

Community Based Rehabilitation & Mental Health

Bangkok, 13 – 14 February 2009



Workshop Report

ASIA PACIFIC COMMUNITY-BASED REHABILITATION (CBR) CONGRESS

The Pre-congress Workshop on “CBR & Mental Health” was Promoted & Supported by

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The Pre-Congress Workshop on “CBR & Mental Health” was organised and coordinated by

Italian Association “Amici di Raoul Follereau (AIFO)



Self-help group of persons with mental illness involved in income generation in Mongolia
CBR Programme

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Community-based Rehabilitation and Mental Health MAIN CONCLUSIONS

50 persons from 20 countries, including countries of Asia, Pacific, Middle East, Africa, South America and Europe, came together for the workshop on “CBR and Mental Health”, organised at Prince Palace hotel in Bangkok (Thailand), in February 2009. The participants represented different stake-holders and included persons from Ministries of Health, Organisations of persons with disabilities (DPOs), user groups, national and international NGOs, persons working in CBR programmes and Mental health Professionals.



This workshop was organised at the initiative of AIFO in collaboration with World Health Organisation (WHO), Government of Thailand and many international organisations including IDDC, CBM, Basic Needs India, etc.

The workshop was organised over a two days period and had three thematic sessions –

- Challenges and achievements – CBR programmes and persons with mental illness
- Persons with experiences of mental illness and their families in CBR – learning from experiences
- Learning materials and capacity building in relation to community based interventions for and with persons with mental illness

Mr. Chapal Khasnabis from the Disability and Rehabilitation team of the World Health Organisation (WHO/DAR) opened the meeting and started with his own reasons of interest in the theme of this workshop – his experience in CBR and issues of mental illness within his own family.

Mental illness is not an issue limited to any one part of world, it touches everyone. In WHO there is a department on mental health. WHO/DAR works together with Mental Health (MH) especially on rehabilitation and inclusion. WHO/DAR is working on developing CBR Guidelines. In these guidelines, there is a separate chapter on CBR and Mental Health (CBR-MH) in these guidelines like on “CBR and Leprosy”.

Often, people believe that mental health is a very medical issue. It is also perceived that interventions in mental health are expensive. People do not know how to work at it at community level. Thus, in CBR programmes there is lack of information, knowledge and skills related to mental health. So many CBR programmes may not work in this area.

There are lot of discussions with Mental Health department of WHO about how we can promote greater involvement of CBR programmes in mental illness. Including MH issues in CBR is important as it will benefit many persons in the developing world. So bringing together stakeholders and work together is important.

MH Chapter in the CBR guidelines is still under revision, so any ideas from this workshop can reinforce guidelines. Conclusions from this workshop can be taken to WHO and find ways to work together.

Ms. Suchada Sakornsatian as the deputy director of in the Ministry of Health of Thailand responsible for mental health programme, said that the evolution of mental



health services have generally similar to community based rehabilitation. It was concentrated on hospital-based psychiatry at the beginning and now there is increasing awareness in many countries to shift emphasis to community-based programmes. Many barriers exist to the implementation of community-based mental health. Some countries have already developed mental health policy emphasising on community services, but their

implementation has been inadequate. There is an urgent need to clearly define the goal and objectives (both long term and short term) of community based mental health programme which is culturally appropriate and reaches out to all segments of population. Mental health services should be integrated into overall primary health care system. Innovative community-based programmes need to be developed.

The following **Main Conclusions** can be drawn from this workshop:

- Persons with mental illnesses are often surrounded by strong stigma and prejudice. Persons with mental illness and their families are often marginalised. Their human rights are often violated, they may be put into prisons like criminals and many countries have laws that violate their human rights. Some times, persons with mental illness are closed in old institutions and kept in inhuman conditions.
- There are few mental health referral services and professionals in many developing countries. Similarly, community mental health programmes are very few and limited. Often persons with mental illness lack access to mental health services and face barriers including difficulties of accessing regular medication.
- Many CBR programmes do not include persons with chronic mental illness in their work. There is lack of understanding, knowledge and skills about management of mental illnesses.
- There are positive examples of CBR programmes showing great deal of convergence with community mental health programmes. Both are based on human rights approach. CBR is an effective and empowering approach for reaching persons with disabilities including persons with chronic mental illnesses.
- There is need to develop capacities of persons with mental illness, their families, communities, primary health care workers and CBR workers about mental illnesses

and how can persons manage them more efficiently at community level. CBR can be the vehicle to extend and support the community mental health services. CBR programmes have to make efforts to promote inclusion of persons with mental illness in their work.

- CBR programmes work through active participation of persons with disabilities, who are supported to form user groups, self-help groups, peer groups and DPOs. Supporting and promoting user groups of persons with mental illness is an effective way to promote their active participation in the CBR programme. If user groups can play decision making role in all stages of CBR programme from planning, to implementation, monitoring and evaluation of activities, programmes can answer their real needs and it is empowering.



- CBR programmes in collaboration with user groups and DPOs should reflect on and raise the human rights issues linked to mental illnesses such as involuntary admissions and obligation of informed consent for treatment.
- At community level, CBR programmes can promote visible social interaction between community volunteers and persons with mental illness, so as to provide positive role models in the community to fight the social stigma. They can involve village leaders and religious leaders in influencing and dispelling myths, and changing attitudes about mental illness in the communities.
- Media links mental illnesses with violence, and mental health laws treat people with mental illness as dangerous. In reality, most mentally ill persons, they have more problems to self, and they face more violence by others. In some countries, the situation is terrible. Mental disorders can be linked with criminals, because of the country laws, and so they go into jail and remain there. It is violation of human rights and requires action at legislation level. CBR programmes in collaboration with user groups and DPOs can promote advocacy for changing legislation and media perceptions.
- If old mental hospitals and institutions close, many of persons closed there can go back to their villages. CBR can be very useful in this situation as CBR is working at community and at PHC level, and they can prepare families and society to receive these persons.

- Health Workers in communities need referral system support, community worker can not do all alone. Only if there is a referral system they can work properly. Persons with mental illness can also need psychiatric nurse or doctors, for providing treatment and then they can go back to community where community health workers and CBR workers can help.
- People with mental illness, particularly with psychosis and schizophrenia, may have hesitation in coming forward to the health services so they are not accessible to health care and are excluded from health care, but CBR can reach them. CBR is an ideal vehicle for delivery of community Services for mental health.
- Livelihood is important, and it goes a long way to restore self esteem and in changing attitudes of others. However, there is need to think of dangers of imposing livelihood programmes as rehabilitation. Thus while vocational rehabilitation and livelihoods are important, ideal solution could be to ensure that the person goes back to his/her community, if possible in the kind of work they were doing earlier. Some times vocational rehabilitation is seen only in terms of handicrafts, bag making, etc. which limits the actual choices those persons can have. Some times, job itself is stressful, leading to psychosocial problems, so it is important to assess if previous job was creating stress. Then it may be better to change the kind of work. People have to look at their choices. Even as therapeutic activity, working together can be useful, but in name of rehabilitation they should not be reduced just to one activity.
- Burnout of aid workers is often overlooked, neglected and aid workers are demoralized. Care givers must recognize their own fallibility; they are “wounded healers”.
- There is a need to promote development and empowerment of user groups as spokespersons for their own rights.
- CBR including community mental health programmes should try to build links with existing Governmental services and promote mainstreaming. If they work outside the formal (Government) system there may be issues of continuity.
- Listening and dialogue is life force of any development for working with persons. CBR programmes are used to work in this way with persons with disabilities, promoting sharing of ideas, experiences, and creation of user groups and self-help groups. Similarly they need to work with persons with mental illnesses, promoting listening and dialogue. In this way, they all come out with individual needs and as they find value in listening and dialogue, in a group persons start understanding the needs of others, and it brings solidarity in the group.
- In awareness programmes, people with psychosocial problems can use their own scripts to do street theatre, that is a means for awareness raising. People know out their own selves and they know what they want others to do in the community.
- Guardianship does not mean that users have no power. Family can not take away power of persons to take away their choice. The role of guardians, it gives a responsibility to the guardian to take care, to support in consultation with the person as person him/herself is unable to take care completely. And it is for a temporary period.

- Informed consent is another area of concern. Some persons feel that persons with mental illness, they can't make any decision. Community leaders or families decide for them. So this is an important area for discussions. Similarly, involuntary admission of persons with mental illness requires debates, since it is very pervasive. People are brought in, some times police would drag them in, when some one is suspected that they may become violent only just because they have strange behaviour, so they ask that such persons need admission. Actual number of persons who really require admission in mental health institutions are very few, compared to the number of those who are brought in.
- Purpose of Self-help groups (SHGs) – they are important for family members to support to each other, develop income generation, to learn to see needs of group, network for inclusion, provide information, share and raise concerns, provide advocacy. To be able to influence society more knowledge about mental illness is needed among persons involved in SHG. They can also look at how to develop services if these are not available, how to mobilise communities, how to do advocacy for government.
- Inclusive SHGs means involving other community members, but in the beginning some people may feel that their needs are different, so groups of persons with similar issues can start their own separate SHG but with time, they need to network and join with others. Ideally, all groups should be mainstreamed. At the same time, there can also be need for peer groups for discussing some issues.
- Preferred terms that can be used for talking about mental illnesses include the following - psychological disability or psychological problem, mental illness, mental health condition, psychosocial impairment or disability. Derogatory terminology should not be used.
- Mental health day: It can be a useful occasion to promote celebrations and events about mental illnesses and usually in this occasion, newspapers and media are also willing to carry messages.
- Certain groups of persons with mental illness are more vulnerable including children, women, persons with HIV, etc. There may be links between child abuse, child labour and mental health. Discourse on mental health of women in the family situation has gained serious consideration in the context of campaign against violence against women.

OPENING SESSION



Opening Remarks from WHO/DAR

Mr. Chapal Khasnabis from the Disability and Rehabilitation team of the World Health Organisation (WHO/DAR) opened the meeting and started with his own reasons of interest in the theme of this workshop – his experience in CBR and issues of mental illness within his own family.

Mental illness is not an issue limited to any one part of world, it touches everyone. In WHO there is a department on mental health. WHO/DAR works together with Mental Health (MH) especially on rehabilitation and inclusion. WHO/DAR is working on developing CBR Guidelines. In these guidelines, there is a separate chapter on CBR and Mental Health (CBR-MH) in these guidelines like on “CBR and Leprosy”.

Often, people believe that mental health is a very medical issue. It is also perceived that interventions in mental health are expensive. People do not know how to work at it at community level. Thus, in CBR programmes there is lack of information, knowledge and skills related to mental health. So many CBR programmes may not work in this area.

There are lot of discussions between DAR and MH departments about how can they promote greater involvement of CBR programmes in mental illness. Since many persons with strong experience of working with mental health issues at community level are in the workshop, so information from this meeting can contribute to the CBR-MH chapter in the CBR Guidelines. There are some issues that need to be resolved. For example, there is no consensus between different CBR stakeholders about terminology to be used.

Including MH issues in CBR is important as it will benefit many persons in the developing world.

There are only a few effective models of working at community level – Primary Health Care (PHC), Community Mental Health (CMH) programmes and CBR. If there is no CMH programme in a place, so what can CBR programme do in that situation, is a key question. Thus this workshop is important as it can provide ideas and suggest solutions in the CBR-MH work. WHO has developed a Mental Health Gap (MHGap) programme and CBR can support CMH programmes in reducing the gaps in reaching persons with mental illness.

