



## GLOBAL FORUM FOR COMMUNITY MENTAL HEALTH

### Summary Report of the MEETING OF THE GLOBAL FORUM FOR COMMUNITY MENTAL HEALTH

30 - 31 May 2007 - WHO, GENEVA, SWITZERLAND

#### Background and Objectives of the Meeting

From 30 - 31 May 2007, the first Global Meeting of the Global Forum for Community Mental Health took place at WHO, Geneva. The mission of the Global Forum for Community Mental Health is to provide a supportive network for all those interested in promoting community mental health services and the prevention of mental disorders. It provides a foundation for sharing information, providing mutual support, and a sense of belonging for users, families, providers, and all who are interested in shifting mental health care from long-term institutions to effective community-based care.

The Forum for Community Mental Health is composed of existing organizations whose mission is in concert with the objectives of the Global Forum for Community Mental Health. The Mental Health and Substance Abuse Department of the World Health Organization acted as the convener of the forum. Christoffel Blinden Mission (CBM) gave substantial support.

Major partners of the Global Forum for Community Mental Health include CBM, Basic Needs, the World Association for Psychosocial Issues and UK Department of Health. A number of individuals have given essential input in the realization of the Forum.

The objectives of the Forum meeting in Geneva were as follows:

- to provide a supportive network for all those interested in promoting community mental health services and care for people with mental disorders, including the involvement of consumer and advocacy groups
- to share selected experiences of regional and country activities on community mental health services and to derive some lessons
- to move from experience to evidence and to discuss ways to identify and overcome the barriers involved in strengthening community mental health services in low- and middle-income countries

The Forum brought together mental health service leaders, consumers and family members who are involved with community mental health services in order to foster a discourse about mental health services and their strengthening in low- and middle-income countries.

## **Meeting structure**

The meeting was planned to be a different kind of event than a typical conference. Since the Forum was seen as an event to bring together people in order to share information and experience with each other, a participatory approach to the event was chosen.

Well in advance of the meeting, participants from a wide range of regional and professional backgrounds were invited. All participants were asked to comment on a provisional meeting program, drafted by WHO staff. Strong efforts were made to consider all modification proposals in the draft of a provisional meeting program.

During the meeting, instead of long presentations by a few to be heard by many, most participants were given the possibility to present their specific experiences in short presentations of 5 to 10 minutes each. Chairpersons were requested to maintain the time allotted to speakers very strictly. Plenty of time was given to open discussions following each session. In addition, two coffee breaks and a lunch break each day, as well as a reception, had been scheduled to allow space for informal meetings between participants.

## **Opening Session: Welcome and Agenda Overview**

In his opening remarks, **Benedetto Saraceno**, Department of Mental Health and Substance Abuse, WHO, Geneva, welcomed all meeting attendees and introduced the founding members of the Global Forum for Community Mental Health: WHO, Christoffel Blinden Mission (CBM), Department of Health UK, Basic Needs, World Association for Psychosocial Rehabilitation.

In addition, he expressed his gratitude to Sivasankaran Sashidharan and John Jenkins for their immense support in the preparation of the Forum.

After a short self introduction by all participants, Benedetto Saraceno pointed out the wide geographical and professional background of the Forum participants and characterized the meeting as an opportunity for mutual exchange by **all** stakeholders: "The mission of the Global Forum for Community Mental Health is to provide a caring supportive network for all those interested in promoting community mental health services for people with serious mental illnesses. The forum provides a foundation for sharing information, providing mutual support, and a sense of belonging for users, families, providers, and all who are interested in shifting mental health care from long term institutions to effective community-based care."

B. Saraceno declared the intention of WHO to promote Community Mental Health in

today's official psychiatric discourse and practice, and to give a voice to the minority of all the stakeholders active in community-based mental health care. After addressing the limitations of the prevailing bio-medical model, he emphasized the importance of the psycho-social dimension in psychiatry. B. Saraceno demanded community-based, comprehensive long-term care for people with severe chronic mental disorders in contrast to today's institutionalized psychiatric practice. Special attention should be given to the continuity in human relationships and collegiality between all stakeholders.

While mental health care providers should refrain from separating mental health problems from their psycho-socio-economical context, thereby medicalizing human suffering, community mental health care promoters should not make the mistake to deny completely the need for management of severe mental disorders. Instead, they should take up the challenge and responsibility to build up comprehensive, community based mental health care, integrating prevention and rehabilitation activities.

Furthermore, B. Saraceno strongly advocated the linking of all community mental health care services to the public health care system. In his view, small-scale efforts in community mental health without sufficient interaction with the public health system risk isolation and ineffectiveness in regard to a sustainable change of the psychiatric system.

Last but not least, B. Saraceno sees a danger in the creation of community mental health care systems for users with minor psychiatric disorders and the parallel continuity of sub-standard psychiatric institutions for those with severe mental disorders.

"The ultimate goal of community mental health is the relief of suffering and the empowerment of the citizens suffering from mental health disorders"

In the end of his opening speech, B. Saraceno asked the participants to forget about any personal agendas for the time of this meeting. Instead, every participant should contribute actively to an open discussion without feeling obliged to the agenda of his/her organization or association.

**Sylvester Katontoka** and **Mahesan Ganesan** were requested to describe what they would expect the forum to do and how that will facilitate expansion of community mental health in their own country or region.

In his comments, S. Katontoka emphasized the urgent need for mental health care on the African continent. According to him, three quarters of all people in the world with serious mental health problems come from Africa. He therefore expects the Forum to ensure that international organizations will target their mental health activities in Africa with emphasis on capacity building in the form of knowledge exchange, training programs, research cooperation and examples of best practices in community mental health.

Although he sees some progress, like in the case of Zambia, he also describes mental health care in Africa as characterized by a lack of mental health institutions, a lack of mental health staff and systematic human rights violations in centralized psychiatric systems.

Therefore, S. Katontoka strongly advocated for a participatory, community based

approach to mental health care based on the experiences and socio-ecological resources of the community. In closing his speech, S. Katontoka once more pleaded to the Forum: “Africa needs not to be left behind.”

Subsequently, Mahesan Ganesan summarized his four major expectations of the Forum:

First of all, he asked the Forum to help him in creating a better understanding of what we mean when we talk about community mental health: “Is community mental health just a reaction to institutional psychiatry? Or is it a completely new approach to mental health? Is it just a set of services? Or a process? Is community mental health the same thing as community psychiatry?”

Secondly, in talking about his experience in fostering community mental health care in Sri Lanka, M. Ganesan asked the Forum to discuss the skills needed by professionals in community mental health, pointing out that many of them, like management or networking skills, are usually not included in the curricula of mental health professionals. Thirdly, he expressed his expectation to reflect on the best practices in community mental health and to learn from the experiences of all stakeholders.

Finally, M. Ganesan talked about the need to convince leaders and colleagues using evidence based research on community mental health and by advocacy towards another mental health approach beyond the dominant bio-medical model.

After this introduction, **Shekhar Saxena**, briefly summarized the objectives and themes of the Forum:

- to provide a supportive network for all those interested in promoting community mental health services and care for people with mental disorders, including the involvement of consumer and advocacy groups.
- to share selected experiences of regional and country activities concerning community mental health services and to derive some lessons.
- to discuss ways to identify and overcome the barriers involved in the strengthening of community mental health services in low- and middle-income countries
- to plan future activities of the Forum

Realizing that not every objective would be possible to cover extensively, he then expressed his hope that this meeting would be only the first meeting of many other meetings to come in the next years. After noting the diverse backgrounds of all participants, he kindly appealed to the audience to work in mutual respect over the next two days. S. Saxena then introduced the program of the meeting.

Finally, Julian Poluda was requested to function as the rapporteur for the forum.

**Susannah Rix** presented the website of the Global Forum for Community Mental Health. In line with the objectives of the Forum, the website is designed specifically as a forum for discussions and exchange of experiences.

In addition, the website contains links and contact details for a range of organizations and individuals interested in the development of community mental health. Contact details of every interested Forum participant can be added to the website. Another page of the website contains links to useful community mental health resources. Forthcoming

events of the Global Forum for Community Mental health are also published on the website and can be commented on by all website users.

The website link is <http://www.gfcmh.com/>.

### **Session 1: “Global Perspectives”** Chair: Itzhak Levav

This session intended to provide a background concept of community mental health, its need in the current context and the present level of resources available for it globally. The comments focused on the shape that community mental health services take, in practice, and in diverse cultural and resource environments.

Lead comments:

- Sivasankaran Sashidharan (10 minutes)
- Shekhar Saxena (10 minutes)

Comments: What does community mental health mean in diverse scenarios? (5 minutes each)

- Malembo Makene
- Budi Anna Keliat
- Rangaswamy Thara
- István Pátkai
- Hugo Cohen
- David Sallah

In his opening words for this session, **Chair Itzhak Levav** appealed to the audience that the time has come to move from experience to scientific evidence in community mental health in order to help strengthen those working in the field. He expressed his hope that the Forum, including the WHO, would take a leading role in promoting community mental health. For this first meeting, he expected the Forum to clarify several issues concerning the model of community mental health, such as the components of the model, the professional disciplines involved, training needs and the goals of community mental health care on the individual and the community level.

