MENTAL HEALTH AND DEVELOPMENT

FROM THE LOCAL TO THE GLOBAL - THE INVOLVEMENT OF MENTALLY ILL PEOPLE IN THE DEVELOPMENT PROCESS

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ABSTRACT

From practical experience at local and regional levels, the author discusses the potential for mentally ill people to be involved in the development process. Insisting on the right of mentally ill people to be consulted in development work of all kinds, the author illustrates failures and successes in supporting mentally ill people. He uses evidence from India and Sri Lanka to show that stigma bars mentally ill people from development processes and that this is a human rights issue.

Drawing on the statistical evidence available today, the global implications of the high prevalence of mental illness are considered in relation to the lack of community facilities. The author concludes that mentally ill people will only take their place in the development process, as does any marginalised group, by finding ways of achieving knowledge, leadership and resources through self-help, and by creating appropriate alliances with other groups in society.

INTRODUCTION

A group of women and men gather in a village agricultural co-operative store, which has been lent for the purpose of the gathering. People wait for the bus to bring some participants to the meeting. Staff from SACRED, a small community based organisation (CBO), hurry to fetch others on their motorbikes. Shivanna, an elderly man, is invited to give a song at the beginning of the workshop. His quavering voice rises up like tendrils of sound into the rafters. As he gives new meaning to a well-known mythological tale so the group discerns beauty held in the air like the grain dust caught in the morning sunlight. The facilitator starts to work with the group and they agree on the ground rules for the morning. All agree that a process writer may record the events of the day. A man unobtrusively pulls out his pad. Like the start of hundreds of such meetings of people that occur all over the South Asian region, an animation session is starting in a small village outside Anantapur, Andhra Pradesh, India. After some time when the group is feeling more at ease and after sorting out the translation needs common to any mixed language meeting, some realities begin to emerge.

Lakshmana of Gotkur village did not have a carer with him and was joined by Yellamma, a 'SACRED' staff. He said, "I have a brother and a sister. My job is cattle grazing. My family weaves silk sarees. I had fits and am under medication". The staff then explained that since he had created some problem in the village, his parents had tied him to a pole and beaten him up. Lakshmana said, "I get angry with my parents because they do not listen to me. They are not taking care of my desire to get married. I am asked to do cattle grazing while my brother works on the loom. They do not let me weave since they fear that I will get fits and will thus destroy the saree being woven. I can make incense sticks. But they do not let me do it, saying that it is not profitable."

The group is composed of mentally ill people, carers and staff members from SACRED. Whilst many animation meetings do take place all over the region, very few of them are run with mentally ill people as the main participants. In talking to mentally ill people living at home, we have found that they are almost never part of community based rehabilitation (CBR) schemes, development programmes or income generation projects. Certainly they very rarely seem to take their place in such programmes as full participants. Sometimes they are involved as the "done to".

They are the recipients of both charitable kindness and, indeed, of cruelty. Like an enclosing institution, the community contains them but does not allow them to participate in the full rituals of society.

TALKING TO MENTALLY ILL PEOPLE – LOCAL ACTION OF GLOBAL IMPORTANCE

In September 2000, a small team assembled in Bangalore, after negotiating earlier to conduct a series of field visits that would permit them to talk directly with mentally ill people, their carers, family members and so on. These discussions had been with the CBOs already mentioned, and a number of conversations with prospective participants had already been conducted. Before leaving for the visits, the team finalised a topic guide to be followed in the field:

1. Introductions (brief introduction about the programme for the day).
2. Introduction game for participants – (variations to be experimented based on the group size).
3. Permission to document the process and permission to photograph.
4. Setting of ground rules for the conduct of the programme for the day.
5. Constituency mapping of the people (and institutions) who interact with the mentally ill people and their carers in an ongoing manner. (This exercise was planned to identify the proximity of the mentally ill to various community stakeholders. It was also agreed that the exercise would be conducted in small groups giving every participant an opportunity to take an active part in the exercise. The exercise came to be called "my world").
6. Clarifications related to the mapping exercise (clarifications, understanding, consequences).
7. Needs discussion, dealing with needs of the mentally ill people, carers and so on (in small groups).
8. Clarification of needs by the whole group.
9. What next? This discussion was initiated to get a commitment from the group as to what they could do on their own and to identify areas where they needed external help. This would be indicative of the possible areas of intervention that could be supported by Basic Needs. Further, it would provide a discussion point with the CBOs.

Once all participants had agreed on the topics, mentally ill people, carers and CBO staff worked in separate groups for all the small group exercises, usually within the same room. Only when the larger group came together again later, were mentally ill people, carers and CBO staff reunited. Occasionally the facilitator asked a staff member to assist with some of the processes.