MH Chapter in the CBR Guidelines is still under revision, so any ideas from this workshop can reinforce the CBR Guidelines.

Opening remarks from Department of Mental Health, Thailand

Ms. Suchada Sakornsatian, Deputy Director in the Ministry of Health of Thailand, responsible for MH programme, was unable to be present during inauguration. She provided the following written statement about her inauguration address:

“I am honoured and delighted to have the opportunity to deliver the speech in an inaugural ceremony of the pre-congress workshop: Community based rehabilitation and Mental Health. I would like to express a warm welcome to all speakers and participants from our neighbouring countries in the Asia Pacific region. I also wish to thank WHO/DAR in collaboration with other UN organisations, international and national bodies for their support in making this workshop possible.

The evolution of mental health services have generally similar to community based rehabilitation. It was concentrated on hospital-based psychiatry at the beginning and now there is increasing awareness in many countries to shift emphasis to community-based programmes. Many barriers exist to the implementation of community-based mental health. Some countries have already developed mental health policy emphasising on community services, but their implementation has been inadequate. There is an urgent need to clearly define the goal and objectives (both long term and short term) of community based mental health programme which is culturally appropriate and reaches out to all segments of population. Mental health services should be integrated into overall primary health care system. Innovative community-based programmes need to be developed.

Our country recognised that there is a wide range of options and philosophies about what community-based rehabilitation actually is and what it should be. CBR can cover very diverse disability related practices. We understand that CBR as the strategies within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities. CBR is implemented through the combined efforts of community stakeholders with the active participation of disabled people themselves, their families and communities. It facilitates both their access to and participation, as both consumers and providers, in appropriate with health, education, social, vocational and other services.

Therefore I was happy to learn that this workshop will offer presentations of the current status and issues related to community-based rehabilitation and mental health services. This is an important step to help us comprehensively develop a framework of strategic plan for establishing CBR integrated into mental health services. I would like to compliment the participants for helping to answer these issues for improving these services.

Finally I would like to thank the Organising Committee for all their hard work and generous hospitality. I am sure the speakers and participants will experience the hospitality and friendship of the staff of the organising committee in person over the two days of the workshop.

Distinguished speakers, participants, ladies and gentlemen, once again I would like to wish you all the best for a fruitful and enlightening workshop and enjoyable stay in Bangkok. Thank you.”

FIRST SESSION: CHALLENGES AND ACHIEVEMENTS – CBR PROGRAMMES AND PERSONS WITH MENTAL DISORDERS.

Coordinated by Dr. Andrew Mohanraj



Introduction to the session

Dr. Andrew Mohanraj coordinated this session. Dr Mohanraj works for CBM, is a psychiatrist and is currently based in Indonesia. Dr. Mohanraj introduced the session:

I have been a recent convert to CBR approach. I started working in government service with biomedical point of view about mental illness, and then over past years, I approach has changed slowly.

Mental health can be looked at separately or can be seen together with other health issues as all services in health ask for priority. MH is also like other health issues, it includes promotion, prevention, cure and rehabilitation. Where does CBR come in? Our priority is to increase social inclusion, make services accessible and affordable to persons with MH issues, and CBR is the only way to reach that goal. CBR focuses on involving families and communities.

Self-help groups (SHG), carer groups, human rights issues, issues of consent in treatment, issues of early identification, etc. can only get priority if CBR approach is taken.

Even among group of persons with disabilities, there are some subgroups that are more vulnerable, including women with mental illness, persons with complex disabilities, women with HIV, etc. There has been some feeling that community-based approaches are more expensive. However, there are some studies that show that community-based approach is more cost effective than biomedical approach specially if we look at issues such as gainful employment, community integration, etc. There are other issues. For example, people with mental illness, particularly with psychosis and schizophrenia, may have hesitation in coming forward to the health services so they are not accessible to health care and are excluded from health care, but CBR can reach them.

Persons with disabilities are increasing, and are considered as the biggest minority group in the world. As people are living longer, and thus there is an issue of more persons getting more disabilities later in life, for example, due to cancer, diabetes, etc. Many of the persons with disabilities have psychosocial symptoms, depression is often there adding on to other disability issues. Thus there is a strong interaction between disabilities and mental illness.

Major issues related to CBR and mental health

Mr. Mike Davies

My comments are from a global perspective. I am from CBM that is supporting around 200 CBR programmes, reaching around 350,000 persons with disabilities every year. 60 of those programmes are working with persons with neuro-psychiatric problems, and there are some vertical programmes of community Mental health. So I am talking from a global perspective, on relations between CBR and Mental Health. CBR is the ideal and cost effective approach for community mental health.

CBR moves from biomedical or clinical model towards social model of disability, with certain common principles that are not disability specific, they apply to all persons, regardless of their impairment.

Convergence between CBR and Community Mental Health: Both CBR and Community Mental Health both are rights based approaches. Violations of rights of persons with neuropsychiatric problems are common. The social model of disability that underlies CBR, emphasises much less on rehabilitation of individuals and much more on rehabilitation of communities. The twin track approach – advocacy for human rights on one hand and service delivery on the other hand, is similar among both programmes. Participatory planning, “nothing about us without us”, the issues of informed consent, are common between the two programmes. Under CBR, the focus is not just on neuro-psychiatric issues but also on reaching needs of social, family, community, interaction with others, livelihood, etc. Both promote access to essential services and focus on persons themselves can do. From my 7 years of experience in this year and I feel that there is great deal of convergence.

Key issues – CBR programmes often do not think of neuro-psychiatric disorders, they do not see them as a CBR target group, so many CBR programmes need orientation on key issues related to mental health.

At community level, still an automatic response to mental illness is send the persons to psychiatric wards in institutions or to mental health services, and do not realise that something can also be done at community level. There is not enough strong body of good examples of community level work with mental illness, that can be shown off to persons to understand it. They do not understand that most efficient interventions can take place at community level.

There is a strong need to deinstitutionalise mental health. There are persons who do not need psychiatric care but are closed inside institutions. There is lack of expertise at ground level, and poor training on these aspects. Thus, orientation can have strong impact.

Effective and articulate groups of users and family are usually not there at community level. At ground level user groups are usually not well organised.

There is some misconception that only psychiatrics can help, but as with the Vikram Patel book “Where there is no psychiatrist”, it shows that a lot can be done at community level without psychiatrist.

Mental health problems in children and young adults are usually overlooked. Finally the cycle of poverty and disability needs breaking.

The way forward: There is a strong need to promote orientation and training on how to help persons with mental illness at community level and to support families. There should be wide public campaigns against stigma, fear, superstition. There is strong need for family support and training. Secure place to stay for the persons is important for rehabilitation.

Livelihood is important, and it goes a long way to restore self esteem and in changing attitudes of others. A lady from New Zealand said, “All I need is a place to stay and a job”. Productive occupation is important.

In different contexts, faith also helps, also in post disaster and community, and it is true for all different religions.

There is a need to promote development and empowerment of user groups as spokespersons for their own rights. CBR works in a twin track mode for advocacy for rights, inclusion and access to services. Consistent availability of medication is also an issue in some countries.

Thus in conclusion, from our experience as CBM, I can say that CBR is an ideal vehicle for delivery of community Services for mental health

Comments

Dr. Andrew Mohanraj: Often people think that as we do not understand the nature of mental illness so only thing we can do is to refer them to the institutions. CBR workers need to be supported for dealing with mental illness. Burn out among persons who care for and deal with people with mental illness, is also an issue.

Mental health issues in Mongolia CBR programme **Ms. Tulgamma Damdinsuren**

I am the AIFO coordinator for Mongolia. CBR programme in Mongolia started in 1991.

Let me give some brief information about Mongolia. The total population is small, only 2.7 million people, but it is a big country, so population density is less and nearly two thirds of the population is nomadic. The change in economy and socio-political system has created so many new problems after 1990.

Our main partner for the CBR programme is the Ministry of Health. This map shows how the programme started in different parts of Mongolia. In every province, doctors were trained in CBR. Initially it was medically oriented. It was reviewed in 2000 and since then has moved towards areas of human rights, livelihood, education, social empowerment of persons with disabilities. Initially it was focusing only on physical disabilities, but gradually it is broader in scope and considers community needs. Thus we found that communities were asking for mental health support.

A survey was done in 2008 that showed that there are more than 23,000 persons with mental illness, of whom 32% are in urban areas. There is a mental health institute in Mongolia, and then there are departments in each province. At present CBR is covering 15 provinces and the national capital.

We found that discrimination is a significant issue, even among other persons with disabilities. Often, they stay at home, and there are no jobs. There are bad attitudes, people feel that persons with mental illness need to be isolated. Family members often have no understanding, and they do not believe that family can do anything.

I would like to present, two good examples of interventions linked to mental health in Mongolia CBR programme. Since activities linked to mental health were started only 2-3 years ago, so the examples are few. A main problem is that of persons living far from each other. Family with persons with mental illness can live up to 200 km away from each other, so it is difficult to bring them together regularly. In urban areas, they often meet and work at medical centre.

Example from Hovd province: micro-project was started by the psychiatrist in 2003. It is implemented in mental health department. There are 12 persons in this project and livelihood is the main issue for all persons with disabilities. They have land for cultivation of vegetables, have started a canteen, where they serve food for hospital staff, they are also involved in handicrafts. This also gives an opportunity for them to be together to sit together and work. Family members appreciate it as otherwise they are always at home and do not know what to do.

Example from Suhbaatar province: This has been started in 2008 by EU project, in Suhbaatar province that borders with China. There are 90 persons with mental illness in Suhbaatar, 60% of them are in the aimag centre. This micro-project also started by a psychiatrist. Department buys safety waste box prepared by persons with mental illness. 15 persons benefit from this project. Old boxes are used to make the safety waste boxes. They also make bedsheets, etc. It is also an opportunity of being together and sharing experiences.

Mental health issues in CBR programme of SSBI in Liberia

Mr. Lamuel Boah

Liberia has a population of 3.5 million persons, with sixteen major tribes and a minority group (American-Liberians, descendents of the ex-slaves) and two major religious groups, Christianity and Islam.

Issue of mental health in Liberia is critical, there is strong social stigma. Mental disability is legal ground for divorce in Liberia.

There is an issue of inclusion of mentally ill persons in the CBR as many of them feel that they don't need CBR or don't fit with the programme. Thus the programme works mainly with persons with severe chronic illness. Access to medical service and referral support are serious problems, especially the costs of medication is a barrier.

Before the civil war, there was a mental rehabilitation centre in Monrovia, but it not accessible to thousands of persons from outside the capital. 14 years of civil war caused immense suffering and trauma, including summary executions, rape, hunger, depression, war trauma, etc. There was complete breakdown of basic social services. People were slaughtered in front of their families and unborn babies were knifed out of their shackled live mother's bellies by combatants under the influence of drugs and alcohol. Many non-combatants resorted to drugs and alcohol with psychological and mental trauma for both civilian victims and ex-combatant perpetrators.

Every where mentally ill persons are seen at street corners, public places and gatherings, and their numbers are growing. The disarming programme of United Nations, DDRR programme, worked for removing guns and firearms, demobilization of warring factions, vocational training for combatants, etc. but they didn't give attention to psychological aspects of ex-combatants. So the much publicized success of DDRR was an exaggeration.

In Liberia, there are 3 kinds of spiritual considerations related to mental illness – (1) it is seen as a punishment to the ex-combatants for their cruelty to innocent persons during the war; (2) a punishment for thieves, so that persons who lost things caused the mental illness with the help of witch doctors; (3) narcotics and substance abuse cause mental illness.