In his leading comment, **Sivasankaran Sashidharan** elaborated on the failures of centralized psychiatric systems, such as the lack of strong evidence for institutional psychiatric care, the primary and secondary effects of institutionalization, human rights abuses and violations and insufficient cost-effectiveness.

He then gave a number of arguments that underlined the need for community mental health services, contextualizing each argument with examples from studies and service user surveys, e.g. in Birmingham and Aceh, Indonesia:

- the failure of the existing model of psychiatric service delivery is evident
- users and carers prefer community based mental health services > the views of

users and carers should determine the nature of psychiatric services thereby making mental health services more acceptable and socially inclusive

- there is strong scientific evidence for the higher efficacy and effectiveness of community mental health services
- community services are more cost-effective
- community mental health services are the only applicable approach in the context of poor health resources and limited access to health services

In summarizing his presentation, S. Sashidharan concluded that centralized psychiatric health systems are not suited in any way to health care intervention and that community based mental health services can better meet the population's needs.

In the second lead comment of the session, **Shekhar Saxena** first reminded the audience of the ten recommendations of the World Health Report on Mental Health from 2001; these include several on community mental health services.

Despite the strong promotion of community mental health by WHO for a number of years, according to the WHO Mental Health Atlas, community mental health care is provided currently in only 68 % of the world. Although there are big differences even in countries that generally offer community mental health services, many countries, especially in Africa and Asia, don't offer any kind of community mental health care. While high income countries have a much higher number of mental health beds in total, only about 55% of all mental health beds are found in mental hospitals compared to about 75% in low income countries. In total, about 80% of all mental health expenditures in the world are spent on mental hospitals. Generally, this proportion is even higher in low income countries than in high income countries.

Last but not least, the generally very low ratio of community mental health care contacts to hospital days reveals that mental health care in most countries is still largely hospital based.

In a closing remark, S. Saxena suggested the WHO Mental Health Atlas (<http://globalatlas.who.int/globalatlas/default.asp>) and the country reports based on WHO-AIMS, a new WHO tool for collecting essential information on the mental health system of a country, for a more in-depth look at all mental health country data ([www.who.int/mental\\_health/evidence/WHO-AIMS/en/index.html](http://www.who.int/mental_health/evidence/WHO-AIMS/en/index.html)).

In the first short comment of the session, **Malembo Makene** talked about his working experience in a community mental health care program implemented by "Basic Needs" in a rural area of the Mtwara region in Tanzania that focused on poor and marginalized people. Using a participatory approach, "Basic Needs" trained health workers and community volunteers on mental health and established mental health outreach clinics where no other health facilities existed. In addition, mental health care has been integrated into the primary health care system through training, the support of health management teams at national, regional and district levels, and the use of existing resources within the area. Community based organisations, traditional healers and community volunteers now play a major role in patient identification, referrals and follow-up visits. Self-help and user groups contribute to social and economic inclusion.

Despite severe constraints, like poor infrastructure, limited human resources, poor supply of psychotropic drugs and the high level of stigma and discrimination, a total of 8,517 people were reached over the three-year period of the program. In addition,

district councils have started allocating resources for community mental health activities, districts have adapted the community mental health and development module, and partner organizations have started income generation activities for service users.

In his closing remarks, Malembo Makene pointed out the need to address the poverty of service users, the importance of permanent consultations with service users and families, and the need to network between a variety of stakeholders in order for permanent positive changes in mental health care to take place.

Subsequent to M. Makene, **Budi Anna Keliat** reported on a program developed in cooperation with WHO three months after the Tsunami in Indonesia, aiming to train community mental health nurses based at public health centres (puskesmas) in Aceh. Community mental health nursing (CMHN) training is divided into 3 steps:

The objective of the basic community mental health nurse training is for the nurses to have the ability to take care of persons with mental disorders in their homes. To date, 552 nurses have been trained at the basic level. This year, the remaining three districts of the eighteen districts in Aceh will receive training, thereby covering the whole province. The training will be followed by three months of implementation, supervision, monitoring and evaluation.

The objective of the intermediate training component is to enable nurses to identify patients, to take care of psychosocial problems, to train the community leaders to be promoters of mental health and to develop village awareness towards mental health. Ninety nurses were trained at the intermediate level. In addition, 1,194 community leaders were trained leading to increased awareness for mental health disorders in more than 140 villages.

The advanced training module aims to enable nurses to advocate, research, and promote mental health and to act as case managers. A pilot program will take place in two phases over a one month period in August 2007 and will be followed by four months of implementation, supervision, monitoring and evaluation.

WHO, USAID, AGB, and CBM have provided most donor contributions. In addition, the Ministry of Health has given financial and administrative support and has declared their intention to implement the program all over Indonesia.

The major findings of an external evaluation described the program as very comprehensive and highly appropriate for the intended nursing interventions. Results of the program include increased community resources in mental health care, better community awareness regarding mental health problems, higher motivation and satisfaction of program participants, increased drug supply, inclusion and supervision of families, and the prevention of immediate admission to psychiatric hospitals.

Finally, B. A. Keliat expressed her hope that the training program for mental health care would be included in the compulsory training program for public health centre staff and that the necessary budget would be allocated for it.

**Rangaswamy Thara** started her comments with the question of why community mental health in India is so important.

First of all, there is a lack of **availability**: few mental health professionals are available in the country, drugs are largely unavailable and often doctors in PHC are not trained in mental health. Secondly, there is a lack of **acceptability** for mental health care: conflicting explanatory models of mental illness exist and people are stigmatized when seeking psychiatric help. Thirdly, there is a problem of **accessibility** to mental health

services: MH services are not present in many states in rural regions, where only traditional and religious healers “treat” people with mental health disorders. Lastly, the **affordability** of mental health care is not insured: there is no medical insurance system and no welfare benefits in case of illness.

In an innovative approach in Tamil Nadu, the successful “Tele-Mental Health” system has been set up. This system allows psychiatrists to talk to patients in a different city via video connection. Although efficient networks of community mental health workers have been put in place, this innovative approach has been necessary to save travel costs and time for the very few psychiatrists in the region. Rangaswamy Thara further emphasized that mental health disorders have to be understood from a family/community perspective. Too often, “human rights violations” like the chaining up of people with mental disorders by relatives, originate from the helplessness caused by insufficient professional help.

R. Thara ended her speech by appealing to the audience that we have very little experience in community mental health and that we need the support of the community and families to understand and to work in community mental health.

**István Pátkai** outlined the mental health approach developed and implemented by Christoffel Blindenmission (CBM) since 2002. After the Tsunami in 2004, CBM emphasized the need to care for people with severe psychiatric disorders. Effective inter-agency cooperation was essential to ensure mental health care for people. Programs reaching 19,000 people with epilepsy and 15,000 with psychiatric disorders in 36 countries, especially in west central Africa and south-east Asia in 2006, underline that this is the fastest growing working field for CBM today. Key areas in mental health care for CBM lie in the care for people with acute psychiatric conditions (e.g., psychosis, depression, epilepsy). In line with the organizational tradition of CBM special attention is given to disabled people who often suffer from discrimination and stigmatization. Training programs (e.g., for community health workers, volunteers, medical doctors, nurses, psychiatrists, etc.) and service development are at the core of CBM’s efforts. CBM strongly emphasises a community based approach as expressed in the final comment by I. Pátkai: “Finally, it is my strong belief with others that the science-based and patient-centered community psychiatry will have a prominent role ‘to write the histories of the future not only of mental health but of twenty-first century health care as a whole’” (Oxford Textbook of Philosophy and Psychiatry, K.W.M. Fulford, T. Thornton and G. Graham, Oxford, 2006, page 780).

Subsequently, **Hugo Cohen** presented his work in setting up community based mental health services during the eighties in very remote areas in Patagonia, Argentina. The decision for a community-based approach resulted from the need to find a treatment solution for a high number of people, especially descendants of the Mapuche aboriginals, living in areas with no mental health specialists available. The most common mental health problems of this population, like depression and alcoholism, derive from the feeling of being uprooted, the loss of identity and poverty caused by exploitation, and deprivation of land over successive generations. Before the start of the program, people with mental health problems were regularly transferred over distances of up to 1,200 km to the only mental health hospital in the region. Usually, they never returned to their hometowns.

The core of the chosen mental health strategy was to train communities on mental health and to develop in a common effort new treatment opportunities thereby empowering communities to deal with daily mental health problems without professional help. For this purpose, “mental health teams”, made up of a psychiatrist, a psychologist, a social worker or a nurse, and some alcoholic patients in the process of recovery, regularly travelled to communities and organized community meetings on mental health outside the hospitals involving users, families, hospital staff, neighbours, police, justice, church, municipality, etc. The topics of the meetings included crisis intervention, the understanding of mental illness, the use of individual and collective resources, and the need for social and economical support in terms of food, drugs, work and housing, etc.

Later on, all medical and non-medical hospital staff was trained in behavioural therapy, psycho-pharmacological management and psycho-social interventions. Follow-up visits and phone consultations completed the intervention.