Four, day-long workshops were conducted: two under SACRED's auspices and two under the Narendra Foundation. As the team worked with the two CBOs, a parallel process of discussion leading to partnership creation emerged. Thus, in effect, between September 2000 and February 2001, the BasicNeeds team found itself working on two fronts that slowly wove together: a consultation process to establish a viable programme and identification of appropriate partners to carry out the work on the ground (1).

To continue with the example already quoted earlier, *the group sat on the floor, on mats, in a hall in the village co-operative building meant for storage of agricultural products. To agree on the topics, three groups were formed of mentally ill people, their carers, and staff and volunteers from SACRED.*

The process writer reported: Group 1 sat in a circle and was at once on the job, building consensus, valuing individual opinions and actively participating. Lakshmana took on leadership role and guided the process. The constituency mapping done by Group 1 had the following

constituents: Mother, father, friends, elders, school, SACRED, agricultural work, weaving, marriage, hospitals and doctors, cultural events etc.

The day wore on with the three groups reporting and then going off to work on a needs analysis. In due course an all group discussion occurred. Voices arose from mentally ill people and carers alike.

One of the participants had gone out of the room angrily and was brought back to the group. The facilitator asked him to sit opposite him at the centre of the group. He did so and stated that he disliked the drinking habit of his father and the family environment. His mother was asked to join the small group and a dialogue was initiated. The larger group keenly observed the processes and the tension that had appeared, slowly dissipated.

One of the mothers said, "if we are not able to deal with the problems, we will consume pesticides and die". (This is the common form of suicide among the farming community due to the availability of pesticides.) Four others expressed their approval vigorously shaking their head. Another mother said, "I will make my son join me in bamboo basket making. He does a good job." Yet another said, "We want people to know our problems and understand us and behave properly." Other opinions included "We want proper medication and guidance," "We want to come together and share problems. This process is helping us to relieve a lot of our tensions. We would like to continue to do the same".

At this point Lakshmana confronted his mother who had joined the group 15 minutes earlier. He told her, "You should treat me the way you treat my elder brother. You should let me weave at the loom and not let me go for cattle grazing. You are worried about my fits and fear that I will spoil the saree if I faint while working. Please remember that even a millionaire eats rice, not gold. Do let me work. Humanness is more important than money". Adinarayan (son and carer of the singer who opened the meeting) summed up the discussion saying, "people with mental illness have their problems, parents and carers also have their own problems, so do the community. We need to come together, place these problems in the open and solve them together."

Much that is momentous seems to confront mentally ill people on a daily basis

1. Mentally ill people want to take part in the events of their community as others around them. For example, a good looking young man longs to marry a girl with the help and advice of his family, according to their tradition (2). But in this case the support is not forthcoming.
2. Their choices can be very limited compared to others around them. Further, the decisions affecting their life choices are taken for them and without reference to them.
3. They can be abused with relative impunity and their civil and human rights can be arbitrarily limited or denied.
4. They want to work, for money for the family, for the work itself, for the pride of working.

CONVERTING OUR CONVERSATION INTO PRACTICE

Working with just over one hundred mentally ill people and their carers together with the Narendra Foundation, SACRED and GASS, the BasicNeeds team has developed a five module programme.

1. Capacity building

This will be the basic module to facilitate the training of the CBO partners and equip them to work with mentally ill people to form their own self help groups. Additionally, carers may form groups both for mutual support and to provide innovative mechanisms of care. Organisational

development of various community institutions can also be provided through the capacity building mechanism.

Coleridge (3), drawing on examples from CBR in Afghanistan, comments that the concept of empowerment can prove "problematic", while "enablement" is culturally more acceptable in Afghanistan. This perception holds good here as well, for there is a responsibility to first engender confidence in the participants and their groups. Yet, one must take care not to overtly challenge the community with what they may perceive as an alarming and incomprehensible notion of power for the mentally ill, until a teaching and learning process has been undertaken.

2. Income generation

If the community were to change its notion of mental illness and its concept of the identity (4) of the mentally ill person within the community, then it might well be through making a little money for the family. Here the programme identifies the capabilities of individuals and those around them who want to be associated with the project, along with suitable trades within the community that can be merged into a micro enterprise. Training the CBOs in micro finance management will be as important as the links with micro enterprise specialists such as the Bridge Foundation in Bangalore.

