was completed, it became a great relief for many.

Indeed not immediately, but after some time, when all the emotions are a little settled, though the deep wounds can never be really healed. We adoptees, most of them carry that cross with us for all our lives. I know quite a few adoptees who have even bigger issues, related to their adoption than I have. Some of them also have been adopted from India. Others, just don´t have the energy and resources like I have to take up a search in India. Therefore I currently started a small e-forum to try to build up some support for Indian inter-country adoptees who would like to find out about their roots.

http://www.people.freenet.de/connectedindianroots

It is also for adoptive parents who want to search for their children.

I do believe this is very important, concerning the amount of unethical adoptions which must have taken place in the last 35 years. How many children have been kidnapped? What is actually the psychological impact on them? How can a therapist deal with psychological issues, if he

doesn´t know the background? How many adoptees get a sort of wrong treatment? I know many adoptees who have to take anti-depressants or other medication. Without that they hardly can make it through their daily life. I know of adoptees who killed themselves, who got drug addicted etc.

This is a huge issue. A simple post-adoption program will not be of big help. Just exposing them to Indian culture etc. and at the end telling them that according to the culture they shouldn´t search for their mothers, is sometimes even more hurting. We are adults and can handle the stigma attached to unwed motherhood appropriately without killing them, as adoption agencies tell us.

I feel that adoptees should be reunited with their natural families. Go through a bonding process again. Nevertheless I feel it isn´t always necessary and healthy. Actually in adoption only the child who grows up himself / herself knows whether it is healthy or not. He/she knows unconsciously the background, knows whether he/she was given away out of inconvenience or the other extreme, may be kidnapped.

I wish a child loving his country, like India, would be allowed to know more about his identity. Maybe someday in the future I can say I'm the SON Of X mother and Y Father!

What pain are the mothers going through who lose their children to adoption? In India there isn´t any research on it, as in the west, those mothers suffer silent. At least in the west now, slowly some support groups are coming up. So slowly Natural Mothers come out of the dark. A study done in the US shows the alarming figures. Do Indian mothers feel different? Or are they just more pressurised to be silent? I believe Nature, or God, has created a deep bond between the family members. It can´t be simply cut. Cutting it has a deep impact, with consequent issues.

Adoption in India is a child-right issue, as well a woman's rights issue. Most of the children are taken from vulnerable mothers / families. Be it poverty, loss of husband, be it gender discrimination.

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Bapu's recent intervention in the Supreme Court

The treatment of "persons with mental illness" took a cruel turn in India when 25 persons kept in chains in a private asylum situated near a religious shrine were burnt alive in August 2001. The Supreme Court suo motu issued notice to the State governments asking them to explain how "persons with mental illness" were housed in other than licensed institutions. The court also required the states to provide information on the state of mental health services in their States. The court appointed two senior advocates as amicus to assist the court in its consideration of the matter. A major point of controversy in the court related to the establishment of mental hospitals with the Union of India contending that it was opposed to establishing institutions and the court on the advice of the amicus requiring the same

Around the same time a patient organization through the private psychiatrist who provided service filed a petition in public interest which amongst other things challenged the administration of unmodified electro-convulsive therapy and the use of "persons with mental illness" for purposes of research with the consent of their parent /guardian. This petition has resulted in interventions being filed by the official psychiatrist society stressing that a ban on unmodified ECT would deny poor patients of state of art treatment and how a number of patients for medical reasons could not be administered modified ECT. Both these matters have been clubbed by the court and are being considered along with some interventions filed by family groups.

It is in these matters that Bapu Trust has filed an intervention on the contention that this matter cannot be considered without hearing the users and survivors. That Bapu has users and survivors both on its Board and in its employ also that we are members of the World Network of Users and Survivors of Psychiatry. We have also impressed upon the Court the relevance of the UN Convention on the matter in hand. The petition has been filed by Amita Dhanda founder trustee as petitioner in person in order that we could present our viewpoint to the court without the mediation of a lawyer.

The court has allowed the intervention and fixed the matter for hearing in the third week of February before which Bapu is required to make its submissions on the user / survivor experience and the deliberations on the Convention to the Court.

At the time of posting this news item, the hearing has been adjourned to the month of September.