Many of the newly developed treatment practices were later transferred to larger town hospitals, e.g., new mental health teams were created, patients were treated in common medical wards, outpatient centres were established and interaction with community institutions was started. The mental health teams also collaborated with 20 local hospitals to identify local priority needs in mental health, and the necessary means to face them. Over the seven years of the program, it was possible to treat 85% of the psychiatric patients without the need of hospitalization. In some towns, the community assembly even remained as a resource later used to face critical community situations such as floods.

This strategy was later transferred to urban populations with the identical purpose: to create capacities at the local level, to facilitate the mental health treatment of people in their own environment and with their own resources, and to avoid referrals to hospitals. This process generated great enthusiasm and motivation within the mental health staff. Finally, the mental health professionals themselves decided that the mental hospital was no longer necessary.

After expressing his gratitude for the invitation, **David Sallah** presented the program “Community Mental Health – building capacity and capability within migrant (BME) communities in England” by the UK Department of Health. In order to engage the community, 80 community groups and NGOs are provided with about 20,000 pounds each to focus their activities on the topic. In addition, around 500 community development workers have been recruited and trained in community mental health.

While hospital admission rates for minority groups are much higher than in the average population, referrals generally occur more often by police, courts and social services and less often by general practitioners.

Black patients (Black African, Black Caribbean, and Black Other) and mixed heritage service users are significantly likely to have higher detention rates and a less favourable experience of in-patient care based on stated perceptions of not being involved in treatment decisions, and being treated less favourably by nurses and psychiatrists - discriminated against on the grounds of race or religious belief.

Therefore, many activities of the program aim to deliver race equality in mental healthcare in the UK by increasing access, treatment outcomes and satisfaction for minority groups. With this objective in mind, unemployed community members are

recruited, trained as 'community researchers' and asked to investigate community concerns, focusing on needs.

## Discussion

Following the presentations, the discussion centered around the understanding of community mental health care. While there was a wide consensus that one should not confuse community mental health care with conventional psychiatric services in the community, it became obvious that the Forum needs a discussion on and a clarification of the model of community mental health care. As one speaker said: "This meeting over the next two days provides an opportunity for innovation. That innovation is essential to develop the potential of the model of community mental health".

Several commentators pointed out the need to encompass the issues of prevention, promotion and development.

While a few professional mental health specialists responded to this challenge by giving examples of mental health activities that relate to mental health promotion and prevention, one user group representative underlined his wish "to explore an alternative mind set of mental health, to think outside the box and to change the paradigm".

Another user representative pointed out that "people who had a psychosis usually have very good insight into their experience and they should therefore be listened to." This was supported by the comment of a psychiatrist who emphasized the need for doctors to unlearn medical knowledge and to learn from the users instead, thereby bridging the imminent divide.

Relating to a call for scientific evidence for community mental health, one speaker mentioned that evidence must first of all come from the people, thereby emphasizing the notion of self-help. Other commentators pointed out the need for self-help groups in clear distinction to the psychiatric system. User groups have the potential to influence policy decisions in order to move from the bio-medical to a participatory, psycho-social approach that also integrates the socio-economic aspects of mental health care.

While one family representative wants to see educational activities in schools in order to address the societal stigmatization and discrimination of service users, one "user/survivor" pointed out that mental illness is attributed to 'losers' in this society, which follows the general exclusion mechanisms in highly competitive societies.

Other service users expressed the concern that psychotropic drugs would be used in developing countries like in the western world and recommended the exploration of the spiritual aspects of psychosis.

In the following, the Forum talked about the financing of mental health services. In a first attempt, the question "why goes all the money to mental health hospitals and not to community mental health centres" was answered with "I feel that psychiatrists are afraid of losing their power". Other commentators raised the issue of sponsoring by drug companies.

The following five reasons were given to explain why most of the money goes to mental hospitals:

- Stigma and Discrimination
- Psychiatrists feel more comfortable in the working environment of a hospital
- Economic interests of the pharmaceutical industry
- Universities concentrate on clinical training and a bio-medical approach
- New and innovative approaches to treatment and rehabilitation are needed in order to allow people to choose between different options

In closing the morning meeting, the chair appealed once again to the Forum not to indulge in concepts of the 'enemy' but to develop solid alternatives in mental health care, to identify best practices and to promote community mental health care in the world.

## **Session 2: "COMMUNITY MENTAL HEALTH SERVICES WITHIN THE CONTEXT OF COMMUNITY DEVELOPMENT"**

Chair: Angelo Barbato

This session intended to explore the practice of community mental health services within overall community development. Comments focused on experiences from across the world concerning the successes and failures of positioning community mental health services within community development efforts.

Lead comments:

Chris Underhill (10 minutes)

Michelle Funk (10 minutes)

Comments: 5 minutes each

- Mahesan Ganesan
- Sylvester Katantoka
- Shadi Jaber
- Achmat Moosa Sali
- Dan Taylor

In the preface to the second session of the day, Chair **Angelo Barbato** advocated for a holistic approach to mental health care: "There is a strong link between mental health development and community development. Every initiative in community mental health only makes sense within a wider approach to community development." He therefore sees the urgent need to address the economic exclusion and human rights violations of **all** community members.

"When you think about community mental health and development, the first thing you should do is to talk to the people who are seeking development ... The best practice of community mental health always links mental health development with community development."

With these opening words, **Christopher Underhill** emphasized his strong advocacy for a serious participatory approach to health within inclusive programs that place mentally ill people into the mainstream of development.

According to C. Underhill, people with mental disorders usually express two major needs: firstly, they look for equitable access to treatment on their own terms and where they most need it, e.g. treatment by traditional healers, access to conventional psychiatry, access to alternative forms of mental health care, etc.

Secondly, they look for ways and capacities to get back to life, to realize their basic needs e.g. by training, income generation programs, etc. and to exercise their basic rights.

Consequently, Basic Needs programs try to mainstream mentally ill people into the economic development sector. Skill development programmes and user groups help to develop self-help capacities on the individual and on the community level. Users and primary carers are integrated from the very beginning and all program components are carried out in close consultation with the beneficiaries. Correspondingly, research is seen as a learning opportunity on how the program affects the lives of people. From the very beginning of every intervention, consultation groups help to extract the issues that are important to people.

As of December 2006, Basic Needs has implemented programs with 41,251 participants thus demonstrating the possibility to work in volume in the community without the need of conventional mental hospitals.

As the next speaker, **Michelle Funk** was invited to share some of her experience in community mental health development in Gambia. With 83% of the population living on under 2\$US a day, Gambia is a country with severe economic problems. While approximately 118,000 people in Gambia are affected by mental disorders, mental health services in the country are very limited and the treatment gap for mental disorders is almost 90 %.

This pilot project in Gambia, developed in close cooperation with the Ministry of Health and a number of NGOs is of special importance for all societies where people rely heavily on the assistance of traditional healers. In a country with deeply rooted traditional beliefs regarding mental health, this project aimed to support traditional healers to provide treatment and care of people with mental illness and to reduce human rights violations related to traditional treating practices just like the conventional mental hospital.

The primary objective of the project was the training of traditional healers in mental health practices. Four traditional healers were trained in a culturally sensitive way to promote the use of medications in treating epilepsy. Due to the dramatic improvements in patient's conditions, traditional beliefs were challenged and the program was extended to patients with psychosis.

On the basis of this success, the program has been up-scaled and new program components have been introduced: health workers have been trained to support and supervise traditional healers, and traditional healers have been instructed how to set up small scale farming activities. In addition, a number of NGOs supported small scale farming activities thereby empowering people with mental disabilities to contribute to the household economy.

Today, 300 people have been treated through the program, the majority of them now living and working independently in the community.

In the future, M. Funk expects the program to reduce the treatment gap from 90% to 45%, to reduce human rights violations, to improve the nutritional status and to increase ownership and socio-economic inclusion of the program beneficiaries.

In the remaining presentation of this session, **Mahesan Ganesan** described his efforts in establishing a holistic, multi-sectoral mental health program for people in Sri Lanka: a consumer organization was founded, vocational training of consumers and other community members was carried out, a micro-credit program was initiated and small business programs were set up. Unfortunately, it has not been able to persuade other development organizations, e.g., local and international NGOs, UN-Organisations, etc. to integrate this successful initiative for mental health in their programs.

M. Ganesan expressed his regret that in general, and despite the successful cooperation in singular cases, mental health activities are still not sufficiently integrated in the diverse aid programs of development organizations. Finally, he suggested a discourse on the root causes for this situation.

Subsequently, **Sylvester Katantoka** described how the launch of the African decade with its focus on social inclusion, full participation, rehabilitation and poverty eradication among people with disabilities, was an opportunity for consumer groups to impact on government mental health policies. He then pointed out the community-based character of mental health care before the time of colonialism and the role of western psychiatry as an instrument of control that separated community development from mental health care. Finally, he addressed the unsustainable and inhuman conditions in the only mental hospital in Zambia as well as the lack of funding for mental health services in general.

His consumer organization lobbies for a community-based, human-rights based approach to mental health care. It wants to de-institutionalize psychiatry and bring mental health care back into the community. Finally, he expressed his hope that more funds will be allocated to community mental health care if it placed in the context of community development. In addition, he believes, that the societal commitment for mental health will increase once mental health is seen from a community development point of view. Last but not least, he underlined, that the community has an important function in monitoring official mental health care programs and in preventing mental health problems to the benefit of the society in general.

