



World Fellowship of Schizophrenia and Allied Disorders
Fourth Quarter 2003

*Excerpts from WFSAD's Review of
WHO draft Mental Health Global
Action Programme (mhGAP) documents*

In 2001, WFSAD agreed to review nine modules of the World Health Organization's Mental Health Global Action Programme (mhGAP) in addition to documents on mental health legislation. Although the final version has not been published, we feel that some of our comments are relevant outside the context of the WHO document. Below we quote from sections of our review.

Confidentiality

Families should not be arbitrarily refused information relevant to the day-to-day care of the relative who they are looking after. On the grounds of confidentiality, physicians can refuse to share information that may impair the recovery of the patient. Withholding information from family members is less likely to happen in Asia compared to most western countries with highly restrictive confidentiality regulations. A common example of failure to share information would be discharge from hospital with no notification to the family resulting in accident, injury or disappearance of the patient. Evidence shows that participation of the family in the patient's care is likely to improve recovery rates. This indicates a much-ignored fact that optimum treatment should include the family caregivers, who are often the patient's sole support. The rights of the family are noted in the U.K. Frameworks for Mental Health under the Care Program Approach.

Involuntary Treatment

Apart from those being admitted involuntarily for a specified period of "safe haven" or "protection", we believe that the purpose of involuntary admission must be to give treatment to reverse a deteriorating condition or to lessen violent behaviour.

If treatment is not given, what is the purpose of admission to a hospital? Why, when friends and family fight so hard to enable a person to get treatment for a psychotic disorder would another obstacle be put in their path by making it necessary to fight for both admission and treatment?

Reducing Hospital Admissions

Community-based care and reduction of involuntary admissions to hospitals are increasingly seen as the goals of the mental health system. These goals are not always the best means to the ultimate goal of improving the health of the individual with a mental illness. Recovery, for those responding to treatment, or stabilization for those less fortunate, are dependent on many factors not necessarily based on the location of treatment.

Medications

A major shift in thought about mental illness, almost a paradigm shift, has occurred because of new knowledge about treatment. More effective ways of dosing and the development of new medications are permitting physicians to treat the "whole person" and lead him or her towards normalization and employment. With the advent of less toxic and more therapeutic medications comes an obligation to provide these, rather than older medications with an inferior side effect profile, despite cost differences. Patients who see improvement in their condition are far more willing to use and continue to use these new medications. Primitive treatments, excessive dosages and custodial care were fought tooth and nail in the past by patients whose negative experiences guided them in their advocacy against medication. In the near future, an atypical depot medication will become available which may also change approaches and responses to treatment.

Personnel

Vast populations and few mental health personnel beg

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A report on the Cross-Border Workshop held in Kenya in October 2003

Three East African Nations participated in this workshop: the host Kenya, Uganda and Tanzania. Dr. Radha Shankar, the WFSAD board member from Chennai, India, facilitated the meeting. Here is some of her report.

The workshop was held in Nairobi and facilitated the networking and fellowship that have become important and integral components of WFSAD-supported initiatives. We congratulate organizers Lilian Kanaiya and Gladys Akoth for their choice of the location and for the very smooth conduct of the program.

Participants included consumers, family caregivers, psychiatrists, psychologists, nurses, psychiatrist clinical officers, policy planners, counsellors and pastors. Participants were drawn from smaller towns and villages, which is so very important when we are trying to build a grass roots movement. The involvement of what you might call non-traditional partners for mental health, such as pastors and non-mental health community supporters, was refreshing considering their importance in low-income countries that have an absolute dearth of trained professionals. Not only do these individuals function as the gateway in to the health system, but also provide valuable support in the community for consumers and family caregivers.

Uganda represents an excellent example of partnerships between policy and program planners and service users. We very much hope that both Dr. Sheila Ndyabangi (of Uganda) and Dr. Scolastica Ndonde (of Tanzania) will facilitate maximum African participation in the WFSAD 6th Biennial Conference in Chennai, India next November.

One disappointing aspect of the program was the limited participation of policy and program planners from the host nation. We hope that they will take a more significant role in future meetings of these associations.

Excellent consumer and caregiver participation was easily facilitated due to the logical structure and flow of the program. Presentations progressed from macro issues to micro issues, from policy to programs, from general to specific and from problems to solutions.

WFSAD will continue to see "dividends" from this initiative in the years to come.

This newsletter is an international bulletin published by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) with the goal of providing information to the world self-help movement for schizophrenia and allied disorders, that includes national and local organizations, individuals coping with illness, and friends and professionals.

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Dr. Nirmala Srinivasan, Founding President of AMEND, Bangalore, receives Ashoka Foundation award

The Ashoka Foundation recently honoured Nirmala Srinivasan with its award for social entrepreneurship in recognition of her work with the AMEND group in Bangalore, India.

Nirmala Srinivasan experienced the stigma related to her mother's mental illness at a young age. Later in life, while traveling with her husband in Moscow, Nirmala was inspired by the liberated Moscow woman and soon after enrolled in a Masters program. To support the cost of her education, Nirmala wrote for newspapers about women's issues and other social justice concerns with a focus on the tribal areas of Uttar Pradesh. Not wanting to stop there, Nirmala continued on to complete her PhD.



Dr. Nirmala Srinivasan, Founding President of AMEND.

At the beginning of her professional life, Nirmala once again was faced with mental illness when her youngest son was diagnosed with schizophrenia. Intense trauma faced the entire family who were without information on how to handle the illness and manage their own feelings of loneliness and isolation. The result was an advertisement placed in the local paper inviting all people with mental illness and their families to meet and share their experiences - the beginning of AMEND (Association for Mentally Disabled).

Nirmala has brought new hope and resources to those who live with mental illness through launching this self-help organization

for the families of people suffering from mental illness in Bangalore. We salute Nirmala for her enthusiasm, drive and willingness to take on new challenges. Congratulations on your award.