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Atypical antipsychotics

Research news abstracted from integrative_psychiatry@yahoogroups.com, an email group of medical and other professionals concerned about an integrated, non-hazardous and non-drug based approach to emotional distress. This review highlights the severe and dangerous health compromises brought about by the use of anti-psychotics.

Richard Bergman and Marilyn Ader's review on "Atypical antipsychotics and glucose homeostasis" outlined the development of non-immune diabetes and surveyed the available literature related to why anti-psychotics may lead to this disease. They got the literature regarding atypical antipsychotics and glucose homeostasis using PubMed. The search included English-language publications from 1990 through October 2004, as well as reports and abstracts from various national and international scientific meetings on diabetes, schizophrenia research and neuro-psycho-pharmacology through 2001-04. They favored original peer-reviewed articles. They reported that the metabolic profile caused by atypical antipsychotic treatment resembles type 2 diabetes. These agents cause weight gain in treated patients. Insulin resistance, usually associated with obesity, occurred to varying degrees with different antipsychotics. The bad effects of these drugs on fat distribution has been clearly shown in animal models. *(J Clinical Psychiatry 2005;66: pp. 504-514)*

For antipsychotic drugs, there are many studies that show that the newer drugs are associated with weight gain, diabetes, high cholesterol, high blood pressure, heart disease and stroke.

In July 2001, a paper in the *British J Psychiatry* 2001 Jul;179:pp.63-66 discussed the problem of venous thromboembolism with antipsychotic drugs. The authors report that "recent studies of good quality confirmed" that antipsychotic drugs are a risk factor for venous thrombosis.

In the Nov-Dec 2002 issue of *Encephale* 2002 Nov-Dec:28(6 Pt 1):pp.552-562, the authors noted that people with schizophrenia had a ten year shorter life span than the general population and a "33% increase in relative risk of death associated with circulatory disease". They looked into the possible role of antipsychotic drugs, and found many possible mechanisms for an increase in mortality and morbidity related to cardiovascular function. A technical list of them was provided: "receptor blockade; conduction disturbance (e.g. bundle branch block); delayed ventricular repolarisation (prolonged QTc interval); left ventricular dysfunction; sinus node abnormalities; myocarditis; postural hypotension; polydipsia-hyponatremia syndrome; weight gain; glucose intolerance. Of these, QTc interval prolongation, with the risk of progression to the potentially fatal ventricular tachyarrhythmia Torsades de Pointes (TdP), is of particular concern as this arrhythmia is unpredictable and difficult to manage. Coupled with these clinical concerns are regulatory issues regarding several compounds that have received warnings or been withdrawn from the market."

In November 2002, an article in the *Canadian Medical Association Journal* discussed one antipsychotic drug (risperidone/Risperdal) and its association with strokes or mini-strokes (transient ischemic attacks) among an elderly population with dementia. They found that there was a doubling of rate of strokes and mini-strokes in those taking Risperdal compared to the people with dementia not taking Risperdal. 43% of strokes resulted in death.

In February 2004, in *Diabetes Care* 27:596-601, 2004, four professional groups reviewed all the studies and issued a paper called *Consensus Development Conference on Antipsychotic Drugs and Obesity and Diabetes*. They found that: "With the introduction of the second-generation antipsychotics (SGAs) over the last decade, the use of these medications has soared…their use has been associated with reports of dramatic weight gain, diabetes (even acute metabolic decompensation, e.g., diabetic ketoacidosis [DKA]), and an atherogenic lipid profile (increased LDL cholesterol and triglyceride levels and decreased HDL cholesterol)…Because of the close associations between obesity, diabetes, and dyslipidemia (*disturbance in lipid profile)* and cardiovascular disease (CVD), there is heightened interest in the relationship between the SGAs and the development of these major CVD risk factors." The four organizations were the American Diabetes Association, American Psychiatric Association, American Association of Clinical Endocrinologists, and the North American Association for the Study of Obesity.

In the Fall 2001 issue of the *J Adolescent Psychopharmacology* 2001 Fall;11(3):239-50, a study discussed children given Zyprexa for bipolar mania. The children gained 11 pounds in the eight-week study. Weight gain is an indication of metabolic dysfunction, like insulin resistance, emerging diabetes, high cholesterol and heart disease.