New development plans such as Poverty Reduction Strategy Paper for Liberia is not considering persons with mental illness. State support for persons with mental illness is non existent.

The CBR programme of SSBI works with persons with different disabilities including persons with mental illness. There is cost sharing scheme that helps with 50% of cost for medical intervention. The rehabilitation hospital Dr Grant Mental hospital in Montserrado county and the mental health division in C. H. Rennie hospital in Margibi county are reference centres for the CBR project.

At community level, project promotes visible social interaction between community volunteers and persons with mental illness, so as to provide positive role models in the community to fight the social stigma. This component has had good impact in the community that it is possible to change the situation of persons with mental illness. There is also awareness campaign activities through, house to house contact approach, poster campaigns, etc. Our strength is in working with families.

Comments

Dr. Andrew Mohanraj: Mental illness is a very big area, not all the persons with psychosocial problems of them need help or support from CBR. At certain point in our lives, all of us can have psychosocial conditions. Not all of them need to come to CBR. CBR can work mainly with those who have debilitating chronic illness, as they are the ones who need support. All of us have periods of psychosocial distress but we do not have chronic illness.

Another aspect, we should be reflecting is to think of dangers of imposing livelihood programmes as rehabilitation. Thus while vocational rehabilitation and livelihoods are important, ideal solution could be to ensure that the person goes back to his/her community, if possible in the kind of work they were doing earlier. Some times vocational rehabilitation is seen only in terms of handicrafts, bag making, etc. which limits the actual choices those persons can have.

Lack of access to treatment and to referral services for persons with mental illness (Group discussions presented by *Ms. Bina Silwal* and *Ms. Graziella Lippolis*):

Referral services are at different levels, starting from the community to tertiary level.

There were many persons with community level experience in our group. Community intervention should reach all the persons in the community so it is important to work with different groups of persons including CBR workers, parents, teachers, traditional healers, student unions, children groups, etc. Their capacity needs to be developed, they have to become aware of issues and problems, about what can be done. By developing their capacity we can help those persons who need referral. Networking and coordination of organisations working with mental illness are needed. Capacity training for short and long term is needed, on awareness raising, formation of children groups, etc. They can identify and create awareness through street plays, songs, dances, etc. At community level there can be many cultural traditional and cultural practices and if these issues are integrated in these practices, it is a more effective to raise awareness and to combat discrimination.

Developing support system in village level including PHC workers, CBOs, etc. for reaching poorest and ethnic groups is important. Often such persons come from economic or socially disabled backgrounds. Then they raise their own voice.

We also need to develop livelihood programmes. Counselling, medical services, can be there but if persons are economically not improved, they remain vulnerable and backward.

Do capacity building on IEC materials to identify issues of people. Different persons can use different approaches to understand. We, persons working at community level are not trained, we lack confidence about how to intervene.

Recognising persons with mental illness as human being is needed. One organisation can not address so need to unite and to share learning and experience.

At national level if we look at mental health as a separate issue, medication may be expensive but not more than HIV medicine, and if we can fight for right of HIV patients to medicines, we also do it for mentally ill persons.

Training curriculum of community work in mental health at national level is needed. If nursing and medical schools are using it, it is easier for the whole country. National level should also provide assessment tool for the whole country with same criteria and with same standards. Mainstreaming national policy at different levels is needed.

Comments & Discussions

Question: What is the sustainability of capacity building, as frequently people leave and change jobs?

Bina: Using different training curricula, are good for community mental health work. Context may be different in local situations, but the training materials used by different organisations, should have common standards. They should know about working at community level. At the same time, there is issue of context, as they need different materials in different contexts, so training materials may not be useful for all communities. For example, material for working in city context is not suitable for rural settings. Training

materials prepared by experts are more difficult to understand for grassroots level, people just put up the poster and do not know how to make its actual use.

Dr. Mani Natrajan: For capacity building of nurses, doctors, etc. we need to provide them with training on mental illnesses. For example, India has National Rural Health Mission programme, that can be used for capacity building.

Dr. Andrew Mohanraj: In Aceh in Indonesia, in the post tsunami period, many International NGOs came in Aceh, they developed comprehensive system to deal with mental health that was not there before tsunami. Before they had only one mental hospital. International NGOs, all are different and do lot of training but they work outside the formal (Government) system and in the long term it fails as there is no continuity, so working with government sector is important.

Influence of Stigma (Group discussions presented by *Mr. Barney McGlade*):

Stigma is a problem every where in every country, it isolates persons. How is stigma created and manifested, there are user and survivors groups also in developed countries like in Australia. Normally society locates it in victims and not in persons surrounding them. There are examples in Bangladesh where the problems are seen in girls, in many Eastern countries there is karma theory, in the west poverty is an issue and linked with magic, that creates stigma. Now with drugs create problems like walking slowly due to many medicines, or obesity, that also create stigma. New drugs for mental illnesses that have less side effects are there but these are expensive.

Stigma affects the daily activities, persons are isolated. Media links mental illnesses with violence, and mental health laws treat people with mental illness as dangerous. In reality, most mentally ill persons, they have more problems to self, and they face more violence by others. Like in Australia drinking problem is more linked to violence and injuries but it is not considered in the same way by the law, while public image about mental illness is considered dangerous.

When people go to church or temple to find solution for mental illness issues, as they feel they have done something wrong or a sin.

In Philippines, families can imprison or chain the persons with mental illness and thus protect them or the community in cruel way. Traditional healers, may reinforce cultural aspects and myths linked to mental illnesses. Before science and supernatural links were seen together.

There are issues related with psychiatry as mental illnesses are linked with chemical imbalance. Some persons prefer words like mad or psychosocial problems. For some it is a spiritual question. So there is a spectrum of issues affecting stigma. There is need to bring different view points to understand the stigma issue. Because of stigma, persons lose jobs and that affects the feeling of self worth.

Early identification is needed. For minor issues like anxiety, people don't go to the doctor so people wait till they are marginalised, before seeking help. Boss in office do not know how to intervene. People are hidden inside homes or they may be left in streets or in hospitals.

There is need to spread images of positive inclusion. How to induce traditional healers to change their own attitude? Medicines are not always the answer and holistic approach is needed including, biomedical, psychological, etc. CBR may be a better approach towards mental illnesses. Medical professionals need to change attitude and involve others. Positive role modelling in community is also important, let people know us and see us, and stop locking us out. We need to work and return to work. It is important to work with public leaders and known persons who had their own journeys of mental illness and if they can share, they become role models for others.

Comments & Discussions

Dr Istvan Patkai: Stigma is part of prejudice and discrimination. We can't counteract ignorance only by knowledge and information, but it is more important to show by walking together and involve persons with mental illness, it is important to realise discrimination and change laws to change discriminatory practices.

Ms. Graziella Lippolis: Stigma in the community requires community awareness. While doing awareness in a village CBR workers were explaining but it did not have much effect. Then village leader came and he talked about it and it made more impact than the CBR workers. So it is also important to involve local leaders from the communities.

Dr. Andrew Mohanraj: Religious leaders also play an important role in influencing and dispelling myths. Everyone deserves to live with dignity and self esteem, how to embrace and include people with mental illness is to be shown. Media role is important they sensationalise that how mentally ill persons are dangerous, so you have to work with them to change their way of looking at it.

Persons in old mental health institutions (Group discussions presented by *Mr. Sibghat Rehman & Dr. Enrico Pupulin*):

We had lot of discussions. These should be deinstitutionalisation, of persons kept in old institutions. Human Rights approach is not applicable in hospital and prisons. Training of Health Workers and PHC workers is needed. We can reduce but we can't stop admission in hospitals so CBR can show examples of how to work together with users and consumers groups, this will reduce stigma. CBR programmes can reduce stigma by working together with persons with mental illness. Lot of people with mental illness are put into prisons and forgotten.

In some countries, the situation is terrible. Mental disorders can be linked with criminals, because of the country laws, and so they go into jail and remain there. It is violation of human rights and requires action at legislation level.

People in those institutions are isolated, but sometimes they are helped, and we have to recognise that personnel of these institutions is working in difficult places. If old hospitals close, where will they go? Many of them can go back to their villages. CBR can be very useful in this situation as CBR is working at community and at PHC level, and PHC workers can prepare family and society to receive these persons who are being abused in the institutions.

Health Workers in communities need referral system support, community worker can not do all alone. Only if there is a referral system they can do. They need psychiatric nurse or doctors, for providing treatment and then they can go back to community where community health workers and CBR workers can help.

A WHO document on chronic conditions asks that persons with chronic conditions have be masters of their own conditions, they need to know about their own disease and condition. They need to make their own decisions. I know the head of a DPO, who has schizophrenia, she is not denying her own condition, but she decides when to go to hospital.

Comments & Discussions

Dr. Andrew Mohanraj: We also have to think of mental health professionals who are overworked and they don't receive enough attention. People who work in institutions often get institutionalised themselves. They lose sensitivity, and do not treat people with dignity. So there is need to raise awareness about the issues of carers. Several countries like UK, Italy have had success in deinstitutionalisation, though in USA it was a failure, in developing world we need to look at these experiences to understand better.

Mr. Chapal Khasnabis: When we started to develop chapter on Mental Health in the CBR Guidelines, we consulted many persons all over. There is an issue of terminology here. There are different terminologies that is being used to talk about mental health conditions including, mental disorders, mental health conditions, neuro-psychiatric disorders, minor mental illness, severe mental illness, mental retardation, psychological problems, psychiatric problems, etc. There are two extreme views, one group asks to use the term "mental disorders" and others does not like this term. So, what term is more acceptable, does it really matter? Think it more about this issue, and give us your suggestion about the terminology acceptable to majority of you.

**SECOND SESSION: PERSONS WITH EXPERIENCES OF MENTAL ILLNESS
AND THEIR FAMILIES IN CBR – LEARNING FROM EXPERIENCES,
Session coordinated by Mr. D. M. Naidu**



Role of organisations of users of mental health services

Mr. D. M. Naidu

I am from an organisation called Basic Needs India, an association that works on community mental health in partnership with experiences of community based rehabilitation. Otherwise I have no qualification as psychiatrist or psychologist. I am also not a person with personal experience of mental illness but I qualify as someone who has been learning from experiences.

I have not conceived as a mission of life to help people in difficulty, but my aim is to show how they can solve their own difficulties, I have learned this from philosophy of Mahatma Gandhi. However poor or ill a person is, she/he has the capability to manage her/his own life, if I believe that my experience with that person changes. Our work has to be based on this belief.

Basic needs India does not have programmes or institutions, it identifies community based workers or groups for having a dialogue, train them so that they include persons with mental illness, actually I would call it persons with psychosocial disabilities as it is very much an issue of family and society beyond that of impairment. Effort is on people having ability to manage their own lives.

Our work is with people. Listening and dialogue is life force of any development. When people are in a group, you feel energy generated in any consultations, male to female, literates and illiterates, when space and time is provided, they all come out with individual needs and as they find value in listening and dialogue, in a group you understand needs of others, brings solidarity in the group. It is easy to miss, so you have to restrain yourself from talking, go with idea of listening. Raise doubts, renewing what they say, ask questions, it generates life force, empathise with others.

In a group in Bangladesh, women are more vulnerable, so we have to be more sensitive to avoid marginalisation. Women SHG of carers, villages there are spread over, and there are already existing women groups, women with psychosocial problems join these groups. Inclusion is important and it should not be tokenism, they become part of group and have a say.

