Count Me In!

By Ratnaboli Ray

Repoliticizing Advocacy and Services in Women's Right Activism

Introduction

"We wanted to give people something to remember, to symbolize the community spirit."

One of the women from our constituency said "The feeling of being valuable - 'I am a valuable person'- is essential to mental health. This too can be described as the crux of Anjali's work. Established in 2000, Anjali's thrust is two fold – one, to establish Mental Illness within the mainstream health paradigm of India and two, to 'speak for' a large population of marginalized people with mental illness vis-à-vis their right to a professional and inclusive system of care and treatment.

Mental Health is one of the most neglected areas of health. It does not feature as a priority when it comes to social development discourse or resource allocation/policy making at the government level, and this is especially so in developing countries like India. Because of the various myths and misconceptions associated with mental illnesses and the neglect given to mental healthcare in general, the sector continues to languish on the fringes.

The context in which Anjali works; what is the need?

Anjali's work addresses several gaps in the mental health sector, as well challenges institutional norms which violate basic human rights in order to bring about long-term changes. Underscoring our model of work is the understanding of the double handicap that women face when it comes to mental health issues. One, India is still largely patriarchal, where despite the education and constitutional guarantee of rights, women still face several socio-economic impediments. These same impediments create a hindrance in the awareness and timely access to mental health services. Mental health concerns are treated as a calamity to befall the whole family, where instead of the physical and emotional well-being of the client, the main concern becomes the shame and stigma associated with it. Therefore, Anjali's primary work lies in addressing the following concerns and looming gaps:

Health is not a priority: For a lot of women, their health is often not a priority. This has been observed with general and reproductive health, but more so with mental health. Depression, a clinical condition, is extremely prevalent women, but is often dismissed because most often the symptoms associated with it such as headaches, moodiness or social withdrawal isn't treated seriously by women. Because of lack of awareness and social stigma or fear of family ostracization, they often ignore symptoms or do not take help, which may be extremely dangerous and detrimental in the long run.

Even in the instances of childbirth and postnatal care, there is no adequate counselling services. Conditions such as Post-partum depression have not even entered the vocabulary of the public, yet they are a reality that several women face in India.

The shortage of mental health services and infrastructure: In a country where more than 20 million people live with acute mental illness , there are 36 hospitals and 3,500 trained psychiatrists, 1000 clinical psychologists and psychiatric social workers. Less than 900 nurses to cater to 75,000 patients. The demand clearly outstrips the services available and burdens the already ill-equipped and underfunded health care sector.

Bio-medical pathologization of women: Research on the prevalence of mental illness in India show that women (15%) are more frequently ill than men (11%). Most medical researches also confirm that the prevalence of neurosis or common mental disorders (depression, suicides, conversion disorders etc) is twice as high in women as compared to men. Till recently, this was attributed to women's biology (hormonal changes associated with menstruation, pregnancy, childbirth and menopause), emphasizing biological determinism as the basis of mental health morbidity. However feminist critique and rejection of such logic, has brought into sharp focus that mental distress is a function of women's social contexts, their role overload and gender burdens. Domestic violence, sexual abuse, early marriage, lack of opportunities and access to information, and low health quotients trigger high levels of emotional distress among women.

Rejection by Families and Communities: Mental health laws, as well as reports of the National Human Rights Commissions have so far viewed the 'mentally ill' as a homogenous, monolithic group of persons, stigmatized by their illness. But it is widely understood that the extent of discrimination experienced, and trajectory of recovery are different for men and women.

Voluntary admissions, hospitalization and discharge favour men more than women. A study of five mental hospitals in the state of Maharashtra revealed that while men are admitted to hospitals for treatment in the early stages of diagnosis, women are "dumped" here only after their illness turns chronic ie when they turn dysfunctional and are unable to comply with their social roles. This pattern repeats itself across India. In the mental hospital of Ranchi , Jharkand, while the female to male ratio at the time of admission is 29% to 71%, the long stay patients are predominantly women: 67% as compared to 33% men. Most Anjali partners and participants have clocked 8-15 years of hospitalization. Our women partners have fewer visitors than their men counterparts.