In 2004, a study in *J Clinical Psychiatry* 2004; 65:pp.1420-1428 demonstrated that Zyprexa was associated with an increase in number of mood episodes, especially depressive episodes, in

people who rapid cycle with bipolar disorder.

In November 2004, an article published in the *J Clinical Psychiatry* noted that the new antipsychotic drugs were reported to induce mania in some people diagnosed with bipolar disorder, something never reported with the older antipsychotic drugs.

In December 2004, there was an article in *J Clinical Psychiatry* 2004 Dec;65(12):pp.1679-87 about weight in bipolar patients taking Zyprexa (olanzapine). The researchers found significant weight gain, as well as an increase in cholesterol, systolic and diastolic blood pressure and pulse rate. The authors concluded: "Weight gain associated with long-term olanzapine treatment for mania was common, substantial, time-dependent, predicted by initial increases, and temporally associated with significant changes in cardiovascular and metabolic measures in bipolar I patients with prolonged illness and already-high basal BMI (*Body Mass Index)*."

In 2004, the FDA required the manufacturers of all atypical antipsychotic drugs to update their labels regarding hyperglycemia and diabetes mellitus. The atypical antipsychotics are Zyprexa - olanzapine (likely to gain weight), clozapine - Clozaril (likely to gain weight), risperidone - Risperidal, Seroquil - quetipine, Geodon - ziprasidone, Abilify – aripipradole.

Hyperglycemia, in some cases extreme and associated with ketoacidosis or hyperosmolar coma or death, has been reported in patients treated with atypical anti-psychotics. A letter from Eli Lilly and Co. dated September 28, 2004, to European clinicians stated that a total of 49 adverse events, including eight fatal events, had been reported for Zyprexa IM as of August 31, 2004. Cardio-respiratory depression, hypotension, and bradycardia were among these reported cases. The letter stated, "A review of the reported fatalities indicates use of Zyprexa IM in a manner that is inconsistent with the Summary of Product Characteristics including excessive dosing and/or inappropriate use of concomitant benzodiazepines and/or other anti-psychotics." The letter outlines the following recommendations about use of Zyprexa IM:

- The maximum combined intramuscular and oral daily dose of Zyprexa is 20 mg, with an initial dose of Zyprexa IM 10 mg as a single injection (use lower doses in elderly patients and those with renal or hepatic impairment).

- A maximum of three injections of Zyprexa IM may be administered in 24 hours. A minimum of two hours should elapse between the first and second injections.

- Zyprexa IM is intended for short-term use only, for up to a maximum of three consecutive days.

- Zyprexa IM should not be administered to patients with unstable medical conditions.

- Patients treated with Zyprexa IM should have heart and respiratory rates, blood pressure, and level of consciousness carefully observed for two to four hours following administration.

- Simultaneous injection of Zyprexa IM and parenteral benzodiazepines is not recommended.

Assessment of the relationship between atypical antipsychotic use and glucose abnormalities is complicated. This is because of the possibility of an increased background risk of diabetes mellitus in patients with schizophrenia and the increasing incidence of diabetes mellitus in the general population. Given these confounders, the relationship between atypical antipsychotic use and hyperglycemia-related adverse events is not completely understood. However, epidemiological studies suggest an increased risk of iatrogenic diabetes in patients treated with the atypical anti-psychotics. Patients with an established diagnosis of diabetes mellitus who are started on atypical anti-psychotics should be monitored regularly for worsening of glucose control. Patients with risk factors for diabetes mellitus (eg, obesity, family history of diabetes) who are starting treatment with atypical anti-psychotics should undergo fasting blood glucose testing at the beginning of treatment. Any patient treated with atypical anti-psychotics should be monitored for symptoms of hyperglycemia. Patients who develop diabetes during treatment with atypical anti-psychotics should undergo fasting blood glucose testing. In some cases, diabetes resolved when the atypical antipsychotic was discontinued. However, some patients required continuation of anti-diabetic treatment despite discontinuation of the suspect drug.

