Availability and Accessibility of Treatment for Persons with Mental Illness Through a Community Mental Health Programme

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ABSTRACT

This article describes experiences in implementing a community mental health and development project in a rural district in southern India, including the position of persons with mental illness when the project was initiated, the challenges faced and the strategies that were developed to overcome these challenges. The authors conclude that when services are locally available, persons with mental illness can be treated and rehabilitated within their own community. They can live with dignity and their rights are respected. There is a great need for inclusion of persons with mental illness in the existing developmental activities and in disabled persons' organisations.

INTRODUCTION

In most parts of the world, persons with mental illness are denied the basic human right of access to treatment, rehabilitation and appropriate mental health care. They and their families experience discrimination and exclusion from economic and social activities (Murthy, 2000). Lack of access to information about their rights perpetuates and deepens a situation of despair for large numbers of people who are not in a position to assert themselves (Thara et al, 1993). As a result, they face chronic ill health, and families experience economic and social burdens, in certain cases leading to destitution (Murthy, 2000).

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Many persons with mental illness are confined to their houses without any treatment, either because their family members do not recognise the illness or else find it embarrassing to be associated with mentally ill relatives, who are commonly called 'mad'. The stigma is so tremendous that people feel ashamed and deny the illness. The first and foremost element that shrouds the realm of mental illness is the stigma attached to it (Hoenig and Hamilton, 1966; Jungbauer and Angermeyer, 2002). The discrimination is seen from the family members right up to the policy makers and the state authorities (Lefley, 1987; Johnson, 1990).

This paper describes a community mental health project implemented by 2 organisations – Basic Needs India and Samuha in a rural drought-prone district (Koppal), with a population of 1,196,089.

Basic Needs India (BNI) is a resource group in community mental health and development. Since the past decade, it has initiated mental health programmes in parts of over 50 districts in different parts of India, by supporting community based organisations (CBOs) and non-governmental organisations (NGOs) to include mental health issues in their existing programmes. BNI and its partners have identified and supported over 18,000 persons with mental illness.

Samuha is an NGO that works in four districts of the state of Karnataka in South India, with the goal of supporting vulnerable people to improve the quality of their lives. The organisation works with over 14,000 families in 145 villages; including children and adults with disabilities and persons living with HIV/ AIDS.

Basic Needs India partnered with Samuha to include a community mental health component in their existing CBR project.

PROBLEMS AND CHALLENGES

Lack of Awareness

The general attitude of the public towards family members of persons with mental illness was that of apathy. Due to the stigma persons with mental illness were victims of discrimination and rights abuse. Superstitions prevailing in the communities played a big role in subjecting them to sometimes harmful and primitive practices through faith healers and other traditional healers. The belief in traditional practices tended to increase when people saw less severe psychological problems being healed by the faith healers, leading

many to believe that it could be the right treatment for people with severe mental illness too (Janardhan, 2009). When this did not happen, people began to feel that this illness could not be treated, and it resulted in many persons being deserted by their families. Some persons with mental illness also left their houses as they were not able to tolerate the harsh treatment meted out to them.

Mr M, a brilliant student, failed in his pre-university examination. Thereafter, he started wandering in the forests and became so violent that his own siblings were scared of him. Due to his behaviour, the community suggested that his parents throw him out of the house. Instead, the family decided to lock him up in a room, with manacles on his legs and hands. Their home was called the mad person's home. Nobody in the community showed interest in maintaining ties with this family.

Mr S was chained and taken to temples for healing. At the time of identification by the community mental health project, Mr S had developed contractures which had led to severe disability, as he was chained and made to sit in one place for years. He had to get surgical interventions for his contractures.

Lack of Treatment Facilities

For persons with mental illness and their families in Koppal district, the only psychiatric treatment available was at a government mental heath institute located more than 300 kms away, involving travel of 7-8 hours. This meant that families had to make the long journey with acutely mentally ill people, either by public transport or by hiring a vehicle to reach the hospital, leading to loss of wages and financial burden on the families. As one field worker said, *"Before they started the community mental health project, people thought that mental illness can be treated only in the mental hospital."*

They were often given medicines for a month or two without being informed about side-effects, follow-up and longer duration of treatment. This resulted in irregularity of treatment, relapse and loss of faith in psychiatric treatment (Janardhan et al, 2004; Janardhan and Naidu, 2006). Families who experienced relapse in their ill member, discouraged others from going for treatment.