Group does not contain only one kind, but there can be many disabling conditions. As a group their voice gets healing options from others of community. Till now their voices are not being heard, people are thought as dangerous to ourselves and to others. They certainly need choices on healing options – you may chose clinical psychology, spirituality, religious, yoga. Some say, I can manage my voices in my head, I have been living with it. Does he have a right or not to do that, to manage on himself or herself? People are managing poverty, office and other problems but also voices and as part of group, one can say that I have other needs.

After stabilisation of the psychosocial condition, they can go back to previous or learn new trades. This morning there was mention of emphasis on livelihood, better to be back to what I was doing, it was said. But we have to recognise that some times, job itself is stressful leading to psychosocial problems, so it is important to assess if previous job was a creating stress. Then it may be better to change the kind of work. People have to look at their choices. Even as therapeutic activity, working together can be ok, but in name of rehabilitation we should not reduce them just to one activity. It should not be always the

same thing, not always paper bag making, embroidery, etc. We need time to learn their capabilities, as they have that capability. One person who had an accident and lost both her legs, they started to talk to her about paper making, handicrafts, etc. She said she was educated, she had capacity and so she started stock broking and does her work on computer in her wheel chair. She even charges people. So it is important to look beyond boundaries, accessing government schemes should be seen as a matter of right. It is not doles, it is a right.

All these bring self worth and human dignity. When I am involved in my own development, and I am linked to development of my community. Then I am not less worthy than others in my community. Contributing to increased family income is important in psychosocial illnesses as care givers are from poor families. Many of them work on daily wages. If due to societal norms and situations, I can't work and take care of disabled person, I don't get meal.

They lock them or isolate and chain them. In a village situation, with husband and wife, if husband is sick, community says that he is dangerous. So leaves him closed in the house and she asks, what can we do? It is human rights violation, but for that person it is a need, as without work both will not have meal. So it is a social issue, you need to work with community. So that community is aware of their needs and their own role in those conditions. Only then human rights can be addressed. Police was used in some examples to restrain persons with psychosocial problems, but community role is important and not blaming.

Initially when I heard the word empathy, I didn't understand the meaning of this word. Once a person told me, that empathy the ability to suffer along with the sufferer. Perhaps it is not wise to use the word "sufferer", but it is important to understand the meaning of empathy.

In awareness programmes, people with psychosocial problems can use their own scripts to do street theatre, that is a means for awareness raising. People know and they know what they want others to do in the community. If they take responsibility for awareness raising, it has better value. They can show to the others their own journey, their own lives and not a story written by others. Media is humour or story, and this results in change of attitude. Awareness should lead to linking value and appreciation of the situation, then attitudes can change.

When so many words are used to talk about psychosocial problems, and if people can't agree on one common term, where is the reasonable accommodation? If I say, I do not care what others want, do we respect others as human beings? In social groups, as associations, persons with psychosocial problems, they contribute, and they don't want to get labelled. There is an organic growth and development, that results from mirroring and re-mirroring. Then you can see the gaps and fine tune them and you are most likely to understand about what is the required action.

Time for reflection is important. Collaboration with federations for lobbying for entitlements and rights is also important. Thus small groups join other groups, make protests, demand for their rights together as a critical mass. When many minorities come together it becomes a huge critical mass and can influence decisions. Formation of alliances at district and state level is important. Looking at national alliances for persons with mental illness, group members support each other and participate in activities and this leads to empowerment.

Use of lucid moments in the symptomatic states, is important for empowerment. Some anxiety, anger, etc are important. Symptomatic and lucid moments are common in each person with psychosocial problems, so make best use of any lucid moments. Appreciating their inclusion in CBR, if they feel they are welcomed and included, can make a very huge difference.

Treatment of persons with mental illness and human rights

Dr. Andrew Mohanraj and Mr. Will Reyes

This is the cover on time magazine a couple of years ago, and it raises the issue of people in mental institutions, who are forgotten and dumped in mental hospitals in Asia. This picture is from a hospital in Indonesia.



Concepts of mental disorders: Chapal threw a challenge to us about so many conflicting terminologies. This is a big challenge among practitioners and even among persons enthusiastic about working with mental illnesses. It requires lot of considerations, to be politically correct. In the past, word like schizophrenics was used, it is today unacceptable to use that, it may be better to say people with schizophrenia. Lot of terminology is no longer acceptable.

Some terminology may be fine for clinical biomedical approach, but clinical classification is stringent classification system, useful for treatment, but not relevant to community. For example to say that someone has “depression with psychotic features”, it may be useful for prescribing the right treatment, but for the person and the community, it has no use.

Stigma is associated with terminology, giving labels can stop others to come forward to seek treatment. Psychosocial disability is the term to be considered.

In my opinion, the comprehensive treatment modality is a bio-socio-psycho-spiritual approach. This is the prescribed approach even from clinical point of view for bio-social issues, even clinicians agree to it. Biomedical is the medication part. Psycho is psychological support, such as counselling, psychotherapy. The social component of mental health issues can not be denied, the awareness of family is important and how can they support. So for clinicians, holistic approach is accepted but they overemphasise the biomedical component. So there is this misperception that when we say treatment it is pure bio-psycho model.

Actually in practice there is a spiritual component is also. Spiritual input is important for persons with mental illness. In developing world, religious leaders from different faiths are involved in day to day life of people at community. We need to take advantage of this fact.

Human rights issues – There are certain catch phrases used in relation to mental illness that are of concern. Guardianship does not mean that users have no power. Family can not take away power of persons to take away their choice. The role of users, it gives a responsibility to the guardian to take care, to support in consultation with the person as person him/herself is unable to take care completely. And it is for a temporary period.

Informed consent is another area of concern. Some feel that persons with mental illness, they can't make any decision. Comm. Leaders decide or family decides, and in many hospitals they may not look into it because of overwork, insensitivity, or because of long time in institutions. So this is an important area for discussions.

Involuntary admission of persons with mental illness requires debates, since it is very pervasive. People are brought in, some times police would drag them in, when some one is suspected or that he may become violent just because has strange behaviour, so they ask that such person need admission. Actual number of persons who really require admission

in mental health institutions are very few, compared to the number of those who are brought in. I was equally guilty of this in my work as psychiatrist, as it is makes things easier, we lock them in and look after them, and we say it is for their own good, but it is for our convenience. Lot of persons are restrained without need. It may not be intentionally cruel by family, or we can say it is cruel trying to be kind, to avoid violence from others or if family needs to work, so there may be different ways to look at it.

International NGOs came in Aceh after tsunami and they saw that persons were put in institutions and they said it is not correct and went off to release them without ensuring community support or ensuring if PHC had enough antipsychotic drugs. Then they finished their projects and left. People went off, caught all those persons who were released and chained them again. After this, communities would be very cautious in repeating this experiment of letting persons with mental illness come out of institutions, and now lot of people oppose it.



This is a picture of a man with mental illness inside a cage, there is a wooden bed. However, we go deeper in this picture and look at the house, only then we realise that for many years this is the only bed in the house, rest of them sleep on floor, so with cage, there is consideration in the family for the person.

The next is another picture from Indonesia. It was an award winning picture, the photographer took a few pictures and won the award in Aceh and went away. Such persons, they didn't need to be put in like this if community mental health services were good, if family knew what to do and they took medicines take regularly, and so in spite of the picture and the award perhaps that person is still there like this. This also raises the issue of media responsibility.



Capacity building of care givers is extremely important. CBR workers need to learn about mental illnesses. And public health and legislation are also important. Awareness to include community leaders, religious leaders, communities, families is to be understood. CBR work leads to establishment of user groups and family support groups that lead to positive advocacy for better services, more resources.

Legislation is a big issue, it is often forgotten that they are not covered by medical insurance so they can't access services and get only basic medication. Involuntary admissions, and informed consent also need legislation.

Community-based psychosocial support in Nepal

Ms. Bina Silwal

My experience is community based psychosocial support work. Our organisation called Kopila was established in 2001 in western part of Nepal for child rights and education. We did a survey on the effect of armed conflict on children after 10 yrs of civil war in Nepal. Results of this survey promoted us to start on psychosocial issues as there were few government services, and there were no other organisations. Thus, we started in 2007 in a pilot project.

Physical health is not full health, when people do not have not mental wellbeing. In our area, 25-30% have mental problems, approximately 20-22% of all outpatient in out-patient department in PHC have psychosocial problems, so we started this programme. There is not enough awareness on psychosocial issues at decision makers at different levels.

We work to create awareness on consequences of psychological trauma. We use these materials to make people aware, and to identify children by participatory awareness approach. We use different tools to discuss with groups, and also provide pilot counselling for those who need those services and for severe cases, we refer them to regional hospital for medical treatment. We also evaluate our work in each district. We wanted to know if our working approach is useful, so did we evaluation and documented the results.

We provided training to different groups including health professionals, children groups, community members, teachers, etc. and facilitated parent-teacher groups, about how to identify children with problems. We learned this approach from an organisation from south Africa. Group members develop self confidence and make their own plans. They make their own "hero book" which involves teaching children way to do autobiographical story telling and art to find solutions to personal and social challenges that they face. We also made training manual on teacher training – how they can help children by starting from their own lives as child, as problems, etc. and this leads to "My desired childhood" books by the teachers. We also provided pilot counselling.

So we make persons aware of their child's trauma through trained facilitators community workers. We did baseline survey in 14 villages, developed education materials that were tested in communities, and we interacted with comm. On these issues, training to parents, teachers and children was carried out.

We have about 2000 persons trained about symptoms, effects of trauma. Children and parents have their books and community is linked with other organisations.

We find that persons with mental illness are not referred, they feel that these are not treatable and need isolation so that these persons roam on streets or are kept in homes. Now there are many persons who are referred to Kopila Nepal. For example, a man was locked for 14 years, and children group found about him and referred and was sent for medical treatment, he was back home after 15 days and is now helping the family. Many persons are fully recovered. Counselling is also provided on how to become a counsellor himself/herself. We learned this approach from north Ireland trauma centre, and we found that it is useful even in Nepali context. Children groups are very strong to play role of change-agents in communities.

It has a domino effect, by providing training to different groups, they provide help others to start similar activities. There are learning methodologies, that are useful for self

reflection and self discovery. Working with small groups helps to empower and to be more sensitive.

Understanding culture is important, for all interventions. 2 years is short time to draw conclusions and it is hard to sustain the programme. Psychosocial component is compounded by poverty, sexual abuse, violence, so we need comprehensive approaches towards psychosocial issues.

Self Help Groups and user and family member organisations (Group discussions presented by *Ms. Elizabeth Cross*)

We discussed the classification of SHG and who should be involved, if it should be inclusive and that is ideal, but there can be persons who have special needs, so our conclusion was that you can also start with groups of individuals with similar needs and then make them wider to involve more persons and also link with communities and other developmental groups.

Role of SHG – There is a wide variety of countries, so the role depends upon countries and contexts. There are other issues like if they need to be formal or informal, who starts them, etc. so this is a very wide area.

Purpose of SHGs – they are important for family members to support to each other, develop income generation, to learn to see needs of group, network for inclusion, provide information, share and raise concerns, provide advocacy. To be able to influence society more knowledge about mental illness is needed among persons involved in SHG. They can also look at how to develop services if these are not available, how to mobilise communities, how to do advocacy for government.

Inclusive SHG means involving other community members, but in the beginning people feel their needs are different so individuals groups of persons with similar issues can start but with time, they need to network and join, and all groups should be mainstreamed. There is also need for peer groups for some issues.