AMEND brings new hope and resources to those who live with mental illness

Seeing a need for community information and support for people suffering from mental illness and their families, Dr. Nirmala Srinivasan launched this self-help organization with aspirations of bringing new hope and resources to those living with mental illness in Bangalore.

At any given point of time there are at least 3 million mentally ill patients in India. Over 80% of the psychiatrically ill live with their families. Only 5 to 10% reach the psychiatrist. 75% of the mentally ill live in remote areas with no access to medical facilities. The families live through the angst, the trauma of living without support, costs of care, shame and stigma.

Shrinking families, migratory trends and working women have left the family of the mentally ill person with fewer second-generation caregivers. The emotional and social burden is unbearable, amounting to fatalism and apathy that comes in the way of the family playing a proactive role. AMEND has grown from 70 families in 1992 to more than twice that number today. It has helped so many to overcome the stigma of the illness. In 1995 it became largely responsible for importing new generation drugs through a mobilized signature campaign to the drug controller. This resulted in a change in the quality of living for the mentally ill.

Nirmala is actively working to sensitize the government at the centre and state about psychiatric disability. She is making government officials receptive and supportive to the cause of mental illness and urging mental health professionals to participate in the process AMEND has started.

Nirmala has designed Family Education and Training for the families, and Daily Living Skills for the users (patients). AMEND has been able to facilitate crisis help for the families to handle

(see AMEND - page 13)



A good news story from Turning Point

Turning Point is a rehabilitation and activity centre started six years ago with a mission to improve quality of life for people with long-term mental illness in India. The rehabilitation includes both social and economic rehabilitation with the goal of allowing the sufferer to re-enter main stream life. The centre acts as turning point in their lives.

As people with mental illness become isolated from society, a sense of utter dejection and unworthiness grows. To confront this feeling of segregation, the first goal of Turning Point is to make the person feel accepted, forget the trauma of seclusion and discrimination and enjoy the pleasures of engaging with others. By gradually giving consumers responsibilities, they realize that they are capable of doing things and being efficient about it. These activities help to increase self-worth and self-esteem. Turning Point works with consumers to improve their attention and how they communicate; to improve their concentration and reaction time; and to change their attitudes and behaviours for their own and society's benefit.

According to Amitava Dutta, someone who has benefited from the support of Turning Point, joining the centre has changed his life. "Before joining Turning Point I had some doubts in my mind. Why should I join a center for the mentally ill? Am I stamped as insane for the rest of my life? Shall I never be treated as a normal person? Shall I never be able to be responsible and mature as other individuals of my age?" Amitava went on, "Ishitadi, my psychologist, answered all my queries. I learnt that being mentally ill need not separate you from society. All individuals can suffer from mental problems like they can suffer from physical problems. I understood that I should not feel ashamed or blame others for this disorder."

Amitava described how his psychologist gave him responsibilities at Turning Point that enabled him to develop his abilities. "Though I was a good painter in childhood, I almost forgot that until Ishitadi asked me to teach sketching and painting. This began to give me confidence in myself." Apart from taking part in all Turning Point activities like physical exercise, news, music, group games, debates, extempore, role modeling etc., Amitabha also took an active interest in handicrafts and computers and was soon able to give instruction to other

consumers in the use of computers. The confidence that Turning Point instilled in Amitabha made him eager to take on new roles and to show what he was capable of. Amitabha continued with enthusiasm, "I felt as if I were back to my old childhood life - that small Amitava who was a hero in his school, excelling in studies, art and playing musical instruments. I got back that old Amitava inside me who used to have ambitions and dreams."

Not only did Amitava increase his roles in the Turning Point centre, he was ultimately offered a chance to go abroad. His psychologist, Ishitadi, encouraged him to send an abstract to a health service conference in England. Through his work with Turing Point, Amitava was able to realize a dream of going to London while presenting at a conference in Stratford-upon-Avon. "I received appreciation from so many people. The Secretary of WFSAD, Diane Froggatt, came forward, congratulated me and took my photograph. I presented my painting to her and she informed me that she would frame it and place it in her personal office beside my photograph. Now I realized I have changed a lot. I am no more that Amitava who had withdrawn from life. Now I have the whole world before me. I think all the delegates of the conference who met me have felt this difference too. I am more than a normal person now and I must thank especially Ishitadi and Turning Point for making a difference in my life."



This painting, by Amitava Dutta, was presented to Diane Froggatt of WFSAD at the Stratford-upon-Avon conference.

Amitava is not the only one who has experienced such a rebirth. Anirban Bhadra also attends Turning Point and has come a long way to overcome obsessions that have been with him for years. He says, "As I myself suffered from this problem, I can feel about it and give some suggestions to the sufferers and help them to come out of their problems. Now I am no longer a sufferer of mental problems but an active volunteer of mental health." Then there are Sourav, Sharmila, Manashi, Kingshuk, Prabhat and Arnab, who now have jobs and are doing them successfully while others have returned to school to complete their

education.

As Turning Point does not have staff, the service users act as volunteers once their conditions improve. Turning Point has been able to serve many people with its limited financial resources by giving service users the opportunity to work and also by utilizing



WFSAD continues to promote "Partners in Care" programs in Korea

Geraldine Marshall was in Korea for 5 weeks during September and October 2003 giving lectures, workshops and seminars to student nurses, masters of nursing students and psychiatric nurse practitioners. WFSAD board member Dr. Susie Kim arranged her schedule.

The seminars included psycho-education for families, setting up self-help support groups, advocacy, the importance of early intervention and recent research on mental illness. These took place at Ewha University, Han Yang University and the Catholic Medical University in Seoul, in Kwanju at the Jun-ju University and in Pusan at Seokang College. In late September several nurses visited from the new Miyazaki Prefectural Nursing University where Dr. Marshall discussed the WFSAD Mutual Exchange and the Partners in Care programs with them. Working with nursing students at the 7 Korean Universities that Marshall visited will lead to more use of psycho-educational practices when the students commence their professional lives as psychiatric nurses. The chance to train and present research demonstrating the efficacy of this education is very important to WFSAD and the psycho-education movement as the task of implementing rehabilitation programs often falls to the nurses.