3. Community mental health

Many people turning up for the meetings are either pre-occupied by their own sense of being mentally ill, or being affected by the presence of mental illness in others. These experiences contribute to their construction and understanding of their own sense of identity (5). If one is very marginalised within one's own community, inevitably one turns inwards to solve "my problem". One may indeed have an illness which can benefit from competent intervention, and it is assumed that any rational person would take the treatment. Yet, it is difficult to recognise that one is taking care of oneself by treatment and that in return one may be less marginalised. The negotiation within the community is bound to be more fluid, and more problematic. In a world where the social model of health is not much practised, most people still feel that a powerful health professional in their area would be of the greatest help.

A common form of extending specialist treatment into rural areas in Andhra Pradesh is the so-called "camp" system. After making the necessary arrangements, the specialists arrive and "set up camp" in a convenient place, such as a district hospital, and see patients for diagnosis on a pre-agreed basis. A majority of clients is looked after locally and only those that need further assistance are sent to a secondary or tertiary place of care. The pressure from mentally ill people, and no doubt their families, to see a specialist is great. However, the success of this model will depend on other timely interventions as well as direct medical interventions. For example, the training of CBO staff to act as "bare foot" counsellors, and the training of local practitioners to supplement more specialised staff will all be of great importance.

In a sense each of these modules is a "place to start" and this module offers the chance to meet a mental health professional and to take it from there. Michael Oliver (6) comments that whilst the resources of medical specialists may be essential, the boundaries do need to be re-negotiated for most disabled people. In the case of those that BasicNeeds is working with, it would seem that it needs to be negotiated from scratch – most of the groups have not met any kind of specialist in mental health provision earlier.

4. Research

This is a three part module with an empirical section for the enumeration of simple information such as how many people are involved, levels of poverty and so on. In order to place the voice of the mentally ill person at the centre of the narrative (7), a series of life stories as told by the people

themselves, will be developed. They will contribute to the collective body of knowledge and will be published with consent at appropriate times. Finally, BasicNeeds wants to develop a research paradigm known as User Led Research (8), supporting mentally ill people to manage their own inquiry. Many of the routine meetings have been documented to contribute to the collective learning and advocacy, and to strengthen the groups of mentally ill people and their carers as they gather the ability to influence others. Even though it takes time and effort, documentation of the processes is necessary in a field where mentally ill people are generally not involved in community rehabilitation and development programmes at present.

5. Administration

This module is of great interest to the CBO partners since it offers training in project management, including logframes and logframe training, budgeting and finance, monitoring and evaluation, and reporting.

Method of implementation

BasicNeeds plans to implement its programme through a partner, known as a 'Facilitation Partner', who will deliver the development programme after appropriate training and capacity building, through Community Based Organisations working in the same region. For example, a large organisation, the Nav Bharat Jagrithi Kendra (NBJK) situated in Bihar and Jharkand, envisages working through six CBOs operating in thirty six districts that they currently cover.

In order to understand the process better and to have a better knowledge of the issues involved, BasicNeeds will also work as a Facilitation Partner with three partner CBOs within its reach in Bangalore. They are SACRED in Anantapur District, Andhra Pradesh, Narendra Foundation in Tumkur District, Karnataka and Gramina Abdyudaya Seva Samstha (GASS) in Bangalore District, Karnataka.

Through these two streams of work, BasicNeeds will simultaneously be able to gather enough information from mentally ill people, and also learn to work with those who deliver the programme at the field level.

Learning at the local level

The lessons learned since April 2000 are as follows:

1. All five modules of a Community Mental Health and Development Programme need to be implemented if the work is to be effective.
2. CBO staff generally felt inadequate to work with mentally ill people because of the myths built up around mental illness. They now understand that many of the techniques they already practise, from the fields of CBR or development, are helpful to mentally ill people as well.
3. Many people are excluded from CBR or development programmes because they are assumed to be unable to take part in these programmes due to their mental illness.
4. If one talks to mentally ill people, it is easy to realise that they have the ability to make decisions necessary to carry out development work in their own communities, and that they must be accorded their rightful place in society. In the process of development, one can assume with a fair degree of certainty, that the pursuit of basic needs will also slowly lead to the achievement of basic rights.

REGIONAL PERSPECTIVES FROM INDIA AND SRI LANKA – NEGOTIATING THE LOCAL / GLOBAL GAP

From the conversations with mentally ill people described above, one can understand how they view the world from their perspective, and how difficult it would be for them to survive in a world where even those who are not mentally ill face innumerable problems. The phenomenon of

globalisation can be described as being as much within countries as between countries, particularly in the differential between the rich and the poor. The access to knowledge, leadership and resources (9) often defines this differential most tangibly. Does access to these assets serve to connect the poor to the wider world beyond the immediate village or community?

