

## D I S C U S S I O N

# Of Human Bondage: glimpses into the human rights situation of the mentally ill in West Bengal

RATNABOLI RAY

Ratnaboli Ray, Managing Trustee, ANJALI Mental Health Programme, Benubon, Flat # A/302, 92/3, Kankulia Road, Kolkata 700 029  
Email: rayram@cal3.vsnl.net.in

“The mentally ill person deserves the same privileges enjoyed by any other human being,” wrote the National Human Rights Commission in its report *Quality Assurance in Mental Health* published in 1999. The mentally ill person is protected by the Declaration on the Rights of the Disabled, adopted by the UN in 1975. The Declaration specifies many rights including the rights to treatment and rehabilitation, to privacy and autonomy, to a life within the community, to protection from abuse and exploitation, and so on. What are the realities in India?

The UN Declaration recognises the right to “necessary treatment in the least restrictive set up and as far as possible to be treated and cared for in the community”. The Mental Health Act of 1987 (revised over the Indian Lunacy Act of 1912) explicitly mentions the right to appropriate treatment and rehabilitation, the right to personal liberty, and the right to improved community and family life rather than the life of incarceration. However, the Act also empowers the judiciary and the police to take any mentally ill person in custody and remand him or her to a custodial hospital. Thus, patients are herded from prisons to hospitals without any commitment to reintegrating them.

Even the best among the state-run mental hospitals in our country have no visiting facilities for patients. There are no fixed visiting hours for family members to meet an institutionalised patient, no visiting rooms, no permission to enter the wards. When family members show enough interest to visit, they must talk from the other side of bars – illustrating the prison-like situation in which mental patients live when in the state’s custody. It is also a comment on how interested such hospital authorities are in involving family and community members in the treatment and recovery process of the mentally ill.

Not one of our State-run mental hospitals has the provision for voluntary admission and discharge.

### **Protection against exploitation and discriminatory, abusive or degrading treatment**

Not long ago, a participant of ANJALI’s rehabilitation programme was in tears. He sings well and looks forward to leading the life of a celebrated singer when he is reintegrated. He had a sore throat and had asked the ward attendant for some warm water for gargling, to restore his voice. What he got instead was a slap. This was three years after the NHRC report was published.

One of the standard complaints that we hear regularly from our participants is that they are refused medicines for

stomach ache. Stabilised patients sometimes long for the taste of home-cooked meals, for a little variation in the bland hospital food. But a request for a green chilli, something average Bengalis are accustomed to having with their meals, is met with vulgar and abusive responses like: “Do you want the green chilli shoved up your — ?” Newspapers – which most of us take so much for granted we hardly think about them as a privilege – are unknown in state-run mental hospitals. Patients interested in the happenings of the outside world must depend on the occasional paper packet, carefully unfolding them and removing the creases to read about reports weeks if not months old. Rehabilitation, personal autonomy, privacy Not a single state-run mental hospital offers rehabilitation facilities. Not just that, it has taken the government two and a half years to grant an initiative like ANJALI – the only one of its kind in this region which works in collaboration with the government – permanent permission to work in the two hospitals that we function in, and to invite us to take up another district hospital run by the state. Privacy is a dream when the only secluded moment a patient has is in isolation cell. Personal autonomy, a concept culturally ill-understood in our part of the world, is non-existent for the institutionalised mentally ill, as should be obvious from the anecdotes quoted earlier.

### **Family and community:**

Ignorance, disdain and fear As the State continues to withdraw from the social sector, the role of civil society is becoming increasingly more important in ensuring a better quality of life in all spheres. In fact, the entire human rights movement depends on civil society to monitor and force the state to guarantee its citizens basic human rights. This is why we need to also examine the general societal mindset in India towards the mentally ill, so as to better understand the situation.

Unfortunately, ignorance, disdain and fear mark the general attitude towards the mentally ill in our country. Lacking a proper understanding of mental health results in any form of mental illness being equated with lunacy. This in turn provokes contempt and dread. Families seek to put mentally ill members in state-run hospitals through court orders, only to forget all about them. Giving wrong addresses, refusing to visit institutionalised patients, tricking patients into giving up property rights, refusing to reintegrate them into the family even when they have been stabilised – these are all common occurrences in our part of the world. One of ANJALI’s leading team members has had a dog turned loose on her by a patient’s family when she went to convince them that their once-ill member was stable enough to be reintegrated.