Before introducing the next speaker, Angelo Barbato referred to S. Katantoka's reference to human rights violations in mental hospitals in Africa by reminding the audience that inhuman treatment methods, e.g. ECT or psychosurgery, had been introduced between the 20s and 30s of the last century in countries like Italy, Portugal and Hungary which at that time were ruled by dictators.

Thereupon, **Shadi Jaber** described his work in a family and user association under the very difficult current circumstances in Palestine. In a society characterised by war and socio-economic hardship, it is not surprising that a sense of hopelessness and reactive psychological disorders are common problems. Therefore, a family and user association has been founded four years ago in order to build trust between families, users and

mental health workers striving for a common effort to develop new mental health services. In this process, new individual and collective resources emerged and self-help capacities were strengthened, e.g. family members and users started to speak about their pain, committees of family members were founded in each district, etc.

Although it has not yet agreed upon clear goals for the future, Shadi Jaber sees an obvious need to work on the issues of stigma and discrimination, to cooperate with traditional healers and to lobby for mental health services in the ministries. Finally, he pictured a vision of a new community mental health movement in Palestine: “it is the first time in Palestine, that users and families speak about their experience ... we are now in the process of establishing the necessary NGOs to care for families and users in Palestine.”

Angelo Barbato then introduced **Achmat Moosa Sali** from Cape Town, South Africa. As Co-Chair of the user organisation WNUSP, A. M. Sali initiated his comments by positioning himself and his organisation in favour of de-institutionalization and community based support. On behalf of his organization, he strongly disagrees with any interventions which are coercive and invasive, and which are implemented within an authoritarian framework. He demands the legitimacy of users’ rights and the legal capacity for self-reliance as it is encapsulated within the UN Convention on the Rights of Persons with Disabilities (CPRD). A.M. Sali made a call to all mental health service users/survivors to “act on your own” and to establish user /survivor-run initiatives. After giving some successful examples of self-run user initiatives like the RSMH in Sweden, self help groups in Uganda or the Runaway House in Berlin, he once again pointed out, that these self-help initiatives should not be confused with MH services. He also emphasized that people with MH problems or psychosocial disabilities should have the right to fully participate in society and to get access to support of their choice, especially psychotherapy and alternative support services in the community. In this, access to treatment and medication should be assured although it is **not** the dominant aspect in recovery. Equal support should be given to both user/survivor run projects and state run MH services. All mental initiatives should be guided by the principles of free choice, partnership and inclusion and a focus on hope and recovery rather than on the existing pathology paradigm of the medical model.

In the following, **Dan Taylor** identified community mental health services as an integral part of the mental health system in Ghana. His user organisation MindFreedom is actively engaged in counselling activities within the communities. Only in very rare situations, additional outpatient services by psychologists at the mental hospital have to be provided. In addition, MindFreedom supports families and carers of people with mental disorders and gives advice on support strategies, rehabilitation and reintegration into society. Awareness campaigns about domestic violence make up another focus of the work by MindFreedom. D. Taylor then expressed his strong belief, that community mental health is closely interacted with community development. Finally, he appealed to national-governmental and all other donor agencies to allocate financial resources and to ensure logistics in order to strengthen community mental health care.

## Discussion

Most of the group discussion focused on the relationship and the possible level of

cooperation between service users and mental health professionals. In general, there was a strong agreement by all Forum participants that cooperation should be actively sought out in order to take on the huge global challenge of establishing community mental health care services.

However, the relationship between service users and mental health professionals has been discussed extensively and possible obstacles for this cooperation have been identified. While traumatic experiences by service users/survivors of the conventional psychiatric system can lead to anger and the refusal of any cooperation, on the side of the conventional psychiatric system, interests of power, traditional hierarchies and the fear of accusation lead to the rejection of cooperation.

Nevertheless, both groups, service users and mental health professionals, are fairly heterogeneous, e.g., some user groups are even sponsored by drug companies. Therefore, one should be aware of simplifications.

Despite these identified obstacles, most participants at the Forum expressed their good intentions to establish new bonds of trust. In this process, mental health professionals will have to listen to the voices of service users, and the service user movement will have the responsibility to help the mental health professionals in developing a new understanding of mental health care. As one participant pointed out, community mental health care on the grassroots level is a long and exhausting task, only to be managed in a common effort.

Community mental health services will have to address the basic needs of service users like housing and employment. In addition, families will have to be integrated in providing community mental health services. Last but not least, mental health care will have to be mainstreamed in public health care just like in society in general.

Despite of all these differences, there seem to be sufficient common grounds on which to build up a global community mental health movement.

### **Session 3: “ENSURING SUPPORT FROM PARTNERS”**

Chair: John Jenkins

This session intended to share information on the vital question of partnerships for community mental health. The comments focused on the experiences in a variety of diverse settings in building usual as well as unusual partnerships.

Lead comments: John Mahoney (10 minutes)

Comments: 5 minutes each

- Mervyn Morris
- Begoñe Ariño
- Mitchell Weiss
- Yvonne Bonner
- Jeya Wilson

Introducing the following session, **John Jenkins** pointed out that community mental health care should be seen through a community development perspective rather than as an extra category of services: “When you start thinking that the Mental Health System should become a Community Health System then we are thinking from the wrong angle,

the wrong perspective. [...] What we should be doing is talking about the citizen rights of people” Being labeled as a mental health patient per se can lead to stigmatisation and discrimination and the loss of basic civil rights.

In his leading comment for this session, **John Mahoney**, Department of Health, England, talked about his efforts to de-institutionalize psychiatric care in resource poor countries. After reflecting on the individual and collective consequences of institutional psychiatric care for human beings, he emphasized the need to provide mental health care in a culturally adapted approach and within the community. High suicide rates and widespread domestic violence show the need for community based mental health care. Although other UN agencies have started to move into the working field of mental health, WHO country offices should take on a major responsibility in promoting and planning mental health services. However, major obstacles like low economic resources, lack of professional staff and poor infrastructure often hinder the implementation of community mental health services.

J. Mahoney then stressed his view, that ordinary people should play a major role in community mental health care. Relating to his work in Sri Lanka, where a psychosocial workforce has been recruited, he pointed out the values of non-professional mental health workers who often bring along the right personal qualities, such as the right attitude towards people with mental health problems, empathy and the ability to provide practical help in daily living problems.

J. Mahoney then emphasized that job training and employment opportunities, as provided exemplarily by “Basic Needs”, must be at the core of all mental health care interventions. Furthermore, he expressed his gratitude for the social welfare provided by the Sri Lankan government to long-term mental health patients. Finally, he stressed the importance of housing for people with mental health problems.

Most importantly, according to J. Mahoney, good and trusting relationships form the basis of mental well-being and should be at the core of community mental health care.

**Mervyn Morris**, Centre for Community Mental Health/University of Central England, Birmingham, presented his experiences in partnering with service users in service provision, research and education. He differentiates between three levels of partnership with service users:

1. “Idea of Consultation”: Creating dialogue, getting to understand where people are coming from and where they hope to go.
2. “Idea of Collaboration”: Identifying common aims and finding the means to support service users.
3. “Idea of Control”: Creating situations where service users can take control of the activities that they are involved in, e.g., in education, research, etc.

This collaborative approach has been demonstrated exemplarily by a NGO providing for some years a crisis house for people with severe “mental health problems” (using these words with caution). Due to the employment of former service users as staff, the service had very positive performance outcomes: over a time period of eight years there was not one single serious, negative event. According to M. Morris, this was a good example of giving people the opportunity to provide help and to simultaneously take on responsibility over their own lives.

Subsequently, M. Morris pointed out the emerging discussion about user experiences, especially about issues surrounding recovery. M. Morris expressed his belief that the dialogue with service users is going to change the way we all think about mental health. For instance, commonly used words like “schizophrenia” or “hallucinations” have already become radically challenged by the way service users talk about their own experiences. Equally, the research by Robin Pajmans shows that users do not experience “hallucinations” as isolated incidents but in relation to their life experiences. Already, a variety of alternative coping strategies have been developed through this research.

Subsequently, **Begoña Ariño** gave insight in her work for families with relatives affected by mental illness. According to her experiences, the effort to ensure support from families is hindered by the following barriers:

- The current bio-medical model of mental health focusing on clinical symptoms
- A lack of a holistic approach to mental health
- Insufficient re-education programs
- Insufficient assessment of families needs
- Insufficient physical health care programs
- Lack of informations to families
- Lack of User and Family Rights
- Lack of opportunities to influence mental health care for families
- Lack of effective, integrated mental health strategies

B. Ariño demanded to listen to and to involve all stakeholders, to provide care to families and to look for partnerships in mental health care. She also expressed her gratitude for the WHO Manual of Resources, Human Rights and Legislation, which she regards as a very positive tool when lobbying community mental health care for governments.

In the following, B. Ariño presented some examples of good practice including the work of “Slovenia Eufora”, a member organization of the European Federation of Family Associations. Having been involved in mental health policy development, “Slovenia Eufora” managed to include the mutual training model “PROSPECT” into the mental health plan. She then gave another example of “good practice” and collaboration by pointing out that the Spanish mental health strategy has been elaborated in a partnership between the Ministry of Health, regional authorities, research institutions and family associations. According to B. Ariño, this approach reflects the Spanish Health Ministry’s commitment to the principles of the Helsinki Declaration.