In Kwang-Ju and Seoul, Marshall met with patients and their families to further their education, improve self-esteem and help them focus on functioning. A weekend at the Dam Yang Retreat Center, allowed for interactions with 50 patients and their families. The Center is a state-of-the-art facility run by the Catholic Brothers from Dublin who also operate St. John's Hospital - a training centre and psychiatric hospital.

Dr. Marshall and Dr. Susie Kim (pictured below) will continue their outreach on patient functioning and are working to have psychoeducation included in the total treatment program.



family resources wherever possible. Working at Turning Point is a goal that most service users aspire to. Those that are given the opportunity to take on responsibilities know that even if they fail, they will get support and assurance and will be encouraged to take a chance again. The people at the centre act like an extended family with many brothers and sisters where a person is not rejected during the time of crisis but gets help and support from those closest.

According to parent Dipali Sengupta, "When I came here with my daughter I had doubts, how far this centre can help me. I was depressed as I had hopes and dreams about my daughter, which I thought were ruined after the disorder. At first she was withdrawn and hesitated in participating in daily activities. Slowly we noticed a challenging and winning attitude in her. She started doing more and more work at Turning Point. In the cultural programme, she was motivated to perform on stage. I was a little worried and excited too. But my daughter performed extremely well with the encouragement of everyone. She also started developing some insight about her problem and a desire to change and modify herself. Now she competes with others to earn money from handicrafts and thus works a lot in the process."

Dipali spoke of the parents' group where ways of working with their grown children are discussed. "All the parents feel that Turning Point has really changed our lives, by helping our children and giving us the courage to think positively about the future of our life." Daily activities such as personal hygiene, cooking, shopping, cleaning, conversation, transportation, physical exercise, money management, etc. often become uncomfortable, if not difficult for these patients to manage. To assist a person to be independent, it is often necessary to learn or re-learn the skills - something done regularly at Turning Point. Each service user creates an individual plan based on his or her personal needs to lead them towards independent living.



Ishita Sanyal (right) is the founder and inspiration behind Turning Point. She is pictured here with Amitava Dutta. You may write to Ishita at sanishita@hotmail.com.

Turning Point encourages active participation in the centre but also in the community through homework assignments. The assistance with social functioning coupled with learning about their disorders and how to deal with them has made Turning Point a success.



REGIONAL NEWS

Alianza Latina WFSAD showed that Latin American groups continue to show they are working to support the global movement of families, friends and people with mental illness to alleviate the many problems associated with these conditions

As October rolled in to Caracas, so did leaders and representatives from 16 emerging Latin American family organizations. They were there for the second meeting of Alianza Latina WFSAD, an alliance formed last year during their first meeting in Guatemala. This second meeting was held during the World Psychiatric Association's regional congress hosted by the Latin American Psychiatric Association. Although less than 50 strong among a group of 2,000 psychiatrists, the energy and passion of these family delegates was clearly felt.

WFSAD sessions were admirably chaired by Prof. Itzhak Levav, a former head of PAHO (the Pan-American Health Organization) and a well-known supporter of families. Dr. Edgardo Engelmann spoke during the WFSAD symposium about the importance of not simply medication but understanding what the medications are and why a patient is taking that particular medication. In his address, he stated that two thirds of outpatients stop medication after two years and of these, more than two thirds do it purposely. Providing information to the patient about side effects as well as when and what the benefit will be, encourages the patient to stay on the medication. Dr. Engelmann also spoke of research that shows that the reluctance to take medication is more related to a lack of social and family support than to the side effects of the medication.

Professor Julian Leff and Professor Dale Johnson (WFSAD President Elect) also spoke during the symposium about problem solving strategies and psychoeducation respectively. Both these experts were well received.

A workshop session on the second day gave delegates an opportunity to share information about the specific problems their organizations were facing and strategies for meeting their own personal goals. For many, having an opportunity to discuss the challenges their organizations face with others who understand their unique and complex concerns was a significant part of the Caracas meeting. The sharing of success stories worked to revitalize the commitment to improving the life of mentally ill persons and their families. These leaders will return home with new ideas, strategies and programs.

Another important topic of discussion was the efficacy of the

Guatemala Declaration. In a workshop for family-leader-delegates, nine points were agreed upon that will be integrated into the Declaration. The new points, which range from including psychoeducation in psychiatric care to advocating for state employment programs, re-affirm the original document. The 2002 fourth quarter issue of the WFSAD newsletter outlines the Guatemala Declaration's original ten points of direction and action for Latin American family organizations. These can also be seen on the WFSAD website.

Plans have already started for another meeting of the Alianza Latina WFSAD to be held in November 2004 during the APAL meeting in Punta del Este, Uruguay. Alianza Latina WFSAD members are encouraging medical advisor psychiatrists in Latin America who support their work and are part of their network, to apply to speak on family work at this congress as soon as APAL is accepting abstracts.

Acknowledgements

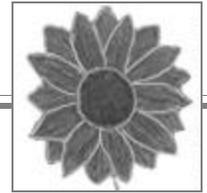
We owe our sincere thanks to the Pfizer Foundation for sponsoring this event under their program "Strengthening Patient Advocacy Around the World" and to Pfizer Venezuela and their representative Oswaldo Parilli and his team for their attention to our requirements.



Dr Edgardo Engelmann, Prof. Dale Johnson (WFSAD President Elect), Prof. Julian Leff and Dr. Itzhak Levav.



Damelis Salazar of CATESFAM, Maracaibo, Venezuela, asks a question during the symposium.