Some families who feared stigmatisation, and were unable to care for their mentally ill family members, gave wrong names and addresses to the hospital, creating problems at the time of discharge.

Lack of Trained Professionals

The Primary Health Care (PHC) doctors were not willing to take responsibility to help the families get treatment; they were not confident about treating persons with mental illness, as they lacked skills and knowledge to deal with mental health problems. Though there was a psychiatrist in the district hospital, people from Koppal were not aware of this and were going instead 300 kms away to the institute.

Poverty

Poverty was one issue that cut across all the other concerns. Families of persons with mental illness resorted to what they believed were cost- effective methods of healing, like superstitious practices, to avoid going all the way to the institute. They assumed that such treatment would be a one-time affair, but eventually spent a lot of money and time at these faith-healing centers. Many families lost all their financial resources in their search for cures for their ill members.

INTERVENTIONS TO MEET MENTAL HEALTH NEEDS IN KOPPAL DISTRICT

Health promotion, prevention, rehabilitation, social integration and equalisation of opportunities for persons with disabilities, including those with mental illness have been accepted policy for the United Nations (UN) and World Health Organisation (WHO) for many years, with an increasing focus on community services. Community based mental health services is a model which WHO has advocated for over a decade (Helender et al,1989; WHO, 1994; WHO, 1995). The participation of persons with mental illness and of persons with disabilities, their caregivers and communities has long been a guiding principle for health care policy development, planning, implementation, monitoring, and evaluation (ILO, 1994; ILO, 2004; UN, 1994; WHO, 1976; WHO, 1981; WHO, 2010).

To meet the problem of inaccessibility of treatment, Samuha took the initiative of transporting all persons with mental illness and their caregivers to the Institute for assessment, treatment and follow-up. Once assessed, the families were made aware of the importance of regular follow-up and medicines. Follow-up meant another day of travel, spending money for the bus fare and losing a day's wage. Also, the rule at Institute was that medicines could not be dispensed to the caregiver unless the affected person was present. After Samuha had discussions

with the Institute authorities, they agreed to dispense medicines to the caregivers on production of the hospital card.

Samuha had facilitated active disabled persons' organisations (DPOs) in Koppal district. Though initially the groups did not agree to include mental health issues in their ambit of work, they agreed when they understood that mental illness was included in the national disability legislation and they began to view it as a development issue. Members of DPOs agreed to travel to Dharwad every month on behalf of persons with mental illness and caregivers to collect medicines for them. This helped the family members, as they now had to travel only once in three months for the follow-up.

Persons with mental illness were included in all government schemes and projects for persons with disabilities at the local level, such as the 3% reservation in the poverty alleviation schemes. Through the introduction of income generating activities, the quality of life of persons with mental illness gradually improved, leading to greater acceptance by the community.

Mrs Y suffered a loss in her hotel business. She was psychologically affected because of this. She took regular treatment for four months and was given a loan of to restart her business. She made a profit on this, then opened a tire repair shop and made a profit in that as well.. Now Mrs Y is building a house. She has become an active member of Village Monitoring Committee, and is also the team leader of a women's self help group.

Mr G was diagnosed as having severe mental disorder. A group of DPO members admitted him to the Institute for one month. After he returned home and had stabilised, it was found that he was very good at conducting rituals at religious functions and weddings. He took a loan of Rs. 3000, learnt about this and started earning enough to repay the loan.

DPO groups made a representation to the District Health Officer (DHO) to address the issue of lack of mental health professionals in Koppal, after conducting a survey in the district to prepare a list of affected persons. This convinced the DHO to request the psychiatrist from the neighbouring district to visit the Koppal district hospital once a week. This did not continue for long as the psychiatrist resigned and his position was not filled. Samuha and the DPOs had to look for alternatives. A psychiatrist in private practice from a neighbouring district, agreed to work with Samuha in conducting camps. With the support of the DHO, mobile camps were started in 5 locations. Once the camps were regularised, and the number of people approaching camps increased, it became difficult for one psychiatrist to manage on his own. Samuha and the DPOs requested the DHO to

depute medical officers from the PHC for the camps. Basic Needs India, Samuha and DPOs in collaboration with the DHO, organised a two day training for the PHC medical officers on mental health, so that they could identify mental health problems and assist at the camps.