Discussions and Comments

Ms. Geraldine Mason Halls: SHG don't automatically become functional on issues such as advocacy, etc. so they need support for organisational development. They also need to learn how they can act on other issues apart from disability. They also need to infiltrate other development groups for a stronger voice.

Ms. Elizabeth Cross: Groups develop differently and they have ideas of their own capacity building. We didn't talk of government supported SHGs.

Mr. Jose Manikkathan: SHG becomes an instrument to get facilities from government, individuals alone can't do it but as a group they can.

Mr. D. M. Naidu: SHG, it is process oriented, it always looks like work in progress. As people move, organise, learn things, they also learn if they want to be informal or formal, move along and develop. Sometimes, oppressed become oppressor in the SHG, one leader projects him/herself, and then it is difficult to deal with, so process oriented development is needed where leadership does not lie with any one person, but it should be highly democratic and people centred.

Inclusion, Rights-based Approach and Participation (Group discussions presented by *Mr. David Webb*)

Our topic of discussion was inclusion, rights based approach and participation and what these terms mean. Initially there was consensus. Inclusion of psychosocial in other disabilities is needed, and all persons with disabilities have equal rights. This is same as what the UN CRPD says. Also we had a discussion about enabling environment. A lot of experiences of persons with disabilities is due to circumstances, families, community, environments, etc. and we need to be careful to recognise where problem lies.

On participation, about inclusion of psychosocial issues into CBR, active participation at diff stages of CBR, also in policy development is needed. So this raises issues like capacity building for DPOs so that they make their own policy positions and do advocacy with governments. Many countries don't have mental illness laws. Australia is reviewing mental health laws and it is a difficult process. Inclusion and legislation to include people's rights, it is important to ensure these discussions in a participatory manner.

What to do in a crisis, when a person is behaving in extreme way, putting others at risk, refusing treatment, what do you do? We had lot of stimulating discussion about this without reaching a consensus or conclusion. Where appropriate, when someone is on risk, communities can make decisions, but if we deprive someone's liberty, we also need to ensure that the person is taken to someplace safe, not tied to cage, closed in jail or given to psychiatric hospital where you are treated against your wishes. Everyone has right to take risk like everyone else, there are persons who do sports like parachuting, thus risk taking is a part of life, and persons with disabilities also need to take risks they wish.

Participation is for all citizens, same as everyone else. There was special mention of double discrimination as for women, indigenous people, etc. Double discrimination can be there in some disability groups, as there is some kind of hierarchy, some disabilities are seen as higher in the hierarchy, and even in psychosocial disabilities there is hierarchy when they say that only real madness is psychotic, so if some times persons with disabilities are not inclusive.

There are two sides, view of experts on one side and views of persons with disabilities on the other, some tension is there and the two perspectives need dialogue. The common goal is right to enjoy all opportunities.

Media has a big role in promoting and creating negative attitudes. Within disability debate, psychosocial issues are neglected. It is a newcomer to disability movement in many ways, and is still catching up. Challenge to recognise this is neglected and lot of work needs to be done.

Discussions and Comments

Mr. D. M. Naidu: Within disabilities, inclusion is not complete, this is an important aspect. Persons with disabilities are no different from anybody else, and in some extreme conditions, it is society's right and responsibility to help that individual.

The term "capacity building" is being used, it means there is one builder and another receiver. With a group you spend time, you understand that no one has less capacity. After capacity building I know I have learned but I do not know what capacities of others I have increased. I prefer the term "mutual resource enhancement".

Terminology issues (Group discussions presented by *Dr. Istvan Patkai*):

David webb talked of double diagnosis, that is same as double disability but he used other words, in human rights ways. A more humble attitude from professional and legal sides is needed. Terminology is a difficult issue, it is also a process. Once you define it, it doesn't finish, it keeps on changing.

Sarmila Shrestha as our facilitator kept smiling and supporting, and tried to be constructive during these discussions.

Terminology discussion is only one aspect of discussions in caring arenas, and we have to recognise that we are in crisis. Fundamental health dimension has become an unholy alliances of direct marketing between pharma companies, while we recognise that there are many other therapies apart from pharma therapies.

User need to become stronger in this crisis. They are questioning many things which we didn't deal with previously. We discussed different terms used to talk of mental health issues – we listed all the different terms that are used, and looked at each of them. Some terms are dangerous or bad terms and those must go.

Our group suggests that some terms can be accepted as part of the process and these are – psychological disability or psychological problem, mental illness, mental health condition, psychosocial impairment or disability.

What do people say in community? There are many denigrating expressions that are used including Psycho-affective disable. We can't change it, we are not making it, it is present in our community, it can change, but it is an acceptable term after tsunami. In the tsunami situation, there were no differences of users and carers in the communities, as all were users, and they accepted some professionals from outside as guests.

Rather than using the term “psychosocial disorder” we propose that we use the term psychosocial impairment. I can use specific terms with my professional colleagues, as to discuss treatment, etc. but those other terms should not be used in public, as others want to collaborate.

People use different terms in their different languages to speak about psychosocial impairment. Only when people get aware of the problems caused by terminology, they raise up this issue in their own languages and a dialogue starts. Various diagnostic categories need to be looked at different uses in diff sectors and contexts. This is essential when we deal with terminology. The changes are indicative of paradigm shift going on in caring professions. Engagement in this should be limited, as these terms will change but it depends upon our involvement.

One key observation, while exploring this background about terminology, we felt that the meaning given to the words is also important. Too many labels can be disempowering, so important to remember that we are talking of persons. Users and care givers, in an emergency caused by disaster of tsunami, brought us all together and helped to understand the feelings of each other, so it helps to remember that all of us are wounded.

Discussions and Comments

Mr. David Webb: This conversation is going on for years and years. We need to ask to people and they need to accept it. As World Federation of Psychiatric Survivors, during negotiations on UN CRPD, we decided to describe ourselves as persons with psychosocial disabilities. However, we do not wish to associate ourselves with psychosocial rehabilitation movement, so there is a distinction.

In my country Australia this word is not used by consumers and providers, there “mental health psychiatric consumer” is used. Now I feel it is disempowers us and personally I now prefer to use “psychiatric survivor”, so terminology changes and evolves. We can acknowledge the accepted word at the current discussions at UN level, and thus psychosocial disability is accepted terminology by the users.

Dr. Istvan Patkai: Even at level of diagnosis we have to be clear about it. It changes, according my different experiences. There have been different aspects in our history that were against human rights, so we need to agree and change. Service givers are discussing this with service users. How many of us are wounded people, and this is a bridge between us, I am not saying it to water down the movement, but perhaps it helps to recognise the other point of view.

Mr. D. M. Naidu: It is difficult to come to a conclusion. It is a process, a journey, we are agreeing to disagreement. No one in the group has clear idea, we can say confused are those who are blessed, as once they will come out, others are living in dream world. Policy makers, WHO, governments, all have different angles to look at. We need to work at empowerment, respect every human being, disability, colour, caste creed, language, etc. and here none of us should be obsessed with psychiatry, or be anti-psychiatric, we are in a spectrum. Find the middle path, that respects persons. If our objective is strengthen CBR, we should create an environment where every one can live with equal dignity. CBR is poor-focused and process oriented.

**SESSION 3: LEARNING MATERIALS AND CAPACITY BUILDING IN
RELATION TO COMMUNITY-BASED INTERVENTIONS FOR PERSONS WITH
MENTAL ILLNESS**

Session coordinator Dr Istvan Patkai



Linkages, synergies and cross-over of ideas

Dr. Istvan Patkai

Thanks to Ms. Suchada from Ministry of Health of Thailand for the warm hospitality. I am from CBM. Today we have a transition from yesterday's discussions about challenges on putting together CBR and Mental Health (MH). To develop together CBR and MH, a strategy is needed, for training and capacity building. It is huge and can't be tackled all in one day but we can give hints. There are so many changes in the world, there is new terminology, there are different treatment interventions and not just of medicines, all areas of care need to be renewed.

Capacity building and training requires linkages – linkages between CBR and community MH and links between MH from classic stakeholders and new stakeholders. The idea of “linkages” comes from S. Africa, they felt that if they think only in individual ministry or departments, they need to work together. Progressive health professionals in HIV/Aids counselling, they brought out this issue and they said that there is need to link up with different services. Similar issues in MH. Mental health professionals need to link with users.

The terms “crossover of ideas and synergies” are terms used by Chris Underhill. Mutual interaction with good practices is creating synergies. Between CBR and MH there has to be crossover of ideas. CBR is the already existing vehicle of community MH.

There is a shift from biomedical to Human Rights model. Many experiences from post-disaster work came also for us in CBM, like after tsunami that brought CBM's work in this area. There are other experiences from the work with HIV, street children, abuses, etc. they also ask for renewal of practices and strategies, and bringing changes into capacity development and training.

Yesterday Naidu said that we should talk of “mutual resource enhancement” as it is not that I come and give knowledge at grassroots levels. When you are running training, you realise that you are also changed and enriched in this work. My experience of work for 20 years was in Africa and last 5 years in Asia, brought me to the community orientation.

Talking about capacity building, I don't want to give any detailed curriculum, it needs to differ according to context but there are new elements in training that I will focus upon in my presentation.

First is the emphasis on stresses and social theory of psychosocial illness – it is not just in crisis but also in developing new perceptions. Classically when we talked of stress, biomedical research overshadowed stress research. Biomedical care of health should be expanded with stress area.

Second, diagnostic challenge to clarify terms – terms are complicated, like international classification of disorders. Even at PHC level these are complicated, and diagnostics and manuals are too much for field workers, there is too much classification, so a definition may hinder care. Simple understanding of affected persons is important, local perceptions are important. A manual from Nepal used simple classification, another book by Vikram Patel also shows that diagnostic challenges can be simplified. They can lead us to context, notice not just negative aspects but also see opportunities, and pay attention to persons. With paradigm shift, we can move away from stigmatising terminology. In tsunami everybody in the communities was affected, while restoring lives, pre-existing boundaries

of vulnerability broke down. For example, people understood that epilepsy can also be due to stress trauma, so new terms came out from shadows, less stigmatising but related to stress. Tsunami, disasters, etc. might offer opportunities for reaching more mentally ill persons. Psychosocial disability is less stigmatising term.

Third, carers also brought out that they were also victims, they said we also need care and we can help others. Burn out of carers needs attention in our training. In India, Indonesia, Philippines experiences we learned that it is important to see stresses come to carers, yet wounded healers can help others. Why are you a carer, what are the motivations is important to understand, as there are deeper motivations that can be strengthened. Carer should also be seen as a contextual issue and not just depending upon compassionate carer. Just giving training is not correct it is also important to support through supervision. How to link with referral is also important.

Learning materials on community mental health

Ms. Suchada Sakornsatian

I am deputy director of Mental Health department of Ministry of Health. It is a young department started just 17 years ago. Originally I am a physiotherapist and then trained as occupational therapist.

Some general information about my country: we have 75 provinces and 17 psychiatric hospitals; some speciality are available only in Bangkok including forensic psychiatry. We have community services for persons who come out of psychiatric including connections with NGOs and temples, DPOs, family and advocacy groups, etc. Thailand has strong village health volunteer scheme that is a key figure for the community mental health problems. 20% of the population had mental illness problems – so we are inviting mental health affected persons to visit schools for creating awareness. Our motto is intervention for community by the community..

Now about the topic of training, we had knowledge but didn't know what to do, so we developed new materials and new interactive approaches where people can share and discuss.

We also work with training of media.

Community Mental health project in the period 2003-05 has been important for community to discuss and guide manuals, they chose what they need and they want to know what they have to do and they are not so concerned with professional diagnosis and labelling.