Families and societies do not want a recovered woman back. Once hospitalized, a woman's role is redistributed to other female members of the family, her husband remarries and her children grow up with an image of a mad, demonic, witch mother. Parents of young women with mental illness reject her for the fear of possible future sexual exploitation or concerns about her marriage and dowry plague them. But, a male patient's economic status in the family is not devalued as easily. Much after his hospitalization, his wife continues to be the caregiver and the family continues to see him as a bread earner.

Abuse and Sexual Coercion: When let out on parole, 50-60% of women relapse (the rate is much lower

among men) due to non-compliance to medication (overtly and covertly supported by families) and the highly stressful community environment they find themselves in -- which ranges from name calling to letting dogs loose on women to physical and sexual abuse. Many women work as domestic maids when out on parole and live in rented rooms, because their families will not take them back. This makes them vulnerable to sexual abuse and coercion. More than 37% of women with mental illness report multiple sexual abuse and coercion, as against 20-29% of women who do not suffer from any mental disorder.

Homeless mentally-ill women who live on the streets are always in great danger. Unable to fend for themselves, they are subjected to violent and sexual attacks, and have nowhere to go for recourse. The police do not rescue them readily when there are referrals due to the lack of space.

The Gender Gaps in Mental Health Treatment: Work in the mental health sector requires a measure of empathy, and sensitivity, yet this is what is acutely absent from our treatment and care. Women in mental hospitals are put through rigid paternalistic scrutiny and surveillance. They are dressed in loose frocks tied at the waist, oversized unisex gowns, and/or uniform saris. Often they not provided with even undergarments with their gowns. They are forcibly tonsured or their hair cropped close to the skull. Patients are covertly discouraged to keep themselves clean and attractive on grounds that they could sexually provoke members of the male ward. Their treatment defeminizes them, dehumanizes them. The lack of personal space to store ones belongings further depersonalizes women. They are denied the therapeutic opportunities of looking into a mirror (self evaluation of one's image). Counselling entails relentless advice and admonition. Inside hospitals, patients who develop close or intimate friendships are harassed and punished by being relocated to separate wards.

Health, clothing, menstrual hygiene, cleanliness and personal space are critical challenges. All psychiatric patients receive the same drugs irrespective of categories viz. the recovered, the curable and the chronically ill. Most times women patients get one or two dresses which are washed once in ten days, if at all. Women are not given sanitary napkins during menstruation – often they live in soiled clothes that are stained in menstrual blood. Group bathing and drying accelerate gynecological morbidity, injuries and infections. These problems are more pronounced for chronic, long-stay patients. There are no provisions for mothers admitted within the institutions to see their children either. Do these conditions create an image, a ray of hope for recovery and care? Would we dare to allow our kith or kin to be admitted to such hospitals? Perhaps not, if we can afford private, expensive care. But how large a percentage of the population can afford that?

Human Rights Violations inside Mental Hospitals: The architectural setting and infrastructure of government hospitals borrow heavily from the criminal justice system. Dark long corridors, heavy metal locks and grills, iron collapsible gates and fans with metal grids to prevent suicides. Grey walls and sepia sheets on beds lined up in dormitories. Most state-run hospitals do not have the human or financial infrastructure to support occupational therapies and/ or conduct rehabilitation, re-integration and

community follow-up visits. Whether the death of a women inside a mental hospital in Maharshtra, or the 1994 Shirur mass hysterectomies of women with psychiatric disorders or the mass burning to death of chained patients inside the Erawadi mental hospital in Tamil Nadu in 2001, state institutions for care and treatment have been grounds of severe rights violations.

Time and again, experience has shown that perhaps mentall illnesses are the only area of health where consent is considered completely immaterial, the mentally ill are treated as a second class group, and one can even go as far as to say, sometimes worse than even a herd of animals.