In February 2005, an article in *Diabetologia* 2005 February 2 looked at the risk of insulin resistance, control of sugar and "bad" fats in the blood of people taking older versus newer generation of antipsychotic drugs. They found that those taking new antipsychotic drugs had much higher rates of metabolic dysfunction than those taking older antipsychotic drugs.

The FDA has determined that the treatment of behavioral disorders in elderly patients with dementia with atypical (second generation) antipsychotic medications is associated with increased mortality. Clinical studies of these drugs in this population have shown a higher death rate associated with their use compared to patients receiving a placebo.

The FDA has always been plagued by a poor monitoring and reporting

system concerning adverse effects of psycho-pharma. Clinical trials professionals hope that the FDA will have a new adverse event reporting system (AERS) in place before the end of next year to help streamline the reporting process. Many research facilities and institutional review boards have become overwhelmed with adverse event data — some to the point where it's difficult to differentiate between serious and less-serious reports. To make matters worse, neither the FDA nor the Office of Human Research Protections have provided clear guidance on event report handling, clinical experts contend. A revamped AERS could help in detecting defects and problems with pharmaceuticals and medical devices before they reach the market. This could, in turn, help prevent embarrassing situations for the FDA and the industry, such as the postmarket adverse event reports that detailed troubling cardiovascular side effects associated with Cox-2 inhibitor Vioxx (rofecoxib), which was recalled by Merck last fall. (from fdanews.com)

Meanwhile, the Indian family carer's email networks have expressed alarm at the way the Indian pharmaceutical company (Johnson & Johnson) has *hidden* facts relating to the causation of glaucoma, leading to blindness, by using their drug Topramate (brand: Topomac). The glaucoma is caused by increased intraocular pressure. Apparently, the warning is carried by American information materials marketed by the company, but has been omitted from the Indian materials. Email from: Captain B Johann Samuhanand, Bangalore: bjsamuhanand@yahoo.co.in Also read about the irrational prescribing practices of Indian psychiatrists by Dr Vikram Patel and others (*J of Postgraduate Medicine, 2005;51 :pp.9-12)*.

Brief news about workshops in mental health

The Department of Psychiatric Social Work (TISS, Mumbai) in collaboration with Kshitij Mental Health Center, Mumbai, held a one day "Literacy program on Law and Mental Health" in February. A key note address developed the significant linkages between law, human rights and mental health, highlighting the gaps and the need for reform. Presentations explored the aspects of the MHA, institutionalization and themes of law, psychosocial disability, disability, certification, marriage and civil status. Over 60 participants attended, from different disciplines, including government officers, human rights groups, rehabilitation workers, carer's groups, students and faculty of law, psychiatric social workers, clinical psychologists, and psychiatrists.

A National seminar on "Mental health & Aging: Focus on women with depression" was held at the Women's Studies Research Center, M.S. University of Baroda, at Vadodara, on the 12th and 13th of April, 2005. Several papers were presented from the department project on the same subject, led by Prof. Parul Dave, Prof. Pallavi Mehta and Dr. Leena Mehta. The project maps the mental health experiences and needs of older women in six cities of Gujarat, making linkages between depression, health, nutritional status, social determinants as well as coping strategies and psychosocial interventions. Studies were presented, highlighting the social determinants underlying the gender differences in rates of depression. The special problems faced by older women, especially widowed women, and women affected by violence, were presented. A finding linking nutritional deficits (folic acid, protein, vitamin C, vitamin B6, fat, aminoacid) with depression was reported. Body Mass Index also significantly correlated with depression. Another study reported improvement of cognitive functions upon treatment for anaemia, as a large number of women studied were found to be anaemic. Alpha biofeedback, meditation and laughter therapies were found to be useful in the recovery process.

Institution

By Cynthia L. Damiano

Inside
Nothing grows deprived of
Sunny skies
In time
Unheard, with no opportunity
To bloom with grace
Instead the buds wither
On stems of
Neglect

Source: Madness Network, Fall 1984, Vol 7, No 4

The Tamil Nadu Government, Department of Social Welfare and Nutritious Meal Programme, issued the "*Tamil Nadu Registration of Psychiatric Rehabilitation Centers of Mentally Ill Persons Rules, 2002*" [TN/ Chief PMC-301/2002], in October, published in the TN Gazette.