Advice for the media

Francisco Morata of the Spanish Federation of Mental Health Family Organizations (FEAFES) provided these tips for responsible media portrayal of those suffering from mental illness during the Alianza Latina WFSAD workshops in Caracas.

1. Use all available sources of information

The media must be able to represent the reality of mental illness well - a difficult task when faced with an abundance of scientific and technical data. To accurately communicate the issues surrounding mental illness, one needs to have access to all the available information. The most valuable sources of information are often those directly affected such as persons with mental illness, families and associations.

2. Present a positive view by placing attention on solutions

Media has the potential and responsibility to create a positive view of mental illness which can be done by placing the attention on solutions - the potential, achievements, advances and the positive human qualities. Avoid over-playing limitations and isolated negative cases. Do not magnify the achievements of outstanding people, but rather emphasize ordinary achievements. Too often, media focus is on problems associated with mental illness.

3. Separate mental illness from events

Do not prejudice nor relegate the cause of a violent or delinquent act to a mental illness. It is not only the mentally ill who commit violent acts with studies showing that a person with mental illness has the same probability of committing a delinquent act as any other person. Those with mental illness that undergo psychiatric treatment can, and do, live in society without risk to themselves or others. Omitting relevant information about all the causes of an act helps to maintain prejudice. Describe only the directly observable facts or the context in which the circumstances occurred and avoid dismissing the illness as the single cause without looking at all causal factors.



Delegates listen attentively to a workshop speaker during the second meeting of Alianza Latina WFSAD in Caracas.

4. Treat mental illness as any other illness

Mental illness is just one of countless number of illnesses and should be represented in normal and usual situations in the community: home, work, leisure, social situations. Present mental illness as naturally as you would present flu or a physical disorder.

5. Fight for rights and resources; do not awaken compassion

Showing mental illness in a dramatic or sensational way will awaken feelings of paternalism, compassion, morbid curiosity, super-protection, distancing, frivolity, etc. These feelings do little to help those who live with mental illness to get the respect and resources they need.

6. Give mental illness a face

Proximity to, and direct knowledge of, people with mental illness helps dismantle prejudice and negative stereotypes as people can see the person more than the label. Persons directly affected must have the opportunity to reach the media without intermediaries or the chance of being exposed to manipulation by third parties.

7. Do not spread or maintain prejudice and false beliefs

Do not make use of old ideas, beliefs, myths, negative prejudice or stereotypes about what a person with a mental illness is like. Many of the beliefs about mentally ill people may be incorrect. Mental illness is not a punishment. Persons that suffer it do not have a double personality. They are not de-humanized and irrational individuals. They are not aggressive. Do not report erroneous information.

8. Focus on the whole person - not just the mental illness

A person with mental illness, just like any other individual, has many sides. Depict people with mental illness in a multi-dimensional way by showing that they have the same feelings, problems and aspirations of others as well as the same strengths and weaknesses. Mental illness is not something global, permanent or immutable - it's something partial and relative. We all know someone with some type of mental illness - acute or slight.

9. Do not stigmatize with incorrect words or labels

In many cases, the circumstance of the mental illness is not relevant to the information being presented, in which case there is no need to mention it. If it is necessary to mention mental illness, avoid labeling individuals by turning their condition into a noun: "a schizophrenic", "a depressive", "an anorexic", etc. Do not use psychiatric terminology in other context, especially when used as a negative or pejorative.

10. Illustrate information with adequate graphic material

The press and television need to illustrate their information as the majority of mental illnesses are not physically perceived. Inadequate photographs are often employed that show external symptoms of other more visible disorders. This practice powerfully contributes to maintaining the confusion that exists among the different pathologies.



WHO Review (continued from cover story)

solutions. Family members are both interested and motivated to educate and train other families. Family organizations can have educational and training roles apart from their roles in advocacy. If community care is to become a reality, community personnel need to be enrolled. Not all staff of mental hospitals are suited nor do they wish to take roles in community care.

Poverty

Poverty remains one of the strongest determinants of mental health. It is imperative that mental health professionals and politicians understand the distinctions between mental illness and mental health. Serious mental illness is not the result of poverty, but poverty is often the result of serious mental illness.

Family Involvement

Talking about the involvement of family caregivers in policy planning and development, advocacy, provision of services etc. tends not to take into account the prior consideration, which is that families must have their needs fulfilled first. This has to be achieved by developing a much better relationship between mental health professionals and family caregivers. Families need information, education and 'training' in the management of mental illness and support for all aspects of their caring role.

Being included in treatment and care plans helps caregivers manage their own reactions.

Going for Treatment

It is important to remember that many families with mentally ill members never seek treatment or visit health facilities. A refusal or inability to pursue treatment or support can be a result of cultural taboos, stigma or ignorance that mental illnesses can be treated.

Who is a Consumer?

While some countries consider the term "consumer" to include families, others do not. It is necessary to include family members in order to attend to the rights and needs of families who shoulder the caring role.

Community Care

Stating that people with mental illness should be treated and cared for at home with the support of families and neighbours does not take into account the complexity of that situation. Problems arise if these proposed caregivers are not equipped to support people with periodic psychosis and the behaviours and symptoms associated with it. Without education, training and



Mental Health Global Action Programme (mhGAP) to enhance the mental health of the population

THE BACKGROUND

The World Health Organization's Mental Health Global Action Plan is an initiative designed to lessen the gap between what resources are currently available and the resources urgently needed in order to reduce the burden of mental disorders. The main message of the programme is that mental health has been neglected and is crucial to the well being of individuals, societies and countries.

This five-year initiative, started in 2001, will focus on strategic partnerships to enhance countries' capacity to comprehensively address the stigma and burden of mental disorders. The initiative will increase governments' awareness and responsiveness to mental health issues; enhance the quality and effectiveness of mental health prevention, treatment and rehabilitation services; reduce stigma and discrimination; and by doing so, take important steps toward reducing the burden of a range of conditions and enhancing the mental health of the population.

active participation with professionals, the sick may be abandoned or left at poorly run private or quasi-religious institutions. In addition, people who have been in hospital for lengthy stays are unlikely to be able to return to family who have simply disappeared or are too old to take on the new and burdensome role of caregiver.