It is easy to imagine how an "ordinary" struggle against poverty can be made a hundred times worse by the stigma of mental illness. Originally seen by the ancient Greeks as a derogatory physical mark such as a cut or burn on a slave, 'stigma' today applies to the disgrace felt by, in this case, the label of mental illness (10). Stigma not only labels people long after the mental illness has disappeared, but also results in very poor service being provided to those so labelled. One would have thought that a hospital would have been the ultimate sanctuary of the mentally ill person, yet Murthy (11) argues that in India, "The services provided by the mental hospitals have been very unsatisfactory. Most of the mental hospitals have remained under developed and unsatisfactory in terms of the services provided and the facilities for care .A recently completed survey of the mental hospitals, by the National Human Rights Commission (NHRC, 2000) presents a picture of neglect and low level of care to the mentally ill persons. A large part of the stigma about mentally ill comes from the poor conditions of the mental hospitals."

Somasundaram (12) reports from Northern Sri Lanka that "People who are mentally ill and even those who have recovered are rejected, ostracised and marginalised by the Tamil society. Mental illness carries a severe stigma in this society. Those who are labelled as having or have had a mental illness and their family are looked down upon, derided with scathing remarks and isolated from the mainstream of community life. Thus, they will not be invited for social functions and even if they attend, people will avoid them or pass negative comments. They will not be given jobs or employment. Children and students will face rejection at school, play and community activities. Marriage prospects of the persons and their relatives, particularly females, will become almost nil. With regard to socio-economic assistance, development programmes, rehabilitation projects and so on, they tend to be left out."

The institution of hospital and the institution of community seem to generate a great deal of conflict that requires mentally ill people to possess a high level of negotiation skills. Why should anyone have to put up with such poor service? Historically, the burden has fallen on medical and social services that are pressed to their limits due to the patient load and limited financial resources. Even as early as 1946 when India's total population was quite a lot smaller, the Bhore Committee (13) noted "Even if the proportion of mental patients is taken as two per 1,000 population in India, hospital accommodation should be available for at least 8,00,000 mental patients, as against the existing provision of a little over 10,000 beds for the country as a whole. In India, the existing ratio is of one bed to about 40,000 population, while in England, the corresponding ratio is approximately one bed to 300 population."

Out of a total population exceeding one billion, Murthy (11) reports that in India, "About 3000 qualified psychiatrists are working in different centres in the country. The number of psychiatric social workers is estimated to be around 600. The number of trained psychiatric nurses is around 600." He adds that "Of the 140 medical colleges in the country, about three quarters have an academic department of psychiatry. In another quarter a psychiatrist functions as part of the general medicine department with no additional staff." According to him, "The actual amount of training is grossly inadequate, as the minimum amount of training required as per Medical Council of India rules is only two weeks of training."

In Sri Lanka, Kathriarachchi and colleagues (14) noted that out of a total population of about 20 million, there were 30 psychiatrists, 3 clinical psychologists, 18, occupational therapists, 10 psychiatric social workers and 412 nurses. They state that many mentally ill people "…end up in institutions like the Mental Hospital Angoda and due to the stigma associated with mental illnesses,

most find it difficult to go back to their homes and families and enjoy the standard of living they had before their illness."

During the initial work of BasicNeesds in India, it became clear how much pain many parents suffered in their roles as carers. This applied particularly to mothers and to other women. The situation is the same in Sri Lanka (14), where it is noted that "The burden of caring for those with chronic mental illnesses was largely borne by the parents. The siblings in most cases did not want to take the responsibility of these patients. While the parents are alive they do everything they possibly can to care for the patients, but they are afraid that when they are dead there will be no one to look after their children, and they will end up on the streets. Most parents felt that a facility which provides residential care for those patients who are unable to function independently in society, is necessary."

Parents coming together as a self-help group is a very powerful instrument for supporting mentally ill people and their families, and there is an example of this system in Bangalore, in the group called AMEND. Generally, however, the most striking thing about mental illness in both India and Sri Lanka, and probably in other parts of the region, is the extent to which the state medical and social service sector dominates the subject. In these countries where the voluntary sector is dominant, the presence of non governmental organisations (NGOs) in this field is quite extraordinarily slight (11, 14).

Noticeably, very few mentally ill people are involved in development or CBR programmes. With few exceptions, perhaps everyone forgot to talk to mentally ill people in the same way that they forgot to talk to other marginalised groups within society such as landless labourers, dalits, women and disabled people. The question therefore is, who has actually stood by people with mental illness? Clearly the medical and social service professions, mostly from the state sector, have done the most in an organised fashion, but equally clearly, it is the parents, families and communities who have taken on the greatest burden of care and its associated anxiety. Almost all agree that it is the community based traditional healer who often sees the patient first, long before any other intervention is considered.