Following the Erwadi incident in Tamil Nadu, this is seen as a progressive step in many circles. Also, formulating the Rules is seen as one way of solving the regime of coercion and oppression set up by the Mental Health Act at different levels of service provision.

Under the Rules, *any person who wishes to establish a Psychiatric rehabilitation center shall apply according to Form 1, to the competent authority* (Rule 3). The competent authority, in this case, is the authority under the Persons with Disabilities Act, 1995. Upon receipt of application, *the competent authority shall inspect the premises to ascertain their suitability; and ascertain whether the psychiatric rehabilitation center is in a position to provide the facilities and maintain standards as laid down in these rules* (Rule 4). Based on the inspection, the competent authority may issue a certificate of registration to the applicant. *Every certificate of registration shall be in Form II and it shall be in force for a period of three years unless revoked by the competent authority as per Rule 10 of these rules* (Rule 5). The applicant may also be given a month's notice before personal enquiry if any further information is sought by the authority. The order refusing grant of certificate would be in the prescribed Form III format (Rule 6). There are Rules concerning procedure for the renewal of the certificate, display of certificates and revocation of certificates (Rule 10). Rule 10(2) stipulates that in the case of revocation, *the competent authority shall indicate the arrangements to be made for the inmates of the home*. *An appeal can be made against the revocation within thirty days from the date of receipt of the order* (Rule 11). Rule 13 stipulates the *closure* of centers whose *certificates have been revoked from the date of revocation of the certificate.*

Chapter III of the TN Rules allows for *voluntary* admission and discharge procedures to rehabilitation centers. *All admissions into and discharges from a psychiatric rehabilitation center shall be voluntary and made on the advice of a psychiatrist.* Further, *the psychiatrist should certify that the person referred to is a mentally ill person who requires only maintenance medication and rehabilitation measures* (Rule 15). Rule 16 stipulates that *all decisions relating to admission into or discharge from a psychiatric rehabilitation center shall be taken as far as possible in consultation with the guardian of the person to be admitted or discharged.* Rule 17 concerns admissions of "orphaned mentally ill persons", *who may be admitted by a friend or a social worker,* after enquiry concerning the orphan status, examination by a psychiatrist, psychiatric certification, and sending a report of the admission to the police. About "*unmanageable*" patients or about patients "*unwilling to stay*", Rule 18 says that such patients *shall not be retained.* Further, such persons may be admitted in appropriate institutions under the Mental Health Act, 1987, or sent back to the family or to the guardian.

Unlike the Mental Health Act, the TN Rules talks about voluntary admission and discharge. "*Special circumstances*" admission, or forced admissions permitted under the MHA, concerning *unmanageable* patients under Section 19, is not found here. Certification is required for suitability of admission, that the person needs only maintenance medication and rehabilitation. This Rule is vague. It is not clear who is eligible for admission. One reading is that only those described as rehab patients or patients in recovery would be admitted here. Persons with expressed need for admission or personal distress of the person, would perhaps not meet the admission criteria. Yet the Rules provide for emergency psychiatric services and regularly visiting psychiatrist. It is not clear why any one needing care cannot be admitted. Further, there is emphasis on maintenance medication, as the most important part of rehabilitation. The total admission and discharge procedure decision-making is given over to the psychiatrist and the family. The user's role in admission and discharge, and voluntariness, is not considered. Patients seen as *unmanageable* have no recourse, but to be brought once again within the coercive regime of the Mental Health Act. There is likely to be misuse and abuse of this provision by persons working against users interests, such as family members, who want to dump a relative. After trying rehabilitation in the private centers, they could label the person as *unmanageable* and put them back in long term custody.

Rule 20 details the facilities that should be available in the center, addressing basic needs, space, water, toiletry items, locker for privacy, recreation and entertainment and occupational therapy. Rule 21 talks about facilities to be provided in training or the work areas, including adequate working space, safety, and adequate remuneration for the work done. The MHA does not talk about rehabilitation issues at all. The Rules stipulate specific details on physical space, privacy, and rehabilitation, though the details may be disputed.