In the third comment of this session, **Mitchell Weiss** from Switzerland, took up the word to formulate some lessons to keep in mind when we look at mental health care:

### *1. Revitalize “social” in the biopsychosocial model of mental illness*

M. Weiss pointed out that because of its explicit concerns with emotional experience and social context, mental health should be among the most interdisciplinary and transdisciplinary areas of public health. But to the embarrassment of the field of psychiatry it is not. He therefore expects the Forum to correct an imbalance that is rather a paradox: Psychiatry should be the clinical discipline most concerned with emotional

and social factors instead of relying so heavily on biological models of achieving mental health. The literature of psychiatry all too often focuses less on social determinants than, for example, infectious disease control for malaria, TB, HIV/AIDS, and neglected tropical diseases; these fields, which are clearly concerned with biological infections, have become more concerned with the role of poverty and vulnerability, recognising them as essential features of disease control and health status.

## *2. Importance of intersectoral aspects of development*

According to M. Weiss, another area that is of interest for international agencies is the question of vulnerability as it has been defined by questions of poverty, the lack of jobs, livelihood opportunities, the experience of victimization and various other features of vulnerability that concern community mental health. The health impact of the social stressors arising from underdevelopment shows they are social determinants of the effectiveness of treatment and community action that affects illness prevention and mental health promotion.

With reference to the impact of poverty, security, and other social determinants of mental health and illness, some programmes are addressing needs for housing and employment opportunities, as the example of a programme in Colorado suggests. Mental health planning, however, should lead rather than lag in balancing biological interests with social and psychological features of interventions and community action.

With these points in mind, M. Weiss asks for greater emphasis on intersectoral community development planning to complement clinical treatment services. Clear links with the interests of women's groups, farmers' groups, urban planning activities and other aspects of development should be identified and exploited more effectively to construct new models to improve the mental health of populations.

## *3. Experience in a mental health program in the Sundarban region of West Bengal, India, initiated by the Institute of Psychiatry, Kolkata*

In Kolkata, community participation identified the need for mental health services and suicide prevention as program priorities. Suicidal behaviour was studied both to prevent and to identify social determinants of the serious emotional problems associated with suicide and deliberate self-harm. Intersectoral interventions linked local agricultural practices, especially procurement and storage of pesticides to reduce impulsive suicidal behaviour, and improving treatment of pesticide poisoning, mental health services, and community support activities.

## *4. Engaging various partners with complementary qualifications and roles*

M. Weiss then emphasised that the particular roles and ways of engaging participation of various partners in community health need to be worked out, recognizing the complementary contributions of doctors, nurses, and community health workers; community leaders; persons with mental health problems; and development organisations (including NGOs, government agencies, and international agencies). According to M. Weiss, clarifying the setting-specific contributions of each is an essential

task for community mental health.

**Yvonne Bonner** from Italy initiated her comment with the statement that she would like to change the title of this session into “ensuring support to partners”. For her, the basic question is: who ensures support to whom?

According to Y. Bonner, the look into the history of psychiatry shows that the first step must be to close mental hospitals. The second step must then be to develop community mental health services. But most importantly, the third step must be to then realize that mental health is a cultural problem.

Y. Bonner also emphasized the need not only to talk about community mental health but to act on the grass root level and to focus on the many examples of “best practices” that are already used effectively.

Furthermore, she underlined the importance of partnerships, e.g. between schools and families, in order to develop a new understanding of mental health. Within these partnerships, people have to be able to stand differences in opinions and experiences. They have to acknowledge the complexity of the working field in order to discover the strengths of a care system that is based on difference.

Networks need to remain flexible. Power-relationships have to be altered and service users and families have to become experts, provide crisis intervention and give trainings.

In the last comment of this session, **Jeya Wilson** elaborated on the vision of CBM and the purpose of global alliances. J. Wilson described how CBM clarified its vision on the occasion of its 100<sup>th</sup> birthday. Since then CBM focused on the development of partnerships in order to reach a wider target group than just those people with visible disability. “Vision 2020”, the global joint initiative by WHO, the International Agency for the Prevention of Blindness (IAPB), the World Blind Union (WBU) and ICBM aiming to eliminate avoidable blindness by the year 2020, became a role model in CBM’s search for alliances in the areas of physical and mental disability.

Today, partnership development is one of the main interests of CBM. CBM’s approach is characterized by community development and education; this includes health education, livelihood development, empowerment as well as social aspects such as legal protection, culture, sports and leisure, etc. In addition, awareness raising activities, capacity building, networking and lobbying are at the core of CBM’s vision. Furthermore, advocacy remains a dominating cross-cutting issue.

Finally, J. Wilson addressed the most important elements of global alliances:

- Shared passion
- Personal contacts
- Personal relationships
- Networks
- Patience and Perseverance
- TRUST

## **Discussion**

The discussion focussed on the role of pharmaceutical industries in international mental health. A number of speakers emphasized that the focus of community mental health care is not on medical treatment. In fact, the more you move away from psychiatry to community mental health care, the less important psychotropic drugs become. Pharmaceutical companies tend to medicalize human suffering by shifting the view of mental health from a psycho-social to a biomedical perspective. Most of the research on mental health is funded by pharmaceutical companies and therefore biased. Collaboration with the pharmaceutical industry would therefore be devastating for a mental health movement intending to open an alternative discourse on mental health.

While one commentator objected to the use of psychotropic drugs as a matter of principle, other commentators asked to ensure access to drugs. Yet, access to treatment is only one component of a wider developmental approach that seeks to empower people, e.g., to make self-determined decisions about their own therapeutic strategies. Several speakers asked for new and critical partnerships with religious organizations, volunteers, researchers, media and, most importantly, between service providers and users.

Other comments of the discussion included the need to consider international mechanisms of service delivery, to question in principle the medical understanding of mental health, to clarify our definition of community mental health and to develop a new language when we talk about mental health.

Last but not least, the demand for more humanity in mental health care appeared to be another cross-cutting issue during the discussion.

#### **Session 4: EXPERIENCES FROM ACROSS THE WORLD – I**

Chairs: Chris Underhill and Benedetto Saraceno

Session 4 and 5 are intended to provide a forum for sharing experiences from across the world on initiatives for establishing or strengthening community mental health services.

Lead Comments: 10 minutes each

- Iyad Al Azzeh
- Tom Barrett
- Claudina Cayetano
- Birgit Radtke
- Pandu Setiawan
- Dejan Stevanovic

After welcoming all participants to the second day of the meeting, Chris Underhill presented the speakers for the following session. He then invited **Iyad Al Azzeh** from the West Bank to open the comments of this next session.

**Iyad Al Azzeh** initiated his comment by giving us a picture of the devastating social and economic conditions in the West Bank. Violence, destruction of resources, roadblocks and curfews have led to deteriorating economic conditions. Although plans for community mental health services have been developed, mental health service provision in the community remains to be more than fragmented. Currently, there are practically no mental health outreach services in most areas. "The socio-economic

situation is so devastating that mental health services are collapsing ... there are no human rights organisations and there is no mental health training for doctors or the police". Trauma, loss, and humiliation – experiences that are part of the conflict – are risk factors for mental disorders that should be treated in the community. Yet, most financial resources go to the hospital in Bethlehem. Therefore, Iyad Al Azzeh sees a desperate need for day treatment centres and community based mental health services. Last but not least, he pointed out the lack of professional mental health staff as another major bottleneck to developing adequate mental health care services.

In a second comment of the session, **Tom Barrett** presented the transformation of the U.S. mental health system from institutionalized, hospital based mental health care to a community based mental health approach. Accordingly, state mental health agency controlled expenditures for state psychiatric hospital inpatient care has gone down dramatically from 63% of all expenditures in 1981 to 28% in 2004. In 2005, from the 5.9 million consumers who received state mental health agency services, only 3% of clients received services in state psychiatric hospitals. Simultaneously, more than 95% (5.3 million persons) of consumers were served in community mental health programs (54 states reporting). 7% of clients received inpatient services from settings other than state hospitals. From 1970 to 2002 the number of psychiatric beds in state hospitals went down from over 400000 to a bit over 50000 beds while there was only a slight increase of mental health beds in private psychiatric hospitals and general hospitals. Only the VA psychiatric services had a sharp increase of psychiatric beds during the 90s. While in 1970 one out of three hospital beds was a psychiatric bed, in 2002 "only" one of every 7 beds remained to be reserved for psychiatric patients.

While Tom Barrett sees great value in reducing hospital based care, he emphasizes the need to provide simultaneously alternative mental health care services. According to T. Barrett, the U.S. experience shows that often enough former consumers end up in prison if no alternative mental health care service is offered. He therefore emphasizes the need to provide sufficient resources in order to establish satisfactory community mental health services. Other lessons learnt include the need to build new partnerships in community mental health care and to respond to housing and employment needs of consumers.