The voluntary sector has provided a limited number of residential models in both India and Sri Lanka, but it now needs to place its considerable experience in community development, to care for mentally ill people and their carers. Mentally ill people need to be invited, encouraged, and motivated to become part of the development process. Clearly they need to be part of CBR programmes, but they should also be part of agricultural schemes, income generation programmes and the whole gamut of programmes currently available to other citizens.

GLOBAL KNOWLEDGE – LOCAL ACTION

There is persuasive evidence that in the developing countries non-communicable diseases such as depression and heart disease are fast replacing communicable diseases as the leading causes of disease burden (15). Jenkins (16) in assessing the importance of mental disorder, points out that "Five of the ten leading causes of disability world-wide in 1990 (measured in years patients have had to live with a disability) are psychiatric conditions: unipolar depression, alcohol use, bi-polar affective disorder, schizophrenia and obsessive compulsive disorder." She concludes that "the contribution of psychiatric disorder to the global burden of disease in 2020 is expected to be immense. The projections show that psychiatric and neurological conditions could increase their share of the total global burden of disease from 10.5% of the total burden to 15% in 2020. This is a bigger proportionate increase than that for cardiovascular disease".

Since 1946, and the days of the Bhore Committee in India, a paradigm shift has taken place in how, and where, mentally ill people should be cared for. Generally the community has been

perceived as being the best place for the vast majority of people with mental illness, supported by a limited but strategic medical intervention (17). This shifts the focus away from large hospitals and institutional care, to alternative methods to cater for the large numbers that are forecast by Jenkins.

The implications for health policy and spending are significant if mentally ill people are to be cared for in an effective manner in the community. This affects, for example, the demand on primary care facilities as mental health becomes an integral part of services (18). It also implies a heavy demand on CBR programmes and development projects. Further, there will be a need to experiment with multisectoral approaches such as integration with primary health care, income generation and self help group development. This will also need to be associated with a willingness to adapt successful programmes from other areas, such as community social enterprises, operated successfully by the state and voluntary organisations in Italy (19).

RESPONDING TO THE GLOBAL CHALLENGE - MENTALLY ILL PEOPLE AS PART OF THE DEVELOPMENT PROCESS

For most people with mental illness, there is a clear understanding that being productive is the only way to get family and community acceptance, apart from self acceptance. The distress of mental illness is so much more when the affected persons are denied the chance to do something about it. Those who have worked hard to construct the five modules described at the beginning of this paper hope that they are first and foremost responding to the need of people with mental illness to be productive. It is hoped that the mental health and development model will be flexible and will continue to respond to the demands and needs of mentally ill people. As one observes the animator applying Freirian (20) principles and the group slowly growing in confidence, one becomes aware of the potential of two traditions blending together. On the one hand, there is the tradition of community development that strengthens the group to carry out its tasks such as income generation, land clearance, or whatever else is needed for the community. On the other hand, there is the tradition that sees the growth of the group as part of a psychotherapeutic process that has proved very encouraging for many people. It is not that these two traditions must flow together. We just need to appreciate and be aware of the proximity of these two traditions. In fact there will be natural opportunities for a satisfying exchange between the two, which make the whole process much richer when it happens.

If mentally ill people are able to take their place in the development process they will also take their rightful place in the fight against poverty. To be poor and also mentally ill is very tough. It is equally true that many mentally ill people are poor and homeless (19). At the same time, mentally ill people can contribute to the development process, just as any other marginalised group seeking upward mobility. They will also have to find the ways to achieve knowledge, leadership and resources by organising themselves. They will need to stand apart from others so as to identify themselves as a separate group with needs, but at the same time, they will need to make alliances with others to fight poverty and injustice jointly.

People who work with various groups of marginalised people will of course see mentally ill people amongst them. To establish the link between human rights, justice and mental illness is the need of the hour. It is very much a part of the development process and requires development programmes to involve mentally ill people.

Shivanna was asked to sing a song to mark the close of the session. As he had opened the session, would he like to close it; asked the animator. Slowly Shivanna stood – a little stiff, as any elderly man would be after sitting in the group for a long while. He flicked his fingers open and shut in time to the music in the hot stillness of the little stone barn. What did Shivanna sing about? 'Hope' of course, 'love' and the 'connectedness' of all things in the universe. Rendering a well-known mythological tale in a well-known musical form, he was immediately understood by his own

community. Yet, in singing of things that matter to all of us he reached us all, the local and the global, shimmering as one, held in an old man's voice in rural Andhra Pradesh.

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