The next step was to make arrangements for the medicines to be made available locally. Although government district hospitals have the provision to procure the required medicines, they often do not do so, and poor people are forced to buy them from expensive private stores. Samuha advocated with the pharmaceutical companies, who agreed to supply medicines to private medical stores at a 50% subsidy, so that people treated at PHCs could buy medicines at nominal rates.

Since there were no professionals trained in psychiatry in the government services, the DHO sent a group of PHC doctors for training at the reputed National Institute of Mental Health and Neuro Sciences. The training was a five-day basic orientation on common psychiatric disorders in day-to-day primary health practice, including assessment, diagnosis and basic treatment. This group then passed on their learning, by training other PHC doctors in the district.

One of the PHC doctors underwent specialized training and was designated as the District Mental Health Officer. The DHO gave permission to this Officer to support the camps held in Koppal district.

Issues and needs related to mental health were included for discussion at the District Visiting Board, consisting of government and non-government organisation representatives. This helped to sensitise authorities about the non-availability of medicines locally

Samuha understood the need to integrate mental health camps with the PHCs, in order to make the camps more sustainable and reduce the stigmatisation of people who attended the camps. Since all persons with mental illness were not enrolled in the PHC registers, Samuha started the process of encouraging them to get registered. However, the PHCs initially were reluctant to take responsibility for persons with mental illness. Advocacy and frequent meetings with the DHO finally resolved this issue, and the number of people treated at the PHCs increased as a result. The DPOs took up the issue of making medicines available at the PHCs. After a series of campaigns, regular supply of medicines became the norm at the PHC.

Samuha's aim was to ensure that the services became system-based and well integrated in the district health programme in Koppal. For this reason, the programme's progress and the needs identified were discussed regularly with the district authorities. Samuha provided information to persons with mental illnesses, their families and the wider community, about the formal responsibility of the government to procure medicines and make them available. This motivated the community to work together and pressure the government authorities at all levels to fulfill their responsibilities. Mental health became the subject of regular discussion and negotiation at various levels of the local governance system in Koppal. *"Mental health became everybody's need".*

IMPACT

More than 1100 persons with mental illness were assisted through this programme over a period of 5 years, and about 60 PHC doctors were trained on mental health issues. The awareness about mental health issues in the community has led to early identification and access to treatment locally. People who benefited from treatment have spread the message, and others have started approaching PHCs on their own for treatment. There has been marked increase in identification of women with mental illness in the project areas. The increase in numbers of self-identification would indicate reduction in stigma. People in the recovery phase are encouraged to share their experiences in public fora, during community group training and celebrations of World Mental Health Day. The community has seen persons with mental illness getting treated within their homes, their recovery, and subsequent involvement in productive activities. This has also contributed to reduction in stigma and has spread the message that mental illness is treatable. Persons with mental illness who were separated from their families due to illness, started rejoining their families. Those who recovered and their caregivers took interest in supporting other mentally ill people, by escorting them to the hospitals for follow-ups, and by sharing their experiences.

The self-help groups, through their savings and bank loans, initiated many income generating activities and with the resultant increase in family incomes, the quality of life of persons with mental illness improved, along with confidence and self-esteem among persons with mental illness.

Implications for Practice

Persons with mental illness are excluded in most CBR projects, mainly because of inadequate skills in identifying and meeting their needs, the prevailing

misconceptions related to mental illness, and the attitudes within the community which are not different from those of CBR workers. Often mental illness is understood to mean mental retardation. The Koppal experience highlights the need for inclusion of persons with mental illness in CBR projects, as mental illness is recognised as a disabling condition worldwide. Persons with mental illness and persons with disabilities have some common issues like stigma, lack of medical interventions, lack of livelihood options, which can be addressed collectively through a CBR approach. The Koppal experience also shows how DPOs and families of persons with mental illness can be empowered to advocate with relevant authorities to address their needs.

CONCLUSION

Samuha has been successful in bringing about active participation of multiple stakeholders in community mental health and in advocating for the entitlements of persons with mental illness and their families, especially in the areas of assessment and treatment facilities and availability of medicines at PHCs, free of cost.

India is a vast country with more 600 districts, and much more needs to be done to reach persons with mental illness living in remote areas. However, with better awareness at all levels, government and non-government organisations are responding positively on this issue. Unlike in the past, people are talking about mental illness and it is being heard. There is hope for a better quality of life for persons with mental illness.

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