Getting a Job

Family organizations have ample knowledge about the ability of people who are mentally ill to get a job. The difficulty lies in maintaining employment, not because of a person's ability to do the job, but because of difficulty interacting with work-mates and bosses.

Family Work Research

A large body of research shows that family intervention (psychoeducation) works to lessen stress on families and to reduce the chance of relapse and recurrent hospitalization. See Falloon, Hogarty, Leff, MacFarlane, Tarrier, etc.

Downsizing

Where there are few mental health services and where WHO is encouraging the downsizing of mental hospitals (asylums), it is dangerous to talk about decreasing the utilization of mental health services. It is estimated that at least 25% of those who need to seek help from mental health services fail to do so for reasons described above. A good system provides for those in need.

Conflict

It is a misconception of nervous mental health professionals that consumer groups and family groups are in conflict. This may have been the case 20 years ago but, with the passage of time, these two types of groups are working increasingly more productively together.

Inclusion

Unless it is spelled out, family caregivers will be left out of the mental health process, especially in countries where radical anti-psychiatry consumers have not yet given way to the more modern, moderate consumers. Where there is a family organization this task is made easier. It is important to engage articulate and well-informed family members.

WFSAD Joins World Health Organization Working Group

WFSAD Executive Director, Diane Froggatt, attended a preliminary meeting of international family leaders to establish what the family movement might contribute to a new body envisaged by the WHO Department of Mental Health and Substance Dependence, called the Global Council for Mental Health.

Other organizations represented at the Families' Working Group were NAMI (National Alliance for the Mentally Ill - United States), EUFAMI (European Federation of Associations of Families of people with Mental Illness), UNASAM (Unione Nazionale delle Associazione per la Salute Mentale - Italy) and the Indian Federation for the Mentally Ill.

The Global Council was conceived during Dr. Bruntland's tenure as WHO Director. Dr. Benedetto Saraceno, Director of the World Health Organization's Department of Mental Health and Substance Dependence, is anxious to build this global coalition where, through consensus, stakeholders will be able to achieve more than they are achieving separately.

The Families' Working Group was the first of eight working groups to meet. The other Working Groups are health leaders, service users, parliamentarians, professional organizations, educators/health professionals and business leaders. Meetings of the other groups will continue throughout 2003.

The group spent two days exchanging information on their organization's views, concerns, activities and goals. Three areas were identified for further discussion with the other working groups:

1. Direct social and emotional support and education to families.
2. Advocating for recognition of the rights of the family.
3. Advocating for family participation in monitoring outcomes of mental health services in the community.

WFSAD looks forward to the next stage in the development of the Global Council for Mental Health.



Photos from Global Council for Mental Health - Families' Working Group meeting. Family leaders and WHO personel (left); Janet McCrae and Diane Froggatt discuss priorities (centre); Jose Bertolote and Rick Birkel (right).



Should he be there? A mother talks of the trauma of visiting her mentally ill son in prison

Once upon a time in lands all over the world, the prisons were full of people who were mentally ill. The people of the lands shook their heads sadly. "We should not be locking these people up with violent men and women who are criminals. It is not safe for them." So they built special hospitals and institutions and the people were happy. Years later, when the people saw that these special hospitals and institutions had become overcrowded and were often lacking in treatment and support, the people said, "these people should not be locked up in these overcrowded, miserable places. Let us set them free so that they can live in the community." So they closed all the hospitals and institutions for the mentally ill. As time moved onward, the people noticed that many of the mentally ill were unable to fend for themselves in the community and many had become homeless. Some had turned to crime and had been put into the prisons. So the people said...

The story above resembles that of a fairy tale waiting for a happy ending.

Far too many mentally ill people are now languishing in jails where they do not belong - mostly because they have committed petty crime. It is a nightmare for families to discover their mentally ill relative has been charged with a crime and will spend time in prison-like conditions both before and possibly after trial. For the person who is incarcerated in this way it has to be far worse.

Stephanie Pankhurst gives us a glimpse of her experience in dealing with dealing with the "correctional system" - a misnomer in the case of the mentally ill. Below is an adaptation of articles she wrote for Australian Schizophrenia Fellowship newsletters. She proposes a hostel system where mentally ill offenders, particularly those with dual diagnosis, can live, work and take their medication under caring supervision.

The phone rings and I grow excited listening to the recorded preliminaries from the correction centre before I am connected to a familiar voice. "Did you see the letter to the editor on prison conditions?" my son asks me. I offer to visit him again. I am his only visitor apart from a relative who went once and stayed a few minutes. Visiting is not for the faint hearted, but we have been exhorted to visit the sick and those in prison. A psychiatrist visits him too but these contacts are sometimes months apart.

It is not made easy for relatives to visit. There are a number of hurdles to face when planning a visit. Staff at the correctional centre adhere to rigid protocol and families feel the degradation keenly. I dial the correctional centre and must wait on the line.

Finally I am able to request a visit, but I am told it is too far in advance. If I am lucky I will get the date and time of my choice, but first I must fill in my name, date and place of birth. Depending on how efficiently paperwork is processed a security clearance may be available when we visit. If there is no clearance, the visit will be "non-contact" and my husband and I will sit with a Perspex screen separating my son from us.

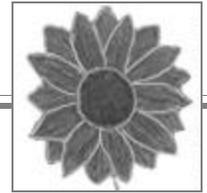
We set out for our hour drive over an hour early as "latecomers" can be penalized with a non-contact visit. Dogs greet all visitors. When the prison puppies get excited the penalty is a non-contact visit - at the very least. Jewelry and watches are not allowed which I know but forget and the metal detector stops the revolving

security doors. I look perplexed until the prison officer points to my wrist. I have already taken off my glasses and shoes and they have been screened separately. Now I have to take my watch back to the locker in the other building. I make my undignified way, in the rain, minus shoes and spectacles. I imagine someone watching the security tapes and agree that I make a ludicrous figure. It cheers me a little.