Mental health and CBR in AIFO's work in India

Mr. Jayanth Kumar

Major issues of mental health in India: Persons with mental disorders are being continuously ignored and denied the social rights they deserve. Prevalence rates of mental illness in the population have increased due to poverty, illiteracy, urbanization, industrialization, discrimination, better diagnostic methods, increased public awareness. Apart from national institute of mental health, institutes/hospitals for mental health, there are very few noted NGOs or CBR programmes that work with persons with mental illnesses.

The results of Decennial Census of India 2001, released in 2004 showed that among the 21,906,769 persons with disabilities in India in January 2001, about 10% were persons with mental disability including persons with intellectual, psychiatric disabilities and there is no specific data pertaining to people with mental illnesses.

In 1987 a new Mental Health Act was approved to consolidate and amend the law relating to the treatment and care of persons with mental illnesses, but its implementation has been limited.

Among the events marking World Mental Health Day is a street parade through the Indian capital Delhi. Only on this kind of occasions, the Indian newspapers carry articles usually written psychiatrists that give a rosy picture. Therefore, the full dimensions of the problems, needs of these persons and their families remain unknown.

Remarkable developments have taken place both internationally and nationally when it comes to prioritising child rights, but the links between child abuse, child labour and the care for a child's mental health are still absent. In India there is no separate law with regards to sexual assault of children. The general law on rape contained in the Indian Penal Code covers child sexual abuse and assault. Similarly, the Juvenile Justice Act 1986 has an impressive preamble, but despite this, the Act scarcely touches upon the subject of child sexual abuse, and completely leaves aside therapy and mental health considerations.

Mental health and women: The most vulnerable problems faced by adolescent girls and women are decision-making in the day-to-day life, self-dependence and career. Rapid changes in the socio-economic and cultural reality, parental expectations, values and norms, rising levels of competition and pressure during examination time and a break down of traditional family structures are factors that accelerate this alarming trend. Examination related anxiety results into sharp rise in girls hurting themselves deliberately, leaving homes or killing themselves. Large number of students and their parents are seeking professional help. On the other hand, discourse on mental health of women in the family situation gained serious consideration in the context of campaign against violence against women. In domestic violence situations, predicament of women is determined by their position in power and relations between the rest of the family members.

Mental health and HIV-AIDS: This is very important issue faced the 21st century. Counseling for dealing with social stigma and creating an alternate support network are the most important aspects of providing emotional support to the HIV-AIDS affected persons. Protect and promote the fundamental rights of persons living with HIV/AIDS who have been denied their rights in areas such as healthcare, employment, terminal dues like gratuity, pension, marital, custody of children and housing.

Mental health and people with disability: Apart from persons with psychiatric disabilities the other disabled persons also suffer from psycho socio problems many times it is not

considered while facilitating rehabilitation interventions. This is particularly with severely disabled persons and persons with more than one disability.

People with disability act 1995 and mental health: after considerable lobbying by NGOs, psychiatrists and families of persons with mental disorders, the disability was included in the "Persons with Disability Act" passed by the Parliament in 1995. But in practice, disability benefits are still elusive for persons with psychiatric disability. The only benefit so far has been the transfer of family pension for them. There is still no system in place to provide travel concession, which would make it easier to reach their rehabilitation centre or hospital. For example, the disability card, which is issued for all other persons with disability except to persons with mental illnesses.

How Indian society looks at persons with mental disorders: Majority of these persons remain without getting help because of ignorance, fear, stigma, misconceptions and negative attitudes on mental illnesses. People do believe the mental illnesses are caused by evil spirits, black magic, witchcrafts, bad stars, and bad deeds in the present/past life. They believe that these hospitals are places where dangerous mentally ill persons are treated and locked up. In addition, in community often mental illnesses and intellectual impairments or sometimes with epilepsy are confused as the same issues. The problem of persons with Schizophrenia is even worse.

Training and CBR activities in AIFO supported CBR programmes: In different training programmes organised by AIFO in India, a module on mental health is included as part of the training curriculum. Identifications and referrals for treatment, parents counselling, advocacy for public mental health facilities, community awareness, mobilizing government entitlements and ADLS activities at homes are some of the activities implemented by the CBR programmes.

Outcome of these activities: Persons with severe mental illnesses are identified and facilitated through SHGs, DPOs, community members and volunteers for treatment and follow up. CBR programmes have advocated for the appointment of mental health specialist at district level hospitals. CBR programmes have active collaborations with National institute of mental health and Neuro science (NIMHANS) in Karnataka. A total of 2727 persons with chronic mental illnesses have been identified and facilitated for various rehabilitation support in 18 CBR projects across India according to the 2007 project reports.

Issues in AIFO supported CBR programmes: Effective implementation of policies, entitlements, initiating more community health programmes etc is an urgent issue requires immediate and equal attention by the state and civil society. Because of the prevailing complex belief, stigma, attitude, myths and misconceptions about people with mental illnesses and their consequences in the society. Hence, in CBR programmes promoting positive attitude among other people with disability, family members and the general community is most important element while strengthening or initiating inclusion of interventions for persons with mental illness along with other disabled people. The training of CBR personnel is another key aspect of CBR where the personnel need to be trained with basic knowledge of managing the inclusive rehabilitation activities implemented for persons with psychiatric disabilities. Sensitization on mental health is also essential for DPOs, SHGs and the general community which will support the CBR team to facilitate the rehabilitation process of people with mental illness along with other disabled persons.

Emerging needs, new and old faces of human suffering related to mental disorders and role of CBR (Group discussions presented by *Mr. Lorenzo Pierdomenico, Mr Jayanth Kumar and Mr M. Srinivasalu*):

The topic for our discussion was abstract. Emerging needs is not so much from persons with psychosocial disabilities but from CBR. People's needs were always there, emerging needs is that CBR didn't include mental illness, many CBR practitioners were not prepared to include mental health issues. CBR has promoted development of many groups and DPOs but not enough mental illness groups.

CBR should cooperate with existing services and should not become a parallel system. New face of mental illness services can be promoted through CBR, it can complement community Mental Health work but can not substitute MH services. It must include users groups and include persons with mental illness.

Many CBR programmes may not be prepared to include mental illness and other are prepared but don't know – so these are two different issues. CBR programme has to consider the CRPD related issues at advocacy level. We should also look at emerging view of CBR, people are expecting CBR to do everything and risk doing less, so we need to look at CBR in a different way.

Joining hands, linking with other problems like alcohol, drugs, etc. (Group discussions presented by *Ms. Sarmila Shrestha* and *Mr. Yasin Wali*):

To be facilitator of the group was a learning process. There were good and realistic discussions.

In CBR there are lot of issues including the knowledge that mental health is neglected. This happens also in developed countries. To fight against this stigma and violation of human rights, all issues have to be tackled by networking and collaboration. Networking is every where, it starts to work, but it also has to develop our systems and we need to develop a memorandum of understanding.

Why people are using alcohol and first time drug users, may be there are other problems like extreme poverty, discrimination, westernization, peer pressure, etc. so their problems also need to be looked at, before blaming people, so there is need to understand.

In disasters there are more mental health problems, mental health persons are excluded and neglected.

Street children is another problems as parents push children out to work and earn, it leads to drug addiction and anti-social behaviour and mental health issues. So joining hands with these other organisations is essential. Then work for mental illness becomes more effective and work together.

Double diseases, like a alcohol user who becomes mental illness, may create more stress and mental problems, also for persons with HIV, etc.

Preparing CBR workers to work with persons with mental health (Group discussions presented by *Dr Minh Chau Cao*): There were 22 participants in our group, and all give many recommendations. There were very wide discussions, we started by identifying categories – who is CBR worker? They are not just front line workers, they also need management skills. From local areas, there are issue of selection of CBR workers – you can use villagers, lower level professionals, any body can be a CBR worker.

Knowledge of mental illness is needed for the CBR workers but not in medical oriented way, but more in psychosocial aspects, and not just through lectures but should be participatory with hands on practical experience. They have to be prepared on human rights, advocacy and attitude, and explanation that you are working with people who are ill and not with the illness. It is not extra work. The skills you can apply like counselling, psychological support, etc. are useful also for other disabilities. You need to prepare them to care for themselves, in terms of workload, in dealing with stress. CBR workers also learn to deal with family, how to provide training of family members. They also need to learn to work with local leaders, community, etc. and to encourage SHGs in beginning that can lead to consumer groups. Collaboration with existing programmes in the areas including development programmes is important. Experienced community workers and professionals can provide training but continued support is needed, and exchange of experiences among themselves are important. DPOs should be proactive and be in the centre of the process of learning.

Discussions and Comments

Dr. Istvan Patkai: We are not doing surveys, we don't want one time diagnosis, we need to move away from diagnostic categories, we need more flexible approach.

Mr. Srinivasalu: In India there were problems with different groups of persons with disabilities. Many of them, and also government law, did not accept mentally ill persons as a category of disabled persons. They had legislation that didn't include mentally ill as disabled people. Mental illness issue is very neglected, it is difficult to include them to CBR, even parents are not included. Now the national disability act has changed the position, now officially persons with mental ill are included in the group of persons with disabilities, like leprosy cured persons.

Mr. Jayanth Kumar: There are two angles, the acute conditions and mild conditions are considered under prevention and mental health services. When the rehabilitation stage comes, it is at institutional level. When the disabling condition becomes permanent or chronic only then they are disabled and role of CBR can come up only at that point.

Dr. Istvan Patkai: How to move away from diagnostic approach to a more open approach, is an important issue.

Mr. Mike Davies: CBM has 200 projects that deal with community mental health as community based strategy. Enablement of medications can be when needed, and under CBR as happens for other disabilities.

Mr. D. M. Naidu: There is a process with CBR workers, when you come across persons with psychosocial problems, do you work with them? They are not included as they are considered dangerous and we don't know how to work with them. Go to them listen to them, when they share, write down what they say – it becomes a story, then humanity enters, you discover that it is not as we thought, it is easier, you can see where you can

help. They are not mad 24x7 there are many lucid moments when they think of discrimination, violations. This story learning is important and they realise that they can help. It is process oriented and time consuming. Only then we initiate, only then they are ready.

We don't do any surveys, only if they come voluntarily. They have the right to join or refuse a group. When people say yes, next step is facilitated and they start with a consultation among themselves.

I divided mental ill persons in one group, care givers in another group and field staff in another group. Each was asked to write down about state of affairs of persons with psychosocial disabilities, they accepted. When carers and workers made presentation, they said that this is the world of people with mental ill and explained it, but when persons with psychosocial disabilities themselves spoke, they said their worlds were different, they are not together, each of them is different. They said we are ready to present our ideas to the world. For example, I don't like the doctor he talks only to my brother never talks to me and nobody loves me.

That was the first step. After listening to them, they became silent, care givers and staff. They, persons with psychosocial disabilities were specific and they told us how we put it together.

Now having understood, we asked can you talk about what you need, what should happen in your lives? Huge list came up what I want, main issue was social inclusion, then poverty, there was very little in their list about mental health, medication, etc. That is how you define stakeholders, they chose to become owners. As a process does it make sense?

Mr. Jayanth Kumar: The disability condition can also be temporary, disabling condition can also be for shorter time. In mental health, there are conditions that last less, can be under CBR as a preventive level and not as disability as they can get benefits from welfare programmes.

Mr. Lorenzo Pierdomenico: CBR should look more to how it can improve working, what it should be doing, how to improve and break gap that is growing.