Mental Health is not a priority in development: While the **GDP has shown** high growth from 3.4% to 8%, the healthcare indicators have not shown improvements at the same rate. India **spending on healthcare** is at 5.2% of the GDP, which is comparable to other developing countries, e.g. Korea, Thailand and Brazil spend 5-7%. (Table 1) However, with only 0,9 percent of the GDP, the government's spending on healthcare in India is low compared to Korea, Brazil or Thailand. [1]

Further research into the mental health sector specifics paints an even more dismal picture. According to a recent study by the Government of India conducted, there is only 1 psychiatrist for every 400,000 people — and a mere 37 mental institutions to serve the country's whole population of 1.2 billion. This is a ripe ground for faith healers, quacks and an overall negligence of mental health.

Structural failures within government-run institutions: Although India is well placed as far as trained manpower in general health services is concerned, the mental health trained personnel are quite limited, and these are mostly based in urban areas. Insufficient staff, unavailability of essential drugs, and other problems at government-run PHCs make it difficult for rural communities to get treatment and they are forced to purchase health-care services from private practitioners. Mental health care is a continuum, which may include a range of therapy and medication, often expensive. Hence, in this case the client and their caregivers are deprived of affordable quality care.

At a structural level, there is gross underfunding and lack of services. A 2008 evaluation of the District Mental Health Program in India revealed a worrying pattern of underutilization of the DHMP funds by the state governments, and the inability of the program to cover all the districts in the country, or roll out the range of its services.

Repoliticizing services and advocacy

So what do we aspire to achieve through political advocacy and services in the context of mental health?

- Better access to treatment, care and aftercare services.

1 WHO/AIMS report on Uttarkhand Mental Health System

- The recognition, guarantee and protection of the basic human rights of clients with mental illness within state run institutions, through legislations and their enforcement. That prevents institutional violence and discrimination at school or the workplace.

- Resource allocation in the health care sector for better training, facilities, replication of services, disability allowances and employment opportunities for the clients and their family members.

The experimentation with polio eradication as well HIV/AIDS awareness creation has shown how successful the programmes can, and how vast the reach of the changes can be if the goverment is involved as an equal partner. Further, this underlines the need of transferring the responsibilities back to the government in treating mental health issue as a priority.

In a developing country like India, where there there still exists deep rooted poverty, unemployment, gender bias as well corruption at the political level, it becomes crucial to work with the state in order to bring systemic changes. One's approach needs to not just stop at evolving alternative or innovative models of treatment and care, but by working with the government we are able to take advantage of vast resources and outreach.

Some of the most basic freedoms and needs, things that wouldn't even cross our minds when talking of 'rights, advocacy, legislations', things that we take for granted, these are not even recognized. This necessiates the stepping in of organizations such Anjali in the sphere. A country which boasts of an 8% growth rate has failed to be inclusive of a large part of its population. Political advocacy not only asks for the accountablity of state-run institutions, but it increases awareness of the civil society on the same matters, hence increases public pressure and scrutiny on the goverment. Left to its own devices, the state may continue to turn a blind eye to these violations as it has done so far.

Mental Health issues do not exist in a separate planet, they are extremely interconnected with issues of poverty, lack of education, unemployment, gender discrimination and poor healthcare access. When we are looking at addressing mental health concerns of the population, we are seeking to challenge the status of these social determinants as well. We are challenging the status-quo in order to bring about several transformative, sustainable changes in both the legal as well as social/economic landsphere. This is activism for dignity, for inclusiveness, for accountability.

Politicizations of advocacy and healthcare services has enabled organizations like Anjali take its work right till the grassroots for effective change. It is a democratic, inclusive process where women, often victimized because of their orientation or sex, have come forward as leaders and trainers have engaged with the issue they are affected by and in a constructive dialouge for change. Anjali's Janamanas project is the biggest example of this initiative.