As the only representative from Central America, **Claudina Cayetano** from Belize presented her rich experience in the community mental health system in Belize. In Belize, the mental health system is entirely publicly funded and has a strong focus on community mental health care. The country is divided into four health regions. Currently there is a total of seven general public hospitals; two in each region, with the exception of one region which has one public hospital, the national referral hospital, and the only psychiatric hospital in the country. Only one of the district hospitals has an acute psychiatric unit integrated into the general hospital. The psychiatric hospital, which is located in the Central Region, has patients with at least five continuous years of admission, long time patients occupy 40 of the existing 52 beds. The mental health outpatient services include home visits, mental health care in mobile clinics, prison visits, school consultations, counseling to the children's home and consultations for elderly people in some communities. The goal of the program is to decrease hospital admissions. The number of people reached by this program increased from 929 per year in 1999 to 14556 patients per year in 2006.

Community mental care services in Belize integrate the use of multidisciplinary team (district health teams), prevention activities early detection and treatment continuity of care, empowerment of consumer groups, partnerships with the medical community and emergency management.

Last but not least, community mental health in Belize aims to stop the exclusion of people with mental disorders and to make mental health care and prevention to everybody's business.

As the next speaker of the session, **Birgit Radtke** presented her working experience in community mental health care in the wider context of a community based rehabilitation programme conducted by CBM in Peru. Although CBM originally focused on people with disabilities and the community development work in 60 rural indigenous communities in the provinces of Puno and Cuzco, it has now identified the urgent need for the prevention of mental illness and the promotion of MH care. Unfortunately, there is a high level of domestic violence, alcohol abuse and physical and sexual violence against children. Reasons for this situation can be found in centuries of oppression, racism, armed conflicts, structural violence and extreme poverty, the loss of land, soil erosion and the disruption of families by internal migration.

The program tries to ensure comprehensive community mental health care and drug supply for people with epilepsy or severe mental health problems. Strategies of community mental health care include networking with PHC centres, training of health workers, the provision of psychotropic and antiepileptic drugs, the formation of self-help groups, networking with NGOs and awareness raising strategies in order to reduce stigma and discrimination. Agricultural activities and income generation programmes are at the core of the intervention.

Positive outcomes of the intervention include increased supply with antiepileptic drugs and a higher quality of life for many people with epilepsy. In addition, new partnerships with the PHC system could be established. Major challenges remain in changing attitudes and practice towards mental health, in improving the socio-economic conditions of communities, and in empowering people with mental health problems.

In the following comment, **G. Pandu Setiawan** started with an overview of mental health care in Indonesia since the end of the 19<sup>th</sup> century. As early as in 1978, a community mental health program was set up in all Mental Hospitals in the country aiming for the "Integration of MH into Primary Health Care and District General Hospitals". Out patient services were provided in Primary Health Care Centers as well as in the District General Hospitals. In addition, mental health care training has been carried out in both facilities. Unfortunately, this program didnt prove to be sustainable due to budget constraints. In 1981, the Minister of Home Affairs made an instruction to all Governors and Bupati-Mayors (Head of Districts) to develop a "Coordination Body for Community Mental Health Development".

In 1999, a major governemental change for more decentralization also changed the power structure in all other sectors. From 35 Public Mental Hospital only 5 remained under the direct supervision of the MOH. All general hospitals were now under control of the local Government either on provincial or on district level.

Subsequently, Primary Health Care was reduced from 17 to only 6 programs, excluding the MH programs. Furthermore, the Directorate of MH was changed to Directorate of Community Mental Health. However, from 1999 'till 2005 it didn't have any formal relationship with all Mental Hospitals. Consequently, the reporting system of MH activities through out Indonesia collapsed and remains to be inefficient until today.

In the aftermath of the tsunami in 2004 in Aceh and the devastating earthquake in Yogyakarta it had to be realized that:

1. There was now good MH care delivery system
2. Mental Hospitals as the backbone of services were almost paralyzed
3. Community MH activities were almost non-existent

Today, the MOH of Indonesia aims to review all aspects of the Indonesian MH Care system in order to develop a "new" model of mental health care integrating the training of CMHN (Community Mental Health Nurse) and Community leaders, capacity building in Mental Hospitals and the installation of "Medical Officers in Mental Health" at the district level.

In addition, strong educational efforts are made to increase the quality of mental health care services. Last but not least, promotion, prevention and rehabilitation activities are reviewed and reconceptualized.

All activities are based on the strong cooperation between the Ministry of Health, the Ministry Of Education, NGOs, family, consumers and carer association and the professional mental health staff.

Due to these promising activities, positive results are expected in the next few years for the benefit of all in Indonesia.

As final speaker of the session, **Dejan Stevanovic** presented his working experience in the usernetwork WAPR in Macedonia.

In his speech he outlined his vision and ideas for mental health promotion in southeast Europe. Since September 2006 he has worked on a webportal for mental health as an effective tool for health promotion. The Portal aims to gather data on mental health and to advocate and promote comprehensive community mental health care. Target groups are all actors working in the area of mental health in Macedonia, e.g. policy makers, users, professionals, etc. Main goal of his promotion strategy is to inform users of psychiatric services on communication strategies with the involved actors in the area for Mental Health and to inform institutions, policy makers, medical staff and professionals on how to increase the quality of their provided services by world standards. It offers information material, such as manuals and other helpful documents and tools published by experts and institutions (i.e. WHO), gives essential information on the work of the NGO APR and follows matters relating to mental health in the media, e.g. the reform process of the psychiatric system.

Advantages of this media approach to mental health promotion can be found in the possibility for all stakeholders to post their essays, stories, ideas, messages, study works etc. and to create an idea exchange community on a global level.

In addition, a regular newsletter is published and innovative tools (idea exchange media) are offered in order to facilitate the exchange of ideas by global experts, users and activists in the area of Mental Health.

Finally, D. Stevanovic invited all listeners to visit the website of WAPR promoting the Global Forum of Community Mental Health. He then closed his speech by appealing to the audience to involve users and ask for their advice in planning community mental health services.

## Discussion

Following the presentations of the speakers, the discussion focused around the integration of mental health care services within existing primary health care systems.

While examples like Iran show the advantages of integrating mental health care within existing primary health care systems in rural areas, this approach is usually not successful in large urban areas, where people with mental disorders are still directly transferred to mental hospitals.

In addition, primary health care services tend to focus on patients with minor mental disorders leaving the severely affected people behind. Often enough this is due to insufficient cooperation between community mental health services and the existing primary health care system.

The vision of primary health care services that implement effective community mental health care backed up by a second level of mental health care services was described. In reference to this comment a number of speakers delivered insight in their experience of linking primary and secondary mental health services. Successful examples include the case of Indonesia, where PHC staff is trained in mental health care, while, on the secondary level, a team of mental health professionals and a small number of mental health beds have been installed in district hospitals. However, special attention is still given to the psycho-social aspects of mental health care, e.g. the social and financial problems of user families, the necessary integration of community leaders in mental health care, etc.

Correspondingly, in Sri Lanka, PHC staff was trained in mental health care and professional mental health staff held monthly conferences in the regional primary health care centres (MOH) in order to consult with patients and to train families and health workers in mental health issues. In addition, community support officers, dedicated exclusively to mental health, supported the PHC staff in case detection, rehabilitation and family support.

While one speaker raised the question of how to sensitize people to mental health issues and how to motivate staff to get training in mental health care, other speakers addressed the problem of lacking professional Indian staff due to job migration to other countries.

Referring to the insufficient mental health care for illegalized migrants in Italy, another commentator pointed out the exclusion of some target groups from primary public health care due to political interests. Therefore, services that run parallel to the public health care system might sometimes be necessary in order to ensure health care for marginalized groups.

Other comments addressed the diametrically opposed mental health strategies by the World Bank and the need to build lasting networks between the participants of this Forum.

In his closing remark of the session, the chair thanked all commentators for their useful presentations and the way in which they brought the personal and the professional view

together.

## **Session 5: EXPERIENCES FROM ACROSS THE WORLD – II**

Chairs: Francisco Torres Gonzales and José Bertolote

Lead comments: 10 minutes each

- Tobias Chelechele
- Eliezer Mdakilwa
- Christina George
- Abdul Abu Bakar
- Chee Ng
- Andrew Mohanraj

In his introductory remarks, **Francisco Torres Gonzales** pointed out the often misleading and contradictory findings of mental health research. As an example, he cited his study of eight regional mental health services in Chile. Four were based on hospital based care and the other four were community based and with a small psychiatric unit within the community. In fact, one of these four services had no beds at all. The objective was to compare the outcome of severe mentally ill patients treated in the mental hospital as opposed to the community-based care. The findings of this study first implicated that the quality of life of the patients was worse in the community based services. Patients treated by the community mental health teams seemed to be worse, clinically, than those treated by the conventional psychiatric service.

First, the researchers had no sufficient explanation for these findings, but finally, it was found out that the research results were biased since more than 50% of the patients who were treated in mental hospitals had abandoned treatment. In comparison, only 2% of the patients treated by community based services had stopped treatment.

In the first lead comment of this session, **Tobias Chelechele** from Tanzania, started with the story of a schizophrenic boy named Ramadhani who was mentally disabled for seven years. He was socially excluded and lived with his mother. His condition had resulted in his parents divorce and his mother had to work to support the family as well as take care of him. His mother had sold half of her coconut farm in order to raise money to help him. More than 10 traditional healers treated him but there was no progress. Unfortunately, the only hospital was far away and too expensive to visit.