When the prisoners finally arrive, my son tells me he has been assaulted. However, he doesn't want anything done about it. This is difficult for me but he is adamant as he has to survive there. "Where were the officers?" I ask but he just shrugs. He has recovered and that is where we are. Moreover, he has moved to a lower security section and the atmosphere is less charged there. The stress of daily living with violent men has been huge. Why

"When the prisoners finally arrive, my son tells me he has been assaulted. However, he doesn't want anything done about it. This is difficult for me but he is adamant as he has to survive there."

(see PRISON - page 13)



A report on gainful employment for people recovering from mental illness - India

How do people feel and what do they do when they are told that their loved one (son, daughter, brother or sister) could be suffering from a psychiatric illness and may require treatment and rehabilitation for some time to come?

For many family members, the first thought could be one of disbelief and denial. Subsequent to this initial emotion, some relatives can experience pain and bitterness, and resort to an endless search for a miracle that will wish away their problems. Regretfully, on occasion, natural caregivers reject the person who is suffering from the illness because they are unable to comprehend the complex nature of the psychological problems.

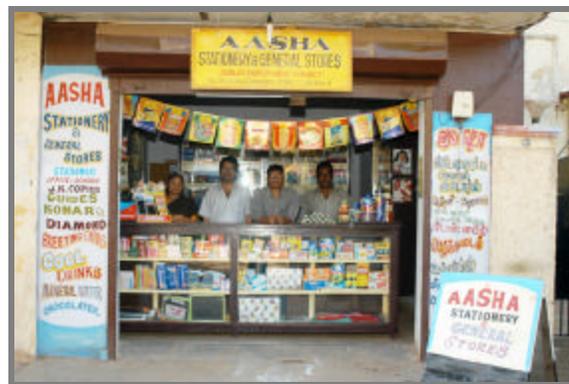
In a family-centric society such as India's, the majority of people with a mental illness live with families - families that don't always have the information or support they need due to meager treatment and rehabilitation facilities. Thankfully, many relatives come to terms with their disappointments and problems, and find ways to support their loved one recover from their problems.

Faced with the reality of an under-funded mental health system and passively resigned family members, a silent but unique movement is slowly growing across India. Small groups of exceptional family members are putting aside their own personal distress to form self-help groups that will proactively reach out and assist other family members and patients recovering from mental illness. Aasha is the first such organization in India. Members of Aasha include patients of mental illness as well as their families who have come together to volunteer their time, effort and experience to others. Founded in 1989, under the guidance of the eminent psychiatrist Dr. M. Sarada Menon, the philosophy of Aasha is very simple - 'self-help'.

The activities of Aasha are many. Educational programs combine technical information and input from professionals with personal experiences and support from other families. This combination of supports assists family members with the recovery of their ill relative. Aasha also runs a transitional residential facility for recovering patients where members provide their time and effort on a voluntary basis. A quarterly newsletter is published by the organization to provide information and guidance to families and is an effective vehicle to fight the stigma and misconceptions

associated with mental illness. To the eighty-year-old editor, and family caregiver, Mr. A. R. Rajagopal, the five-year old newsletter is much more than a labour of love. It is a testimony of his commitment to provide dignity and hope to families and patients.

It is often not recognized that people with disability, whether physical or psychological are averse to sympathy or pity, and only seek opportunities that will help them realize their potential. In keeping with this sentiment, ABILIS, an organization of people with disabilities based in Finland, selected Aasha as the recipient of a start-up grant that will support work opportunities for people with psychiatric disability. The initial funding has provided a platform for Aasha to run a stationery shop in the Perambur area. The Aasha shop employs both recovering patients and one family member and reinforces the reality that people with mental illness can work productively, efficiently and often with a sincerity that is lacking in the so called "normal" population.



The AASHA shop is located at No.35, Bunder Garden Street, Perambur, Chennai and employs both recovering patients and one family member.

Visiting the shop provides ample evidence of both the enthusiasm and the skills of the employees. Employees maintain logs of every query for an item, track fast moving items and decide about inventories, participate in pricing strategies and close accounts each day. Competing in the open market and dealing with

suppliers, customers and the vagaries of a small business has been a big confidence booster for the employees. As one of them said gleefully, "I do not feel like a patient any more. I am like any other owner cum worker in my own small concern."

And what of the future? Can a small shop run by people who are learning on the job survive? Ratna Chibber coordinator of the Aasha shop speaks softly, but with a passionate intensity "Many people predicted that our shop would fail. But, I am not afraid of failure, because you need much more than business sense to survive. You need hard work, honesty and a commitment to a goal. Our Aasha family has all of this in plenty. So failure will not happen." In fact, with the rich experience gained from the first shop, plans are underway to start shops in other locations with a similar staffing pattern.

Information for this article was provided by Dr. Radha Shankar who can be contacted at radhashankar@vsnl.com.



October 12 2003, Belarus

30 patients perish in a psychiatric hospital fire

On October 12 2003, 30 patients of a psychiatric hospital in Randilovshchina, Belarus were killed in a massive fire. Another 31 suffered from minor injuries.

The patients were men and women unable to live in the community due to their inability to function independently and their family members' refusal to care for them. The victims all lived in a one-story wooden building which was constructed in 1905 with locked doors and bars on the windows.

Officials said the fire was set by a patient who had tried to burn down the building twice before. It was reported that the patient was among those killed.

Investigators also considered the possibility that the fire was the result of negligence on the part of the staff. There were no staff members in the building at the time of the blaze. Reports state that a nurse and an orderly were sleeping in a separate building on hospital grounds when the fire broke out. While protocol, in situations like this, calls for an immediate request for help, the two staff members were reported to have panicked and tried to put out the fire and rescue patients themselves.