Anjali's strategy

Anjali works with a group of people who have suffered both 'stigma' and are 'voiceless'. They are men and women who suffer from chronic mental illnesses, living in state institutions of care and treatment. Anjali's mission is to move from institutionalization to full rehabilitation of people with mental illness, ensuring participation and consent of the mentally-ill in all decisions related to her life. We recognize that the stigma attached to people with psychosocial disability is as destructive as the condition itself. Anjali gives its participants a voice and, the confidence to interact and negotiate with families, doctors and other caregivers. Anjali continuously creates spaces enabling people with acute mental illnesses to exercise their right to self determination.

Anjali's work with the government:

Anjali is the first organization in the country to work in partnership with the state government of West Bengal , operating inside the state hospital premises, using state infra-structure and professionals, rather than creating parallel systems such as a half-way home. This strategy has ensured optimal use of available resources and ensured that the state does not withdraw from its responsibility towards health especially for most marginalized communities.

Anjali has been able to reach out extensively to poor and middle class patients of mental illness in rural and suburban West Bengal, riding on the extensive flank of the state-run health systems. Since there is a strong tendency to not spend family/personal resources on mental patients, there is acute dependency on subsidized government care for the mentally ill. Thus, Anjali sees a strategic advantage in re-directing an existing system of care, rather than creating new systems.

Anjali works in 3 mental hospitals in West Bengal: Pavlov Mental Hospital, Lumbini Park Mental Hospital, and Bahrampur Mental Hospital. We provide institutionalized patients with a comprehensive package of healthcare services and therapies that supplements those available to them in the government mental hospitals. In the process, Anjali has professionalized care and treatment inside state systems. And evolved a process that avoids coercive and non-participatory forms of treatment by different categories of care givers.

Anjali's mode of operation inside government mental hospitals involves referrals by medical officers, a development of case history followed by a psychiatric evaluation based on which Anjali maps suitable therapies. Records are maintained over a regular period of interval, and re-evaluation takes place based on their progress, and suitable changes are prescribed. A process of tracking down the family begins where the necessary steps for reintegration, follow-up and aftercare are followed. Wherever possible, Anjali facilitates job placement and/or assists the participant to run a small enterprise. Additionally, Anjali networks with doctors (including psychiatrists) for free service to our clients after reintegration. We also

have legal experts offering legal aid (including and up to fighting cases) for our clients in case of disputes over property, job and so on.

Janamanas

'Janamanas' was launched in November 2007, as one of Anjali's definitive steps towards de-institutionalisation, community care and demanding every citizen's right to mental health/wellness. It is a collaborative project with the State Government Department of Municipal Affairs, to work with the most neglected, marginalized and economically backward section of the population using available Government infrastructures.

Janamanas has integrated marginalized groups such as those with mental health problems within mainstream society with confidence to interact and negotiate with families, neighborhoods, local elected representatives, doctors, other caregivers and the government and judiciary at large. The programme has also built civic engagement of municipality citizens with mental health. This large volunteer base, created through trainings, has shifted from stances of violence and fear to serving as care-givers and friends of persons who are mentally unwell. Women, who are our primary target to bring in this huge shift in the community, themselves went through attitudinal change and are now have taken up importance positions in their families, communities and even in the municipal administrative system.

Janamanas had worked with 108 women associated discriminated by their gender, class, caste and lack of formal education. 50 women emerged as forward line of leaders who are now running the kiosks established in their communities. The rest are working as primary mental health workers supporting the kiosks as outreach persons.

Conclusion

Repoliticizing of services and advocacy is necessary to provide a democratic healing space as opposed to custodial care. When we look at the mental health care sector today, there is work to be done before, during and after – the process becomes meaningless if we cannot transform societal attitudes and government negligence to complement the work being done by advocacy and health care service providing agencies and non-profits. If we are to look at mental health as an integral part of our lives, we must look at empowering ourselves and those who cannot speak for themselves, a bottom-up approach for solutions through rights, information and accessibility.

"You create and distribute your new currency, listener? You don't allow the government to control your grammar structure, listener?" is what we have to say!!!