After some time, his mother took him to a community based mental health meeting, organized by Basic Needs, that offered treatment nearby, only a five minute walk from their house. Ramadhani was now able to access proper care and his condition improved dramatically. Today, he has a good job in a security company, supports his mother, and he and his mother now have a much better quality of life. He has trust within the community and is a good example for others.

After this introduction, T. Chelechele described the overall progress in Tanzania regarding to mental health care. Recently, one hundred fifty primary caregivers were trained. In Dar Es Salaam, between 2005 and 2007, the number of people who accessed mental health treatment rose from 201 to 972. Almost half of these people

are doing productive work, and 111 mentally ill people now contribute to the livelihood of their households. Still, there are only six professional psychiatrists in the country. He also stated that there are more mentally ill people than previously thought. There are approximately 2,500,000 mentally ill people in a country of 36 million inhabitants. These people are stigmatized socially and professionally, do not have a legitimate voice, need a more consistent drug supply, as well as more primary caregivers. T. Chelechele appeals for help and advice regarding ways to manage these issues.

The second speaker, **Eliezer Mdakilwa** introduced the work of the Tanzania Users and Survivors of Psychiatry Organization (TUSPO).

Since 2004, they have tried to mobilize people and provide community awareness campaigns on mental health. TUSPO is especially concerned with the issue of rehabilitation. It promotes the message that mental illness is not only the concern of traditional beliefs but also can be cured by medication and counseling. Instead of relying only on traditional healers, they communicate to the public that there are other options. E. Mdakilwa himself was able to change his lifestyle and improve his situation after speaking with a counselor.

TUSPO advocates for improved out-patient treatment and better access to counseling. In his approach to mental health care, TUSPO promotes activities to foster the individual and collective development in society. The organisation has worked with various partners and supporters (for example from Sweden) to establish income generating activity for people recovering from mental illness. TUSPO's main intention is to re-integrate patients back into their family, society, and into their respective occupations (e. g. carpentry, brickworking, construction, farming, etc.).

In order to facilitate this, TUSPO looks for partnerships with families, community leaders, etc. They work with government authorities and NGOs and seek to help men and women equally. One major aspect of TUSPO's goals is to overcome poverty that makes it even more difficult for people with mental illness to cope. TUSPO not only helps people to obtain sufficient medication but also to battle the stigma associated with mental illness that makes it difficult to mobilize funds and raise support. Like Tobias Chelechele, Eliezer Mdakilwa also hopes to collaborate with supporters from elsewhere in the world.

**Christina George**, psychiatrist from Tamil Nadu in India, then gave us an example of "A Post Disaster Intervention Emerging into a Community Health Program"

C. George spoke about her experiences in mental health outreach programmes supported by CBM after the 2004 tsunami disaster. Prior to the Tsunami, she worked "as a typical ivory tower psychiatrist" within the safe confines of her hospital. She was aware that she was lacking a community approach but did not know how to bridge the gap between the hospital and the community. In her comment, she described many lessons learned over the last three years during her work in community mental health care.

After the tsunami struck she recognized the need for training of mental health community workers. According to C. George, the less professionalized people were, the easier they were to train. Initially the training focused on counseling, emergency mental health, listening skills, and case identification. By now, training also addresses needs assessment and life skills training for children and adults.

The target population of the programme was about 75,000 people spread over 5 villages. In each village, one social worker manages a centre. Each centre also functions as a children's club and a space for caregiver groups. To ensure that their program was in keeping with what the community needed, all health workers cooperated with church leaders and women's groups, who were especially efficient in bringing the community together.

Community outreach programs for mental health, primarily focused on development and livelihood. Monthly sessions provided instruction for basket weaving and others skills in the afternoon, while morning sessions would address mental health issues and, later on, mental illness. These groups have expanded into other closed groups that advocate various aspects of mental health and disease.

Immediately after the tsunami disaster, the community interventions started with home visits, three days a week. This was complemented by a monthly clinic providing counseling using a developmental approach that addressed not only livelihood skills, but a larger context including health promotion, social development, and community empowerment. If necessary, the clinics are complimented by family approved hospital based care. All patients are followed up in the community hospitals and, if necessary, readmitted in the general hospital units for short periods.

The fourth speaker of this session, **Abdul Kadir Abu Baker** from Malaysia reported on the mental health care system in Malaysia, consisting of four mental hospitals and a number of psychiatric units in general hospitals. Since 1996, mental health has been combined with the primary health care system. Nurses, doctors, and health care workers are trained in mental health issues (early detection, early treatment).

Malaysia is a higher middle income country with a highly literate population of 25 million. But the country has a proportionally low public health budget with 2% of this budget spent on mental health, and 77% of this allocated to mental hospitals. There is also a low proportion of psychiatrists, nurses, and social workers to the general population. On the other side, there are 778 centers providing follow-up services and some activities for psychosocial rehabilitation. Recently, a nation wide mental health campaign has provided information on diet, exercise, quitting smoking, and stress management.

In Sarawak province the main mental hospital is complimented by four psychiatric units situated in general hospitals. But, a high rate of readmissions, overcrowding in the acute mental wards, custodial care, and poor outpatient follow up were reasons for a structural change in care. Various steps were taken to improve the acute wards including private and individual rooms, hierarchical care, and no locked doors. To prevent re-admission, patient led rehabilitation, self-help groups, shops, cooperatives, education, and job placement were established. Eventually readmission was reduced by 60% and overcrowding was resolved. Group homes were established for long stay patients.

In rounding up his presentation, A. K. A. Baker showed an image of Hospital Sentos, a newly planned rehabilitation centre, with a chalet and a number of cottages for patients.

The fifth speaker of this session, **Chee Ng** from Australia described his extensive experience in "facilitating community based mental health reform in the Asia Pacific":

Chee Ng spoke about his experiences to engage and support government and institutional policy makers and professionals to bring about changes in community based mental health reform in the Asia Pacific. Over the last 15 - 20 years, there was a dramatic change in the Australian mental health care system. There has been a transformation from predominantly institutional care to community-based structures. For example, in Victoria, there is not a single psychiatric hospital anymore; all hospitals have been replaced by comprehensive community mental health services.

A growing group of organizations is aware of the need for mental health reform. An Australian based consortium, Asia-Australia Mental Health, provides a network of pooled and expanded knowledge between government agencies, NGOs, the corporate sector, and philanthropic foundations. Their approach is to establish high level networks and close working relationships with key decision makers in the region to provide access to leading models of service delivery. This is driven by a strong cross-cultural understanding in order to build and maintain strong inter-sectoral linkages.

For example, in China, mental health care has traditionally been hospital based, with a severe lack of professionals, resulting that a large part of mental health support rests upon family. Building on the longstanding cooperation between Australia and China, the AAMH has worked collaboratively with China to develop a community care delivery project, called 686. This involves 60 demonstration sites, one urban and one rural for each province, with each site covering 400,000 people. The intent is to improve the prevention and treatment of psychosis, with 60,000 users registered. More importantly, it is becoming a human resource for the community-based mental health service model.

An International Advisory Committee was also established that draws on the best expertise from both Australia and China to advise on the development and implementation of the local strategy. This is to ensure timely and useful responses to program needs combined with active participation in the monitoring of the project. Annual meetings bring together representatives for discussion in Beijing.

For this program to work it is recognized that training and capacity building must be based in Asia. To provide delivery to such a large demand, centres of excellence have been built. Partners include Asia-Australia Mental Health, The National Institute of Mental Health at Peking University and the Chinese University of Hong Kong. A tripartite program has been established beginning with the training of mental health professionals followed up by intensive training for key people in the collaborative countries.

According to Chee Ng, a variety of key lessons have arisen. Firstly, it is important to point out that there is no standardised answer. The broad socio-economic and political restraints must be understood for each site. Culture is central: mental health care models cannot simply be translated from culture to culture. They must be established in collaboration with the beliefs, attitudes, and resources of the local context. Timing is everything: it is important to build in flexibility for different entry points and scheduling for health reforms. Achievement must be appreciated and promoted: system strengths must be built upon and successes broadly promoted. Reform needs to embrace and occur at all levels and sectors: beliefs and attitudes must be influenced in partnership.

Intensive mentoring for leaders provides expertise and advice. According to Chee Ng, it is also essential to establish a working and supportive network for these leaders. This is the aim of the Asia-Pacific Community Mental Health Development Plan which was initiated by the WHO. This project addresses practical approaches to community health care in each region. The group is working on a draft for each country to share best practices or alternatively how to generate solutions to problems and gaps.

Finally, the sixth speaker of this session, **Andrew Mohanraj** from Indonesia gave a brief history of his experiences in Aceh after the tsunami with the International Medical Corps during the rescue and emergency phase, and CBM during the rehabilitative and constructive phase. He stated that both of the organizations are examples of best practice among the NGOs. The tsunami of Boxing Day, 2004, killed 130,000 in a very short time, destroying much of the social and family structure of the area. There were no primary or secondary mental health facilities in this area and only one tertiary hospital. There were only three psychiatrists in the whole of Aceh, located in the capital. In his presentation, A. Mohanraj explored whether the tsunami brought in a positive legacy to Aceh. He feels that it did. There was an influx of NGOs and United Nations agencies and although there was a lot of confusion at the beginning, the situation seems to be stabilizing.