About staff, (Rule 22) the Rules stipulates *a full time social worker or a clinical psychologist, a visiting psychiatrist and a psychiatrist on call*

for psychiatric emergencies. No mention is made of medical emergencies, though Rule 27 stipulates period health check up. Under the Mental Health Act, only psychiatric programs can be run as the capacity of other professionals in service provision was not considered. The Rules do not consider non-professional involvement in mental health care, for example, where a care giver group or a user group can initiate, develop and run residential programs on a full time basis.

The Rules talk about the "*free movement of inmates*", prohibits chaining or being fettered, but *does not prohibit the temporary restraining of a person from causing harm to oneself or others.* The Rules do not define *temporary.* The Rules do not define *cause of harm to self or others. Unmanageable* patients are to be managed under the procedures given in the Mental Health Act (Rule 25). The Rules do not define *unmanageable.* The Rules do not specify what is the nature of restraint to be used, for how long, what is the review process, etc. There is scope of extensive misuse and abuse of this Rule.

Rule 29 stipulates inquiry concerning *complaint made by or on behalf of such mentally ill persons as to their treatment and care*. The Rules do not mention anywhere the role of users' participation in their overall treatment and care. Nor do they mention how the institution is to create an environment of open and free communication. Where these issues are not addressed, it is difficult to imagine that users will be able to freely correspond with higher authorities about redressal.

The TN Rules is a result of greater owning up by the Disability Commission of Tamil Nadu in the area of psychosocial disabilities. It is an achievement that the barriers in the Mental Health Act are being addressed through positive use of the Disability commission's office. However, it is expected that such a legal document would be in letter and spirit of the Persons with Disabilities Act, which is an act of equal opportunity and non-discrimination. There are some major problems with the TN Rules, which make it coercive and discriminatory: One, is the possibility of forced treatment as the emphasis of rehabilitation is on medication compliance. The user is not foregrounded at all in the Rules, and issues such as ECT, informed consent, etc. are not touched upon. Second, the fact that physical restraint is being allowed: If psychosocial disability is another type of disability, this raises hard questions. We do not expect blind people or persons with orthopaedic disability to be restrained physically. Why this discrimination against persons with psychosocial disability? Thirdly, the route to go back and utilize the involuntary commitment procedures of the MHA is left wide open in the Tamil Nadu Rules with respect to orphaned, destitute people as well as "unmanageable" patients. Finally, human rights and civil liberties issues with respect to care and treatment are addressed only cursorily (as in, *no chaining*).

There is a rush by many state governments to look at the TN Rules, 2002 as a way out of the present impasse created by the Mental Health Act. The Mental Health Act does not have any criteria or procedure for starting a rehabilitation center for persons with psycho-social disabilities. Because of this, there are many gaps with respect to licensing and monitoring of such facilities. Persons desiring to start such facilities find the law and the procedure intimidating. Also, the Act covers only the psychiatric aspects, and not about rehabilitation or recovery. Authorities working under the purview of the Act de-recognise rehabilitation facilities, as happened in the case of a rehab center in Maharashtra recently. This resulted in the closure of a much needed program as the city where it was located was very poorly serviced by any kind of mental health, rehabilitation or recovery program.

Strict enforcement of the Act in other parts of the country, such as Tamil Nadu and Karnataka, is resulting in undue pressure upon the sector being imposed by the legal authorities. This is the perception among the NGOs working in the rehabilitation. The TN Rules seems to lighten the legal force upon the sector. It will now be easier to bring people into rehabilitation programs and there will be a legal way of talking about rehabilitation without it always entailing custodialisation in a mental institution.

The TN Rules is in that sense a gain over the Mental Health Act. However, the TN Rules is a regressive step from the Persons with Disabilities Act, with which it is supposed to comply. It infantalises the persons with psychosocial disabilities, liberally allows proxy consent, and reduces the process of recovery to medication compliance. In equalling recovery to medication compliance, the control (over admission and discharge) is once again given back to the psychiatrist. In doing this, it robs the users of psychiatry of dignity and autonomy, and the capacity for self-reliance. This fact is further accentuated by the stipulation that the psychiatrist in consultation with the guardian, can make an admission. The concept of "voluntary" has no meaning here, as the user is not even seen as an agent in this process. The TN Rules, 2002, then ends up being another psychiatry driven, coercive instrument just like the MHA. It is more in alignment with the custodial regime of the MHA, than the positive legal regime offered by the PWDA. These issues must be discussed further on a user platform, before any state government starts to mindlessly replicate the TN Rules.