One of ANJALI's clients, now in a short-stay home where he is learning dairy and poultry farming, provides a sad example of how families treat their mentally ill members. His parents had been caring enough to leave money and property for him. While under treatment for chronic schizophrenia, he was forced by his sisters to sign everything away. Then there is this gentle lady in her mid-50s, currently a participant in ANJALI's rehabilitation programme, who has spent nearly a decade in incarceration. Entirely stable now, she is languishing in the hospital as her son continues to give false addresses and remains untraceable, despite the best efforts by ANJALI's social workers.

Another client, in her mid-40s, a bright and talented performer, explained, her voice muffled with suppressed tears, that she did not like using abusive words but sometimes someone inside her made her use those words despite herself. She was describing a schizophrenic hallucination. However, her sister refuses to listen to this candid explanation, choosing to view the problem as one of 'bad behaviour'. Such selective perception characterises familial attitudes towards the mentally ill in our country. Use of strong words by the 'normal', especially by women, is more often than not accepted as a mark of assertiveness and independence. When it comes from a mentally ill person, it becomes an indicator of violence, non-conformity and, therefore, non-acceptability.

#### **Education and employment**

In the absence of state-sponsored legal or social assistance towards education, training, employment and protection of rights, the mentally ill have virtually no protection against apathy and antagonism. Their families are often economically poor and socially marginalised – for whom people unable to earn their own living can prove an unmanageable burden. Given our poverty and monumental unemployment problems we need a movement towards awareness-raising and lobbying for special privileges for the mentally ill. However, civil society entrepreneurs working for development, better quality of life, and freedom from discrimination for marginalised social groups are strangely apathetic towards the mentally ill as a special group. In recent years there have been movements for ensuring better privileges and options for the disabled. Laws have been changed through successful lobbying. Corporate

houses now have a quota of jobs reserved for the physically handicapped. Public conveyances and amenities have special arrangements for them. However, the activists involved have not felt the need to include the mentally ill within their movement.

In the absence of any comprehensive awareness-raising drives by either social activists or the government, there is little scope for the scenario to change in the foreseeable future. Human rights for the mentally ill will remain a pipe dream.

#### **What is to be done**

The recognition of hurdles is the first step towards removing them. So we believe in ANJALI. The bleak picture painted above is just an objective description of the situation as it is now. However, there are bright patches within that general picture of gloom. An endeavour like ANJALI is an example. We have chosen to act in partnership with the government because the majority of our population depends on the state-sponsored health care system. It is important to work inside that system and bring changes from within, rather than set up alternative systems which will have limited reach. It is a positive sign that the government has allowed us to function and has finally acknowledged our efforts through granting us a permanent permission. In less than three years, we have been able to reintegrate 27 clients into mainstream society. Some of those families are now partners in ANJALI's efforts, ready to share their experiences with the families of current clients to convince them to give their mentally ill members a chance. Pharmaceutical companies have come forward to further ANJALI's cause by offering financial and other help. Stores have agreed to stock ANJALI products for sale. Many more such initiatives need to be identified and utilised if the mental health scenario is to change substantially.

We must remember that the state is not an abstract entity but consists of members from this same society and culture. The lack of understanding and distrust that characterises our attitude to the mentally ill is, therefore, bound to be reflected in the mindset of the administration. Any attempt at guaranteeing, securing and protecting the human rights of the mentally ill has to start with sustained awareness-raising campaigns aimed simultaneously at civil society and the state.

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SAME was set up following the development of a number of informal contacts across the sub-continent. It is meant to respond to the need to promote discussion on issues in medical ethics in this part of the world, to exchange ideas, provoke meaningful debate, and strengthen valuable relationships between the people of our countries.

We hope that you will find this discussion meaningful, contribute with your own experiences, press reports and comments on issues in medical ethics, and forward this invitation to friends and colleagues in this region.

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