India: CBR and Mental Illness
Bangalore, 12 December 2006

Introduction: AIFO has promoted the adoption of community-based rehabilitation (CBR) approach in all its projects in India. A meeting of a selected group of projects involved in CBR activities was organised to promote discussions on services for persons with mental illness in CBR.

Jayanth (CBR Coordinator, AIFO India): Persons with mental illnesses face similar difficulties as other disabled persons, but often they are worse because community and family perception about these disabilities is worse. The psychosocial problems are worse. Sometimes, we have encountered persons with mental illness, who are kept tied in chains.

While persons with mental illness are persons with disabilities, it is important to remember that other disabled persons may also have mental illness. NIMHANS, the psychiatric hospital of Bangalore organises community camps on mental illness, but after the camp, no body in the community knows what they are supposed to do.

Daisy (Cochin): For us leprosy was the main concern. When leprosy started deceasing, we started looking at the needs of persons in our communities. We felt that mental illness was the group that was most neglected. They do not have any visible deformity but if we look closely, we find that the person with mental illness and the whole family, both are isolated and disabled.

Persons with mental illness are hidden in the communities. We went to look for them through neighbourhood groups, with whom we already had contacts for long years of leprosy work. Initially most of the families did not come out to us but slowly we could approach and understand. Most of them don't go to the mental hospital or other mental health services. For them, it is as if their life is finished – there will not be any marriage, any work, anything, they will be completely isolated.

Things come out when the person becomes violent. So much of these problems could have been avoided if they could go to the psychiatric unit in general hospital earlier and take their medicines. Once we identify, we accompany them to get medicines. However often, they take medicines only in the acute phase and as soon as they feel better, they stop taking them. Convincing the persons to continue taking the medicines is difficult.

Not taking regular medicines is also linked to financial issues. The cost of these medicines is an obstacle and hospitalization has costs that families may not be able to cover.

At community level, the stigma is even worse than that of leprosy. In the family more than one person may be affected and the disability is affects all the family.

To start working with mental illness, we went through some books and manuals. We also invited some experts to conduct training. We are in regular contact with a psychiatrist. But, we are very much aware that we require more training. At present, we are working with 174 persons including some persons with epilepsy and intellectual impairment.

Narsimha (Malavalli): We are working with mental illness since the beginning, since 1990. At present, we have 138 persons with mental illness in our project. We work in collaboration with NIMHANS, as they conduct mental health camps in the villages. We provide support for buying of medicines and do follow up to ensure that persons take their medicines regularly. We also provide counselling for the family. As part of counselling, we explain about different mental illnesses, availability of services, the existing national mental health act, etc.

Some persons participate in our vocational training programme. They can also join a self-help group. We find that the issue of mental illness is closely related to traditional beliefs and practices. We do not oppose such beliefs but advise them to visit the hospital. Some of the persons, who have overcome the acute phase, are part of the disabled persons' organisation. The major groups of mental illnesses in our project are depression, manias and behavioural problems.

Ida (Bellary): The project follows about 40 persons with mental illness. The activities include home visits, follow up, counselling and promoting community participation. Often family members are not very collaborative and so information may be collected from neighbours. We also conducted a psychiatric camp but not many persons came forward to get free check up and advice. Many persons also don't come up for regular follow ups.

There is no psychiatric centre in Bellary, where we can refer our persons requiring hospital services because the district hospital is 110 km away. However, we do have a nursing home with a psychiatrist in our area.

Our CBR workers and staff require specific training on how to handle persons with mental illness.

Prashanty (Gudivada): made a presentation on activities of the project with persons with intellectual impairment, raising up important issues on gender and mortality of disabled children. This project is doing limited work with persons with mental illnesses.

Leela (Mandya): The project has 35 persons with mental illness. One of the biggest issues is the cost of buying medicines. Temporary solution is to look for grants, but once grants finish then what can be done?

Primary health care centres and units do not have any medicines for persons with mental illness. Affected persons face lot of problems, in terms of finding a job or finding a life partner.

CBR personnel requires specific training on how to work with mental illnesses.

Celine (Kollapur): The project started CBR activities in 1998, however they are not working so far with persons with mental illnesses. CBR staff requires specific training on role of CBR in mental illness. Another problem is that there are no referral services for mental illnesses in our area.

George (Sumanahalli): Project intends to start working with persons with mental illness. There are only 7 persons with mental illness followed by the project now. These activities are in collaboration with NIMHANS. Project will follow the persons after they come out of a hospitalization at NIMHANS. At the same time, NIMHANS wants to collaborate with Sumanahalli for vocational training. The project also works with persons with intellectual impairment and epilepsy as part of CBR activities.

Trevor (We Care): Out of the 980 persons with disability identified by the project, 18 are persons with mental illness. Only recently we realised that persons with mental illness are part of persons with disabilities. I have a masters degree in psychology and another person from the project has been sent for a five day training course on mental illness. The project is thinking about setting up of a day-care centre and this work can be linked with community cell at St. John's medical college.

George (Mangalagiri): presented some personal considerations about mental illness, issues of stress related to schools and the community stigma against persons with mental illness.

Narayan Kaji (WATCH, Nepal): In Nepal, persons with mental illness may end up in prisons. Many persons for getting married a second time, declare their first wives as being mentally ill. There is a gender dimension of mental illness as daughters with mental illness may be turned out of homes.

Conclusions: For most of the AIFO supported CBR projects in India, their experience with mental illness is limited and relates mainly to referral to specialized institutions or psychiatrists, counselling and social integration. Almost all projects ask for specific training for dealing with persons with mental illness in CBR setting.

Dr Pupulin, from Board of AIFO, participated in the meeting and advised for organisation of proper training on mental illness for CBR staff, before starting these activities.

Dr. Sunil Deepak
AIFO, Italy