The Cuckoo's Nest & Beyond: Humanizing Institutional Care

The Anjali Experience, Calcutta.

In the understanding of 'normal' people, the world of the mentally ill is a cuckoo's nest – it does not exist. Institutional care in India is strongly based on this notion. The state-run mental hospitals in India are far too much like prisons. They have intimidating structures, concrete buildings with high walls and locked doors, barbed wire windows, collapsible gates that stand between inmates and their visitors.

The laws and rules governing these institutions are forbidding. Admission is done through court orders. There is no concept or practice of voluntary discharge. Orthodox psychiatric practices are still used. There is no room for patient consent. The rules are made to suit staff advantage. The dignity of patients is NOT a consideration.

The hospital staff comprise of over worked psychiatrists and uncaring care providers. There is little understanding of the rights of patients. Family members are not organized to demand proper care and treatment. The level of patient representation in the planning or design of programs is negligible. Ignorance, disdain and fear underlie the attitudes of the families of patients, resulting in stigma. Mental hospitals still serve as dumping grounds of unwanted relatives.

❖ Where Anjali Steps In

Anjali, a rehabilitation program working in two state mental hospitals in West Bengal, stresses the need to allow patients to participate voluntarily. Anjali works with both male and female institutionalized patients. Anjali works with the philosophy that patients are human beings first. The emphasis is on discarding the brutality so often associated with psychiatric treatment.

Anjali has something to say to patients, to families, to the hospital staff, that mentally ill persons are also people who deserve to be treated with dignity and that they have a right to self-determination.

Anjali seeks to usher in systemic changes in the sphere of mental health care and treatment. Anjali works at raising awareness and understanding about mental health among policy makers, civil society actors and other social change-agents.

❖ Anjali's strategies

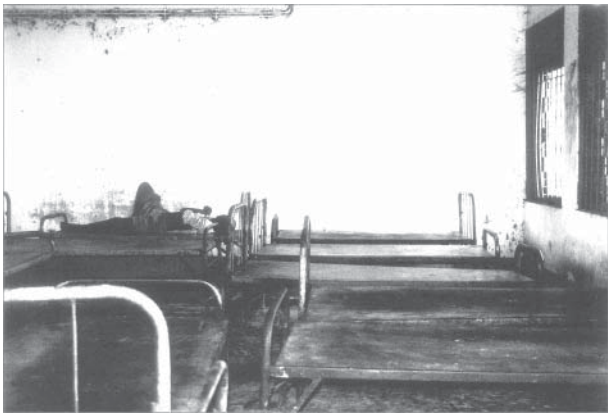
- Partnership with the government to ensure optimal outreach and changes within the system
- Evolving as a significant actor in consolidating a movement around mental health issues
- Creating an environment for concrete realization of the economic and social rights of the mentally ill

❖ Anjali's activities

- Offering Rehabilitative Services
- Facilitating the Process of reintegration
- Post-Reintegration Monitoring
- Engaging all levels of Hospital Staff
- Developing Referrals & Linkages
- Lobbying with the Government
- Creating Enabling Environment
- Advocacy & Awareness Campaigns

❖ Therapies Offered

- Life Skills Training
- Cognitive Therapy
- Creative Therapy
- Recreation & Relaxation Therapy
- Occupational Therapy
- Psychotherapy
- Audi-author (a program of using story-telling and story writing as means of healing)



❖ **Other Services**

- Economic Empowerment
- Organizing Shelter
- Family Counselling & Follow-up Care
- Organizing Special Events

The *Anjali* program was created by Ratnaboli Ray, a clinical psychologist, and an Ashoka Fellow. She can be contacted at rayram@cal3.vsnl.net.in