Ms. Bina Silwal: I am expecting more to hear about challenges faced by CBR workers – while a person is identified is mentally ill, that person is not eligible to work for NGOs and government, so how can we change that? I lose my job, so even I am under stress, though I don't go to mental health service. A man in Indian army, had an accident, and had mental illness and lost his job. Women who are married, if she is diagnosed as mental illness, for her husband it is legal to get second marriage. We have this problem with 2 women, they are rehabilitated, they can do everything but their husbands are not ready to accept them and in court, they can do it legally. Make a mandate for fighting that and join hands.

Dr. Istvan Patkai: Advocacy role is important to promote human rights and make more tangible steps against discrimination, but we have to ask for change of laws.

FINAL SUMMERY SESSION
Coordinated by Ms. Suchada Sakornsatian



Dr. Andrew Mohanraj presented the conclusions from first session. Challenges and achievements – CBR programmes and persons with mental disorders –

Mike Davies presented “Global perspective of CBR projects of CBM” – the major issues in his presentation touched on CBR being cost effective, rights of people with neuro-psychiatric disability, the issue of consent for treatment, livelihood, accessibility to services, currently most CBR programs worldwide do not include people with mental illness, orientation of primary health care workers in mental health services and support for CBR workers and attention towards “burnout”.

T. Damdinsuren presented “Mental Health Issues in Mongolia”. The highlights of her presentation included: CBR work with formal (Governmental) sector; Stigma and discrimination against people with mental illness; and Livelihood projects and rehabilitation centers.

Lemuel Boah talked about “Mental health issues in Monrovia-Gardnersville CBR programme in Liberia”. The highlights of his presentation included: Psychological impact of war on victims as well as perpetrators; Lack of proficiency excluded mental health component from CBR programmes; No coordination between formal sectors and CBR programmes in Liberia; National poverty reduction strategy takes into account people with mental illness.

Group Discussions

Group I discussed “Lack of access to treatment and referral services for persons with mental disorders”. The highlights of the discussion were: Capacity building to help strengthen referral system; Working with traditional healers; Public awareness-Traditional practices, beliefs; Livelihood- intersectoral approach; National policy/regulation; Standardisation of curriculum for training; and Simple diagnostic tools.

Group II discussed about “Stigma, marginalization and livelihood problems”. The highlights of the discussion included: Stigma in different countries- stained, karma, magic, evil spirit, side effects of medications; Role of media; Early identification needed; and Livelihood reduces stigma.

Group III discussed “Persons with mental disorders in institutions like old mental hospitals, prisons etc.”. The highlights of the discussions included De-institutionalisation; “Institutionalization” of mental health workers; Effective CBR programmes reduces burden of mental hospital; Include consumer groups in CBR movement; and Mental health issues neglected in prisons.

Conclusions The take home message from the first session includes the following – CBR is emerging a cost effective concept in rehabilitating people with psychosocial disabilities; Need for proficiency in MH issues among CBR workers; Need to work with the formal sector; Recognise the role of traditional healers/religious leaders; CBR is effective to reduce stigma and discrimination; Livelihood as an important component in rehabilitation of people with psychosocial disabilities; Need for national policy /regulation ,legislation (involuntary admission, informed consent); and, incorporation of MH in CBR reduces unnecessary institutional care;

Mr. D. M. Naidu presented a summary of the second session: The theme of this session was “Persons with experiences of mental illness and their families in CBR”. During

this session there were persons who talked about their own experiences. D. M. Naidu spoke of role of user organisation and the importance of understanding how can persons solve their own problems by themselves. Persons become a group with solidarity to voice their views and seek help of other marginalised groups and talk of entitlements and rights. They take major part in awareness raising and provide materials for street plays, campaigns, etc. User group members also focus on group needs, using asymptomatic and lucid moments of their lives to express themselves and their wishes.

Andrew Mohanraj spoke of healing and not just of treatment. He mentioned the Bio-psycho-social-spiritual dimension of mental illness.

Bina Silwal spoke on community-based psychosocial support involving mainly post-trauma children and other persons after conflict, and their methodology of using storytelling and art for healing through self-expression in the “hero books” and “my desired childhood” concept.

In the group discussions, one group focused on terminology used when we talk about mental illness. The group looked at all the different terms used by people, their meanings. Each group of people had reasons for their own choice of words they preferred. In the end 3 terms were highlighted that were acceptable to the majority – psychosocial disability, mental health condition, mental illness.

Discussion: Following Mr. Naidu’s presentation, there was some discussion. Ms. Suchada Sankornsatian felt that there is problem of terminology even after 25 years of discussions. She pointed out that WHO CBR manual uses the terms “strange behaviour”.

Dr. Istvan Patkai presented a summary of the third session: The theme of this session was “Learning materials and capacity building in relation to community-based interventions for persons with mental illness”. He explained that as Mr. Naidu had said, in reality it is not capacity building but mutual enhancement of resources.

Dr. Istvan Patkai made a presentation on “Cross over of ideas, synergies and linkages between CBR and Mental Health” and highlights of his presentation included the following - Emphasis on stress and social theory vs. vulnerability; Context and resilience vs. bio-medical diagnosis; The “wounded healer” experience of caregivers; Prepare for supervision and referral; Training at various levels; Train knowledge, attitude and management; and teach empowerment, rights and responsibilities.

Ms. Suchada Sakornsatian made a presentation on “Learning Materials on Community Mental Health” and the highlights of her presentation were - Training modules, leaflets and awareness programs for various levels and stakeholders; In addition to training methods, technology, attitude and management were also emphasized; not just theoretical training but also home visits; Special roles of volunteers and monks; and referral issues.

Mr. Jayanth Kumar made a presentation on “Mental Health issues in AIFO supported projects in India”. The highlights of his presentation included - Additional responsibilities for workers addressing psychosocial issues; Celebration / Mental Health Day as an important component strategy; People with physical disability have also Psychosocial problems.

Group I discussed “Emerging needs, new and old faces of human suffering related to mental disorders” and the main points of their discussions included - Emerging new roles of CBR workers; and needs for training.

Group II discussed “Joining hands, linking with programs (disaster, alcohol, street children etc.)”. The main points of their discussions included - These areas addressed as linked programs and bringing not only burden but also opportunities for expanding mental health work.

Group III discussed “Preparing CBR workers to work with person with mental disorders”. The main conclusion of their discussion was that new knowledge and also management skills to be incorporated into the training program.

Discussions & Comments

Dr. Francesco Colizzi made a comment about importance of monitoring the genetic researches on mental illness and understanding the consequences and stigma, diagnosis, etc. For example, there is new research on genetics of schizophrenia, and they say that it can bring less stigma, but there are many other issues about such research. Also important to evaluate somatic diseases in mentally ill persons as there is lack of medical attention, that they can have general health problems like anyone else. In fact, the life expectation in chronic psychosis is 10-15 years less than average life expectation. When a person is recognised as a psychiatric patient, the person receives less attention to other medical issues, they can also have problems like diabetes and hypertension, etc.

In terms for terminology as first fundamental step to focus on schizophrenia, and other psychotic conditions, not on other depression, anxiety, etc. severe mental illness are more stigmatised, more marginalised, more poor, etc. by using international ICF etc. have terms of severe mental illness.

Dr. Mani Natrajan: We need to work with formal sector, more compassion, etc. Government sector is problematic etc. so their involvement needs to be considered.

Mr. David Webb: About genetics comment, I want to stress that nothing has been shown yet. It is speculative. About life expectancy, so many of us are hiding and there are high suicide rates, and our society’s current response is contributing to it.

About giving importance only to psychotics, I had severe depression, it is not severe mental illness? Many of us who suicide, we are not severe mental illness, we should be ignored?

I wish to develop more networks with persons with disabilities, but today’s forum is different. There are persons talking of psychosocial from their own living experiences. I can understand to see its importance, also to see a concern, it is beginning and long way to go. Slogan of disability movement is “nothing about us and without” yet this group here is discussing the issues without persons with psychosocial disability except for me. It shows how marginalised we are.

Jayanth talked about disability when an impairment is permanent. In 1979 hospitalised after burns, in 1990 again, struggled for 4 years, I was in hospital many times, medical diagnosis didn’t help, treatment didn’t help and finally a spiritual discovery set me free, I don’t offer it as universal solution. I am not cured or rehabbed or recovered – it would be dangerous for me to think that, I risk for falling back. Even among persons with disabilities

I face discrimination. I have a 10 year gap in my CV so it is hard to hide it and I don't want to hide it, I want to be honest. I continue to face discrimination. I am grateful for my difference, it wasn't for that I wouldn't be where I am today in my life. Persons with disability have a gift, to tell what it means to be human and for society to learn to receive that gift. By embracing and engaging more fully with disability, do you feel your life is not being enhanced by being working with disabilities? It enriches and enhances all of us.

Dr. Sunil Deepak: As this workshop has been organised in a way that didn't have someone covering cost for different persons but coming together with our own resources, so that affected who has come here. I don't want to justify any thing, but there are other persons in this workshop who have personal experiences of mental illness but it is their choice not to talk about it.

Countries/project feedback on taking home from this workshop – each country/project was given the choice to prepare a short statement about their carry home messages from the workshop.

Guyana (Ms. Geraldine Mason Halls): Guyana has 1 psychiatric hospital far away from capital, it serves a population of 700.000 persons. We have 2 psychiatrists for whole country. Challenges are limited access to psychiatric services, limited personnel, use of traditional biomedical approaches. CBR programme in Guyana works with individual persons with mental illness, and our challenge is to include more structured approach to mental illness. Listening to many presentations in this workshop, I feel that we have to do more for advocacy among DPOs, with staff of psychiatric hospital and also need users of CBR programmes who have benefited, need for social support network among existing groups, need to link with local government perhaps by starting to work near psychiatric hospital, where there is more opportunity for support, we can think of a pilot project in that particular region.

We need to do more in preparing CBR workers, families and communities about mental illness. And this is a challenge so hopefully by the time of next conference we shall have greater success.

India (Mr. M. Sarfaraz) – There is no confusion about mental health, it needs immediate attention, all agreed in our group. Strategies of implementation that we need, can be separate for each state as we are different, or we can cluster some states, but we can work together. We recognise that nothing is possible without bringing all stakeholders together, including persons with mental illness and families, NGOs, government. We shall take it forward towards more concrete things.

Indonesia (Mr. Mike Davies) – I also speak for *Philippines* and other countries only on behalf of CBM work. For our stakeholders in CBR including Ministry of Health is a top priority. In future most of our work is going to be through CBR, including both advocacy and service delivery. Now 45 CBR projects and 22 other projects are already involved in MH, there are also a few vertical programmes of community MH, that were started in the last 5 years. Thus, there is scope for experimentation, for trying future approaches. We do plan to extend community MH in context of other CBR work in the region, also to encourage development and involvement of users and SHG in all CBR projects. We move towards increased support for family training, livelihood, advocacy for service access, in lobbying for positive change in attitudes and support, continue to engagement with professional associations to bring change in their attitudes and practices, aware of the role of “wounded healers”, so we have to look at ourselves.

Japan (Mr. Takechi): In my opinion, from the presentations and experience sharing, I noticed about psychosocial issues are deep and difficult, your passionate speeches moved my mind, I thought of fertile approaches and CBR. In Japan MH is a big issue, many young women 20-30 years have depression in Tokyo, job stress is another big area of problem, persons living alone and no affective support, no one takes care. It can be useful to try CBR approach to promote treatment and support persons, users can give hand for others.