"As a result of such poorly thought-out actions, by the time emergency personnel arrived, one of the hospital's wings was completely engulfed in flames and the roof and ceiling had collapsed." Emergency Situations Minister Valery Astapov told Belarusian television.

Human rights activists blame the fire and massive loss of life on the dismal state of Belarus' psychiatric hospitals, which are poorly funded and largely unreformed since the Soviet era.

Society for Welfare of the Schizophrenic (SWS) responds to the Mental Health Hospital Fire in Randilovshchina, Belarus

SOCIETY FOR WELFARE OF THE SCHIZOPHRENIC
27/12, Topkhana Road, Dhaka-1000. Bangladesh

Press Release
15th October 2003

Society for Welfare of the Schizophrenic (SWS), Dhaka, Bangladesh notes with grave concern the sad incident of fire at a Mental Health Hospital in Belarus at dawn on Sunday the 12th October 2003, burning 30 mentally ill inmates to death, source AP, Minsk, Belrusia through The Daily Star, 14th October 2003.

That, as it appears from the news, there was no hospital staff in the building when the fire started, where there were 62 patients, clearly indicates the extent of negligence prevailing in the hospital. Statement of the spokesman of the president that, one of the victims 'had tried to burn down the building twice before' indicate how frustrated the inmates were due to ill treatment of the hospital authority. It is not clear whether they were kept individually chained or not. Else how could so many physically able persons be burnt to death by fire in a wooden house?

SWS prays for peace of the departed souls.

SWS also condemns the irresponsible act of the Govt. of putting blame to one of the victims rather than being ashamed of their own shameful inaction and apathy. How do they know who set the fire when there was no hospital staff in the building when the fire started? Why they did not take precaution when such attempts were made earlier by one of them, more than once? SWS condemns the low level of commitment and insolent attitude of the Govt. towards mental health and mentally ill persons and calls for attention of international community, including WHO, for immediate address of such situation all over the world.

Badrul Mannan,
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Readers will remember WFSAD's press release in response to the tragic deaths of patients in a private institution in Erwadi, Tamil Nadu, India, two years ago. We hope that that by publicising and responding to these terrible events we will help to reduce human rights abuses.

Below, we have included part of the statement of Jim Crowe, President, Board of Directors, WFSAD.

**WFSAD ABHORS THE INHUMAN
TREATMENT OF MENTALLY ILL PATIENTS
WHO DIED IN A FIRE WHILE CHAINED TO
THEIR BEDS IN A FACILITY IN TAMIL
NADU, INDIA**

Twenty-six persons incarcerated in a private mental asylum in Erwadi, Tamil Nadu, India, died recently in a fire, as a result of being chained. Erwadi is a holy site. People bring their sick in the hope that faith will cure them. Families sometimes leave their relatives there in the care of others. The appalling conditions under which these mentally ill people were restrained are not unique to India. They exist throughout the developing world and are not unusual. This tragedy, however, serves to bring global attention to the plight of these unwanted and often abandoned people and to make us examine a number of factors, which contribute to this situation.

It goes without saying that we must attend to the human rights violations of the mentally ill. We must also improve education and support for families caring for their mentally ill relatives. They are the primary caregivers who resort to putting their relatives in these places because they receive no education about the illness or any support from the state.

One cannot, however, focus on a single responsible factor. The causes are many. Not least among them, however, are the misconceptions and ill-considered beliefs of the population. The establishment of a government public education campaign about the true nature of mental illness would be one huge step to lead Indian society towards a better understanding of psychiatric conditions and a more humane response to care and treatment.

Prison (continued from page 10)

are people with an acknowledged disorder imprisoned with violent men? And why is there insufficient supervision?

We chat for awhile and his mood is positive. I ask if he has been writing. He says no, but he has been reading. Not only books, but the paper too, it seems. My feelings undergo another roller coaster ride when he tells me about his new living conditions. "Instead of choosing from a trolley of books which someone else has chosen, I can go to the library." His face lights up at the thought of walking through a room full of books and choosing whichever he likes. I look at his expression and it is as if he is back at the library, savouring his newly found freedom. This is truly a scholar before me and I silently rejoice with him. But what of those with limited interests because of their disorders? Their only pleasure may be to visit, and that, infrequently, with their relatives.

Under the present system, the future prospects for this young man are bleak. He works four days a week making furniture and has reached the highest level of proficiency. Why can't he live, work and take his medication under hostel, rather than prison, conditions? This is not an isolated case. Our prisons are full of people with mental disorders because the system saw fit to empty the hospitals leaving the mentally ill without help.

Stephanie Pankhurst is a pseudonym for an Australian family member.

AMEND (continued from page 3)

critical or dangerous situations. A local ambulance facility has been made accessible to the AMEND community.

In 1999, Amend initiated the Karnataka Association for Psychiatric Disability (KAPD) with the support of the World Fellowship of Schizophrenia and Allied Disorders. KAPD is a network of NGOs in the field serving as an advocacy lobby.

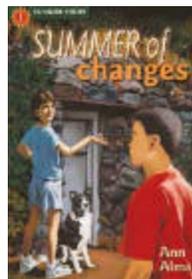
As a part of the 10th year celebration, AMEND, with the help of professionals from the National Institute for Mental Health and Neuro Sciences (NIMHANS), published booklets on 5 topics related to mental illness. The public awareness campaign reached people through 250 NGOs and government networks. 200,000 copies were made of which 150,000 were in the local language and only 50,000 in English. Since then, AMEND has collaborated with the Indian Psychiatric Society (IPS) and is now an associate member - IPS Karnataka Branch. Since 1999, AMEND has worked on sensitizing employers and finding employment for AMEND consumers. Recently, Nirmala became involved in political advocacy and providing support to others to work on the implementation of the Indian Mental Health Act.