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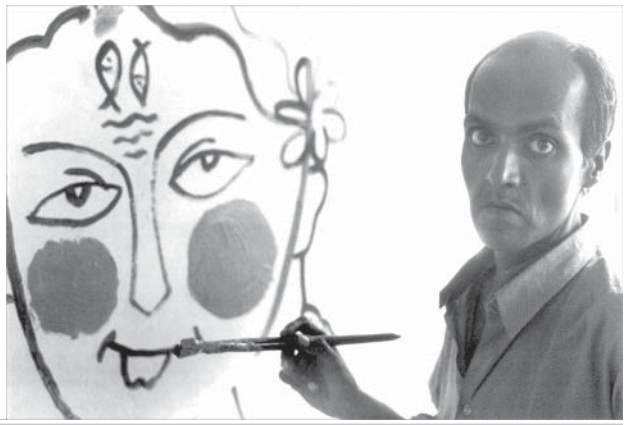

Audio resources in advocacy

Karen Barth Menzies, "The rising tide of pharmaceutical lawsuits: What the practitioner needs to know about the future of psychiatric drug litigation". Safe Harbor: Los Angeles, Non-Pharma III, June, 2004 (Contact: www.alternativementalhealth.com)

The audio CD describes the work of Karen Barth and colleagues at Baum, Hedlund, Aristei, Guilford & Schiavo, a law firm which has been involved since 1995 in bringing class action suits against psycho-pharmaceutical giants. According to Karen Barth, the lawyer representing victims in some of these suits, "*each of the top selling SSRIs has been found in courts of law to be a causative factor in acts of violence and/or suicide*". The risk of suicidality and violence following use of SSRIs is not so well known, as these drugs have been promoted widely as wonder drugs for depression, and various kinds of problems. The last 15 years has seen a spate of class action suits against psychopharma companies, resulting in compensatory payments as well as stealthy payoffs by the offending companies.

Prozac was implicated in a bank robbery case (*Christopher DeAngelo)* wherein the court judged the accused "not guilty" because of diminished capacity caused by Prozac and Xanax. Barth notes that there is nothing coincidental between the FDA approval of Prozac in 1998, and the near doubling of officially reported figures for depression in 2001. Much of this malady is market induced, showing, if anything, the effectiveness of marketing strategies.

In this CD Karen Barth describes the chronology of law suits against various psycho-pharmacological companies (Eli Lilly, Pfizer, Smith Kline Beecham, etc.) Research data and hard clinical data from experts since the 1990s showed the risk of suicidality linked with Prozac. In the 1990s a MDL (multi-district litigation) was filed against Eli Lilly, wherein cases filed by many litigants against Prozac was presented together, as a class action suit. The Advisory Committee meeting in 1991 noted that there was "no credible evidence" of such risks, but added that there was "no data" to back up any kind of firm conclusions. In 1991, the FDA and Eli Lilly together developed a scale to measure such risks in all clinical trials. But the FDA did not enforce this on the clinical trials when they actually happened. So, even after 12 years, when the committee met again, there was still "no data".

Karen Barth goes on to describe the famous cases that have been brought to trial: the *Wesbecker* case, the Eli Lilly secret settlement, and the *Forsythe* case. In the *Wesbecker* case, a man killed and injured several fellow workers, before killing himself. There were confounding factors in this case and the drug link to the violence was difficult to prove. A famous case involved "unimaginable" sums of money being paid to litigants and to various people in order to hide evidence relating to Prozac related violence. The verdict of "no evidence" given by the court in this instance was used by the company Eli Lilly as yet another marketing tool.

In a case from Wyoming, Smith Kline Beecham had to pay off large sums in compensation (6.8 mn USD) while accepting that suicide and homicide was due to the consumption of their drug, Paxil / Seroxat. Since 2001, Paxil manufacturers have added relevant warnings to their labels, while continuing to mislead the public by marketing their drug as "not habit forming". A further case was filed by the annoyed public asking them to withdraw these claims from their advertising.

Untitled

By Lynne Morris

Suffering severe psychiatric pain
I am allowed the
nurturing of nurses and aides
on the mental ward
who respond to me
with fear
and with the knowledge that
criticism will help me.

The kaleidoscope
of constantly critical words
facial expressions
and body language
maddens me permanently;
then they further
compound my craziness
by expecting me to praise them
repeatedly
to show I am sane

Source: Madness Network, Fall/Winter 1982-83, Vol 6, No 6

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