Liberia (Mr. Lamuel Boah): Looking back at major issues of MH in Liberia, we see that there are issues of ignorance, isolation, hatred, lack of professionals, etc. We have ideas to involve more persons with MH, involve stakeholders to come up with strategies and active involvement of ministry, campaigns in churches and schools. Other issues for us include promoting greater collaboration and affordability of treatment, follow up after treatment.

It has been stimulating and fascinating this experience, so as to get different ideas back to our countries for implementation. How to adopt these approach for our context is our challenge.

Mongolia (Dr. Batdulam): I am a neurologist, mother of CP child, and also national manager of CBR programme for 2 years. Mongolia CBR programme is paying more attention to livelihood for mental illness but this work started only 3 years ago. Here I have learned from many experience from others. We shifted from socialism to democratic governance in beginning of nineteen nineties. This raised different social problems like alcoholism, street children, also shifting to nomads to settled families, many nomads emigrate to capital and don't know the differences of living a settled life. Economic differences are producing challenges. As Mongolia CBR we collaborate with government. We have made a contact with medical school by including CBR in students' training curriculum. We also need to emphasise in mental health issues in collaboration with Ministries of Health and Education, improve self help groups, highlight good practices of livelihood, promote communication campaign for change of attitudes in collaboration with National Commission of Human Rights, and strengthening capacity of medical staff.

Nepal (Mr. Prakash Wagle) – Mental Health is an important issue, sorely needed in Nepal, it is not recognised as health or development issue, it is seen as incurable condition or a spiritual issue, ignorance and superstitions in this area are high. Out of 35 psychiatrists in Nepal, there are only 2 psychiatrist outside Kathmandu. There is just one hospital with 50 beds for a total of 50 million population. For further treatment, persons can get only symptomatic treatment. This issue can be integrated in CBR, there are many CBR projects all over the country. They have a net work, they have SHGs of users, they launch advocacy initiatives, and these 65 members of networks need information on mental illness. It is possible to think of informal sector that can provide training to health post in-charge and female community volunteers, not only in CBR but also through mothers groups and parents groups and clubs. These can be asked to take interest, some referral system is needed. More can be done.

New Zeland (Mr. Robert Choy) – Area of mental health is new area for me, I have learnt very much from this experience, it has been enriching and transforming for me personally. In New Zeland the situation about MH is regressive. I don't understand the local disability issues and now I start to understand them better. We can support funding and look critically at new requests – are MH considered? Is treatment is being considered in holistic way? Is there is adequate training for health workers, families, users, etc? is there is an awareness component built in? is there linking with other programmes such as child rights, street children alcoholism? is work with formal sector considered? are there livelihood component? I had read the MH guidelines from our own organisation.

Pakistan (Mr. Yasin Wali): I am a physiotherapist in Ministry of Social Welfare, also represent CRDP supported by AIFO. Attitudes towards MH is very bad, and barriers are very high. We physiotherapists also study some mental illness but physiotherapists rarely work with MH. National level CBR network, is there. Psychiatry services are only in big cities and even their practices are in the old model. Psychosocial disability is not considered a disability and early identification is a problem, only when problems become chronic, they are identified. We started in last 10 years, not working yet with mental health. We shall try to establish this in our network but not so easy to start as already lack of qualified psychiatrists, but they can't pass knowledge to CBR workers.

Vietnam (Dr. Chau Cao): We don't have much experience in this and learned from you. Government should have policy on MH including early identification and intervention. There are many persons with MH issues, if we can have a government policy it can improve reference system, referral system in terms of one system from top to down, hospital at provincial level, but also at home and community. So there is no follow-up and support. Family should take greater role, but there is lack of knowledge. We have to change the attitudes in the community. As they don't take care and attitudes need to change. CBR should play an more active role in integration of MH in community, we have long time experience for CBR but there is not enough work on mental illness. CBR should start at family and community level.

Bangladesh (Ms. Rubiya) – We just started thinking of mental health as an issue in 2006, so it is relatively recent experience. This two days session gave us information and future directions. I work with Action aid in Bangladesh. About MH in Bangladesh, it is marginalised issue, and their families are marginalised from all development initiatives, their human rights is being violated every day, everyone ignores mental health, it is seen still very much in clinical and medical context, whole families suffer in the communities. Our is a right- based organisation, a lot of advocacy work is done on human rights in disability, raising awareness is most important. We have published 2 posters with messages – mental health is not separately, it is part of health, and if whole body is like a boat, you have to take care of mental health as boatman; we doing advocacy with government, but in Bangladesh we still follow lunacy act, so we are trying to repeal this act, like in India they have disability act. On 10 oct international mental health day, we organise celebration and protest, get clinical persons, civil society, academics all together for generating ideas, dialogue. It is not just clinical issue, also needs social and rights perspective. We don't do no direct work, but we work with partners. National forum of persons with disabilities is trying to set up a subcommittee on MH. Last year we had a cyclone, and we said that relief is important but also psychosocial care. So in consultation with WHO, Institute of MH, and other persons for this initiative, and to form a parents platform. It helped us to form this forum with parents. We also work with acid burn women, raped women, in the same way as there is also psycho-trauma. We continue our work, we work with 150 local organisations, we share these experiences, and promote initiatives for capacity building of our partners on MH and continue advocacy work.

West Africa (Mr. Paul) – CBM is involved in many activities of health promotion, rights, etc. Families identify themselves to volunteers and CBR workers, they were already used to our work in eye-care. We organise meetings and discuss together, issues such as education, etc. Psychiatric nurse involvement is compulsory, most countries have these in West Africa even if there are no psychiatrists. Sometimes we buy the drugs and there are drugs revolving schemes. We are starting user groups. There are 18 projects with CBR and MH, one hospital, and one CSP in Nigeria.

Final Remarks

Mr. Chapal Khasnabis: I would like to thank all the organisations and persons involved in organising this meeting. There was a lot of resistance about organising this meeting. The challenge does not lie here, here people are already converted, the challenge lies outside where the situation is more complex and there are some parallel works. Initially when disability issues were taken up, it was seen as a medical issue and was completely under the control of professionals and under the medical model. They felt that only they have the competence and no one else can do it. It took a long time, but slowly the situation has changed and it has evolved. I would like to thank AIFO for organising it. Thanks also to CBM for their support and all the other organisations and partners.

I am happy that many of you found this experience so useful. We want us to continue, our bigger plan is to organise one congress every year in rotation. Next congress is in Mexico from 8 to 10 December 2009. Then in 2010, there will be Africa CBR congress in Nigeria, then again in Asia in 2011 and may be a world congress in 2012. In future we want to associate such workshops with each congress as a regular feature.

There has been some criticism that CBR is not evidence based, there is no scientific evidence. Here you can see that CBR is a reality. Those who come here they are professionals and they are documenting their experiences in presentations to show to answer this criticism. It is a people centred activity with scientific background and knowledge.

Terminology issue is a big problem. It has a long history, there are also territorial issues. There have been 3-4 suggestions from this workshop on the terminology and these may guide on how to move forward. There is a dedicated chapter on mental illness in the CBR Guidelines as within CBR, this issue is marginalised.

Most persons in this workshop underlined so many times that CBR is a good vehicle to take up MH issues.

Whole CBR concept is changing and evolving over time. There was a huge review of CBR in Helsinki, where it was asked to change. Poverty is a big issue for the persons with disabilities and we don't take that, it will never be sustainable. CBR Guidelines have a component on reduction of poverty and promoting livelihoods. People writing livelihood chapter write that unless persons with disabilities come out of poverty, all other issues will just remain. So it is a key area.

Synergies between CBR and community MH programmes are important. There is still a long way to go.

David was talking about his own life experiences. For us working for CBR, there are so many different positions. Professionals say that we are agents of DPOs and DPOs say that we are agents of professionals. For example, you can't speak of CBR in the Independent Living Movement, because they refuse it. However I know that we don't have any hidden agenda, we shall move. India's great poet wrote a song where he says if no one comes with you, go alone. So we are ready to go.

CBR Guidelines will be the next big step. We want to get them out, promote their implementation and continue to put users groups in the centre and work with them, as we continue more and more user groups will come.

Thank you.

Dr. Sunil Deepak: Chapal has already said almost every thing I would have said. I would like to explain how this workshop came about. When we thought of bringing persons from different AIFO/Italy supported programmes in different countries, we thought that it will be good opportunity for our own learning and we should maximise it. We felt that mental illness was an important issue and we wanted to learn more about it along with our partners. However we also realised that just by ourselves it will not work as we will be like a good of illiterates trying to talk about education. It was fortunate that WHO/DAR immediately supported our ideas and facilitated links.

Mike Davies from CBM was very supportive from the beginning and he brought in many key persons from CBM with their knowledge and experience like Dr Istvan Patkai, Dr Andrew Mohanraj and Mr. Willi Reyes. Chapal suggested Mr. D. M. Naidu from Basic Needs India and to have him has been an enriching experience. Other members of IDDC also supported like Handicap International.

We didn't have much resources to organise this workshop and it was wonderful to discover so many persons who came with their passions and idealism and shared knowledge, experiences and their own costs. Thanks to all of you.

I would also like to thank my colleagues in AIFO who were so supportive and especially Ms. Felicita veluri who did so much work to make this workshop happen. Finally thanks to the staff of the Prince Palace hotel who were always willing to support our requests and help us.

Thank you all again, this workshop is now closed.

PRE-CONGRESS WORKSHOP
COMMUNITY-BASED REHABILITATION (CBR) AND MENTAL HEALTH
 Hotel Prince Palace Mahanak, Bangkok, 13-14 February 2009
FINAL LIST OF PARTICIPATANTS

	COUNTRY	NAME	FAMILY NAME
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02	Bangladesh	Sayema	Chowdhury
03		Rabeya	Sultana
04	Belgium	Graziella	Lippolis
05	Congo	Freddy	Sanduku
06	Egypt	Mervat	Hana Maher
07	Guyana	Geraldine	Mason Halls
08	India	Jose	Manikkathan
09		Jayanth	kumar
10		Alice	Joseph
11		Aley	Chinothuvattukulan
12		Manimozhi	Natarajan
13		John	Peter
14		Sarfaraz Ahmad	Syed
15		Moham. Shahnawaz	Qureshi
16		M.	Srinivasulu
17		D. M.	Naidu
18		Sara	Varughese
19		Nicholas Guia	Rebelo
20	Indonesia	Andrew	Mohanraj
21	Italy	Enrico	Pupulin
22		Sunil	Deepak
23		Francesco	Colizzi
24		Marco	Colizzi
25		Marcelo	Carrozzo

26		Simona	Venturoli
27		Francesca	Ortali
28	Japan	Takechi	Masato
29	Jordan	Maha	Al Rantisi
30	Liberia	Lemuel	Boah
31	Mongolia	Tulgamaa	Damdinsuren
32		Enhbayant	Lhagvajav
33		Batdulam	Tumenbayar
34	Nepal	Bina	Wagle Silwal
35		Sarmila	Shrestha
36		Prakash	Wagle
37	Newzealand	Robert	Choy
38	Pakistan	Sibghat	Rehman
39		Yasin	Wali
40	Philippines	Michael Peter	Davies
41		Istvan	Patkai
42		Wilfredo	Reyes
43		Barney	Mcglade
44	Switzerland	Chapal	Khasnabis
45	Thailand	Suchada	Sakornsatian
46	Vietnam	Lorenzo	Pierdomenico
47		Minh Chau	Cao
48		Thi Phuing	Pham
49		Van Ton	Nguyen
50		Elisabeth	Cross