BOOK REVIEW

Ann Alma's novel explores the journey of a young girl who has a mentally ill mother

Summer of Changes is a novel for young people by Ann Alma. It tells the story of an eleven-year-old girl whose mother has schizophrenia and is no longer able to take care of her. Framed as an adventure story, *Summer of Changes* follows Anneke as she goes alone into the forest and braves a cougar. Along with the action, the story paints a sympathetic picture of the Anneke's relationship with her sick mother and how she comes to terms with living with foster parents. Here is an excerpt in which her foster father explains schizophrenia.



Summer of Changes is available from:

Sono Nis Press
Postal Box 5550, Station B
Victoria, British Columbia
V8R 6S4
Canada

Email: sononis@islandnet.com

Web: www.sononis.com/book098.shtml

After a long silence Larry put his hand on hers and said, "You know your mom has schizophrenia, don't you?"

When Anneke nodded, he continued, "When you lived here before, we didn't think you were old enough to understand, but I feel that you are now."

He stopped and she nodded again, waiting.

"Schizophrenia means your mother's brain doesn't always work like ours."

"I know that," Anneke interrupted. "But she can take medication. It fixes everything."

"It's not that easy," Larry said. "The medication might be changed at times. It works differently for different people."

"You mean," Anneke said in surprise, "there are other people like my mother?"

"Oh, yes. Many. About one in every hundred people has schizophrenia. Most of them are fine if they take their medication. They lead normal lives." He patted her hand. "Some, like your mom, have a problem for awhile. Then they need to be in hospitals or group homes. Your mom will go to a special hospital in Trail to try new medication. Right now she is not well. She hears voices that tell her things."

"Yes," Anneke said. "She says the goddess tells her to do stuff, like make little fires."

"Exactly," Larry said. "And that's dangerous."

"So," Anneke asked, "does that mean when Mother gets the right medication she'll be OK again and we can live in the trailer like before?"

Larry shook his head. "Your mom is confused. Even with the right medication she will have a lot of other things to work out with the counsellor."



Beyond Your Own Needs: Enhancing Caregivers Skills
A Four-Day Residential Workshop for the Caregivers of Schizophrenia

23-26 January 2004
Apte Hospital, India

For more information contact:
Institute for Psychological Health
Tel: (+91-22) 2543 3270 / 2536 6577
Email: iph@healthymind.org



International Conference on Schizophrenia: From Investigation to Intervention - Optimising Schizophrenia Care

Co-sponsored by the World Health Organization and the World Psychiatric Association

29 January - 2 February 2004
Chennai, India

For more information contact:
Dr. R. Thara, Director
Schizophrenia Research Foundation, India
Email: scarf@vsnl.com or info@icons-scarf.org



International Society for Bipolar Disorders Regional Group Conference
Bipolar Disorder: Improving Patient Outcomes

5-7 February 2004
Sydney, Australia

For information contact:
Conference Secretariat
ICMS Pty Ltd
Tel: +61 3 9682 0244
Fax: +61 3 9682 0288
Email: bipolar2004@icms.com.au
Website: www.icms.com.au/bipolar2004



WFSAD Biennial Conference - The Power of the Family Movement: Sharing the Knowledge

November 2-4 2004
Chennai, India

Preparations are underway for the 6th Biennial Conference of WFSAD to be held November 2-4 2004 in Chennai (formerly Madras), India. The biennial conferences serve a number of purposes including creating and strengthening networks, providing information and training to family delegates, to showcase achievements of family organizations worldwide and to promote the mission of WFSAD. This three-day conference will be hosted in partnership with two family organizations in India. Members of both Aasha, the oldest family support and advocacy organization in India, and the newly formed National Federation for the Mentally Ill, an all-India association of family organizations have been working closely with WFSAD Board Members and staff to organize this conference. Topics covered at the conference will include creating employment opportunities; providing housing; current treatment options; research on how to care; and more.

The WFSAD General Meeting of Members will also occur at the Conference and will bring together a vast source of knowledge and inspiration from WFSAD's 22 national family organizations.

On November 1, just preceding the conference, WFSAD will launch a Training College in Chennai that will offer training in methods of comprehensive care, capacity building for family organizations and leadership enhancement. Training will be offered to family leaders and mental health professionals in the form of one-day sessions.

Send us your events to be included in this section of the WFSAD newsletter.

Email: info@world-schizophrenia.org
Phone: +1.416.961.2855





Become a member

There are three categories of members:

National Voting Member Family Organization
(Annual dues \$100 US or \$150 Canadian)

Associate Member Family Organization
(Annual dues \$50 US or \$75 Canadian)

Individual Associate Member
(Annual dues \$25 US or \$38 Canadian)

Check the right category and submit your information below along with your payment by US or Canadian cheque or by money order obtainable at your bank.

Name:

Organization:

Address:

Fax:

Email:



Donate through the Sunflower Petal Circle

Join our circle of donors by making a regular gift to WFSAD through your Visa or MasterCard.

You may make quarterly donations of \$25, \$50 or another amount of your choice, or a one-time gift for the year.

Contact our office and a member of our staff will be glad to help you with this.

The board and members of the World Fellowship for Schizophrenia and Allied Disorders would like to convey their sincere thanks to the following corporations and foundations for their support of our programs during the past year.

The Pfizer Foundation
Pfizer Neuroscience
Astra Zeneca
Nona and Bill Heaslip
Eli Lilly (Asian Region)
Janssen-Ortho Canada
The Phrenz Group

Without your support, we could not possibly deliver the growing number of programs that we are committed to. Below are examples of the programs that have received support:

Families as Partners in Care
Mutual Exchange / Outreach - Asia
Mutual Exchange / Outreach - Africa
Mutual Exchange / Outreach
South America
Mutual Exchange / Outreach - Russia
Education and Support
Website Program
Publications Program

World Fellowship for Schizophrenia and Allied Disorders

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