A. Mohanraj then described the IMC three prong strategy of offering psycho-social support, clinical services, and an outreach program in cooperation with traditional healers. He mentioned also that the IMC assisted the people of Aceh with mourning, a very important tradition for Islamic people. In Aceh there were large pits dug where bodies were deposited and covered without funeral. Mohanraj stated during his comment that this was extremely upsetting for these communities. The IMC built simple structures, called 'quiet houses', at the various burial spots, which enabled the relatives and the local communities to meditate, pray, and contemplate. He feels that this gesture made a big difference.

For clinical services, the IMC operated mobile units in the beginning and also provided services at the barracks and the IDP camps with the idea that the nurses who were being trained would later be absorbed into the government system. Workshops with traditional healers were also carried out, not with a patronizing attitude, but in order for mutual education. This eventually provided a lot of cross-references to the traditional healers, which led to the decrease of fear and stigma in the community.

CBM takes a long-term view of interventions and involvement and also has three aims: capacity building, community sensitization, and advocacy. One of the key things that CBM has done is to support the nurse training program previously mentioned by Budi Anna keliat, specifically providing motorcycles for nurses to carry out home visits. Along with this, in their three year plan, CBM is incorporating livelihood projects; supporting psychiatry units and psychosocial rehabilitation units in two major districts in the province; assisting psychiatric specialization; as well as supporting an epilepsy program, with the aim to use epilepsy as an entry point to a more comprehensive CBM program. They also managed to edit, translate and publish the Indonesian version of Vikram Patel's, *Where there is no Psychiatrist*, and plan to distribute it to the primary health centres in Aceh. Mohanraj also underlined that all the activities of the IMC and the CBM

strictly followed the principles that B. Saraceno mentioned yesterday; that they must work within the existing system. But while working within the existing system, positive reforms could also be initiated.

So far in Aceh, there are many achievements. The community mental health nursing program is up and running, with the ultimate idea of placing two trained nurses in each primary health centre. Discussions have been initiated regarding establishing a medical officer in mental health training program. Active discussions are going on regarding funding. And very importantly, CBM has brought into the fold the Indonesian Psychiatric Association and the government who are now extremely positive towards this program. It has also been pointed out that a draft version of the mental health policy has already been submitted to the governor's office in the province of Aceh. It is going to be legislated soon.

Because of the decentralized nature of the government in Aceh, the district administrations play a key role in the support of mental health initiatives. There has been a change in mindset and they are now giving budgetary allocations for mental health. The new governor in Aceh, an ex-rebel, is doing an excellent job and is very receptive to the exchange of ideas. There are discussions about sustainability, about how, with some incentives, the community health nurses and eventually the medical officers in mental health would be absorbed into government service.

Finally, A. Mohanraj closed his speech with the comment that Aceh would be a model province hopefully to be replicated in other provinces.

In his closing comment, **José Bertolote** reflected on the lessons learned by the six presentations from users, consumers, community grassroots workers, and professionals. He identified three topics that were more or less common to the presentations: firstly, the value of training was evident. Not traditional training, but the training of people at the ground level. Secondly, partnership and the working relationship to a partner appeared to be vital. And thirdly, the importance of understanding and respecting cultural specificity became clear.

There are two areas of great concern. One is sustainability. Almost all speakers spoke of sustainability. Tobias Chelechele asked for sustainable supply of medication, where the access to medication was overcome. According to J. Bertolote, an increasing demand for drugs is a clear indication of success and will lead to additional work that mental health workers are often not prepared for. According to J. Bertolote, this example shows that the sustainability of practice should be considered from the beginning of every programme.,

The other area of concern is in the role of traditional healers in mental health care, particularly in relation to Africa. J. Bertolote proposed to deconstruct the different positive and negative attributions to traditional healers by talking about them like about the different types of mental health professionals.

Finally, J. Bertolote identified a lesson of hope: how to transform disaster into a lever for positive change. He reminded the audience how some very interesting, very innovative, very challenging community based programs have risen from disaster. For him, this is a lesson of hope and the best memorial for the people who perished.

## Discussion:

In the following discussion, speakers first concentrated on the issue of training. Techniques of on the job mental health training were given and the need for regular monitoring and supervision was emphasized. The question of over-training was raised and there was a consent that new and innovative forms of training must be found.

Another question was raised concerning the role of mental health problems in infectious diseases like TB and HIV/AIDS. It was put forward that we should also be giving some attention to this other aspect of mental health care that complements our interest in those disorders that have traditionally been treated in hospitals.

Once again, in light of experiences with tsunami victims in Malaysia, the importance of prevention was raised.

Finally, it has been pointed out that despite all efforts to decentralise mental health services, in most cases, mental hospitals survive all reforms and still absorb all of the resources. Frequently, governments or international agencies like the World Bank or the World Psychiatric Organization counteract initiatives for community mental health services.

This is a place where the WHO can play a key advisory role. A call is made from this Global Forum for Community Mental Health to challenge some of the protectionist positions of those organizations who resist change.

## Session 6: CONCLUSIONS, FUTURE ACTIVITIES, and CLOSING REMARKS

Chair: Benedetto Saraceno

At the outset of this session, all the participants were divided into three small groups to discuss and draft conclusions and future activities to be undertaken by the Forum in the next two years. Subsequently, all groups presented their results in the last plenary session.

Following this short presentation of all group results, Benedetto Saraceno took on the task of summarizing all conclusions in his closing speech. Doing so, he identified a number of **themes** identified by the Forum, a number of **functions** to be undertaken, a number of **tools** and some important **rules** of the Forum.

The discussion on the selection of **themes** focused on the need to include the issue of human rights violations in other institutions, e.g., in forensic institutions. Furthermore, several speakers pointed out the ongoing process of re-institutionalisation of mental health care on the grounds of an alleged need for more public protection. Other contributions addressed the issue of different age groups in mental health care and the need to ensure the basic needs of health care users. Other commentators stressed the importance of allowing alternative approaches to mental health other than medical treatment thereby ensuring that community mental health services become more than just conventional psychiatric services in the community.

The discussion on the **functions** of the Forum once again emphasized the importance

of the sharing and dissemination of information on community mental health, e.g., on “best practices” in community mental health care. It then addressed the need for innovative, participatory and evidence based research. The Global Forum of Community Mental Health will also be a place to develop a new model of community mental health and to foster new partnerships and inter-sectoral links. Coming to the question of resource allocation, B. Saraceno appealed to the audience to develop new approaches to resource mobilization and expressed his gratitude even for the smallest practical or financial contribution. Angelo Barbato then proposed a joint venture with the Institute Mario Negri in Milan that would ensure the necessary equipment and office space for a possible secretariat of the Global Forum for Community Mental Health. Yvonne Bonner suggested involving the office of Reggio Emilia in Italy.

The discussion on the selection of **tools** underlined the need to decentralize the Global Forum of Community Mental Health by planning two regional meetings, e.g., in Africa and South East Asia, and a number of country meetings per year. Furthermore, all participants were asked to contribute actively to the discussion on the Global Forum Website. Print media should be developed in order to reach people with no Internet access. Study visits can be an important tool to identify “best practices” of community mental health services.

At last, two important **rules** were discussed in the Forum: firstly, while the Forum is generally open to funding by private companies, it will not accept any kind of funding by pharmaceutical companies. This is due to the fundamental conflict of interests between the objectives of the Forum and those of the pharmaceutical industry.

Secondly, the Forum will be as inclusive as possible by inviting all people who practice community mental health care. This will add to the credibility and responsibility of the Global Forum of Community Mental Health.

Finally, the following themes, functions, tools and rules have been agreed upon:

#### **Themes:**

- Stigma Reduction
- Human Rights
- De-institutionalisation from mental hospitals to community based mental health care
- Mental health problems in “other institutions”, e.g., forensic institutions, orphanages, residential homes, etc.
- Community Development
- Poverty alleviation
- Empowerment

#### **Functions:**

- Sharing and dissemination of information, e.g., on “best practice” in community mental health
- Development of new principles on community mental health

- Capacity building in community mental health
- Evaluation & Monitoring of community mental health activities
- Development of curricula
- Advocacy, e.g., to policy makers
- Innovative and participatory research
- Resource mobilization
- Building partnerships and inter-sectoral linkages

**Tools:**

- Website
- Electronic Forum
- Print Media
- Study visits
- A global meeting at least once a year
- Two regional meetings a year
- Country meetings when possible
- Support to community mental health projects

**Rules:**

- Involvement of all people who **practice** community mental health
- No funding by pharmaceutical companies

In his closing words, Benedetto Saraceno articulated his satisfaction that the Global Forum of Community Mental Health has proven to be a place for sharing, teamwork and mutual respect. He then expressed his deepest gratitude to all Forum participants, especially to those who came on their own expenses, to CBM for making this historical event possible and to the secretariat of WHO.

Finally, he once again reminded the audience to look for common ground in order to initiate a powerful movement for community mental health.

In other closing remarks, several participants expressed their gratitude and satisfaction with the meeting and appealed to other participants to bring all efforts together to build up on this experience. As one of the final commentators put it:

“This is a very good start .... let’s keep on working, we have a job to do.”

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