

WFSAD Newsletter

World Fellowship for Schizophrenia and Allied Disorders Q4

In This Issue...

The Rights of Families	1
The Aasha Employment Project	7
Family Members as Case Managers – Report of an Iranian Study	9
The tale of an Ambulance.	12
Social Cognition and Schizophrenia: What's Emotion Got to Do with It?	14
Ian Falloon Memorial Award For Implementation Of Family Work	17
US Mental Health Plans to have Same Benefits as Plans for Other Medical Problems	17
Hope House	18
Street Play Draws Public Interest	20
Assessments for Schizophrenia	22
News from Korea of Amendments to the Mental Health Act	23
News and Info in Brief	24
Families as Partners in Mental Health Care	27
A Guidebook for Implementing Family Work	

THE RIGHTS OF FAMILIES

The rights of families have interested national, regional and local family organizations for many years. In countries across the world family organizations drew up lists of families' rights digging into their experiences with their mental health systems and the general attitudes of their society. Their demands were – and are - not excessive. They boil down to the need to be respected and listened to, because, after all, they are the chief carers, and when the above needs are met they can take on their role without shame and without isolation. We present a three-part piece on this topic. The first and major section is by Anil Vartak, Chairman of the Schizophrenia Awareness Association in Pune, India. It is derived from his presentation at a symposium -"International Diploma on Mental Health Law and Human Rights" organized by ILS Law College, Pune, in collaboration with WHO, Geneva.

Key Rights of Families and Carers *By Anil Vartak*

The Rights and Responsibilities of Families

Families and carers carry the responsibility

- For housing, feeding and clothing their unwell relative
- To ensure their unwell relatives take their treatment
- To find and use rehabilitation programmes
- To bear the brunt of disturbed behaviour
- To face stigma and discrimination
- For third party legal liability in some countries

Family Care giving role

- The family is usually the primary and only care giving unit
- Caring comes out of compassion and love
- Families have to make sacrifices in terms of time, resources and career advancement.

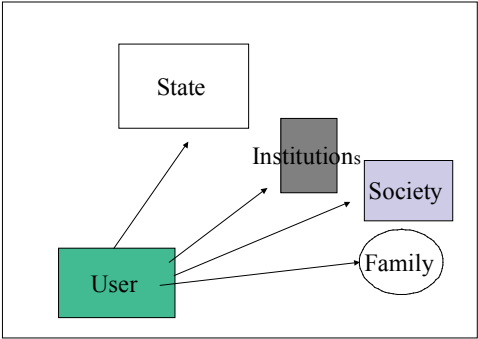
Hence family's views/opinions should be respected and the family should have rights in order to perform their care-giving role effectively.

There can be three positions as far as rights of persons with disability

continued...

are considered. In the first position the user is independent and has rights vis-à-vis all four segments in the society.

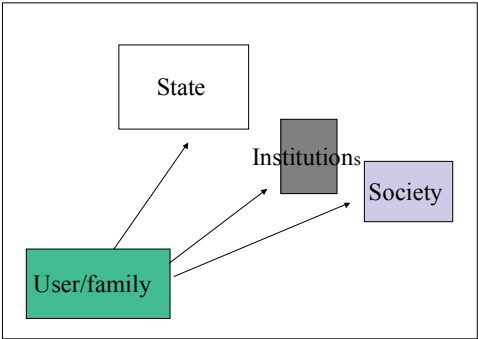
Extreme position



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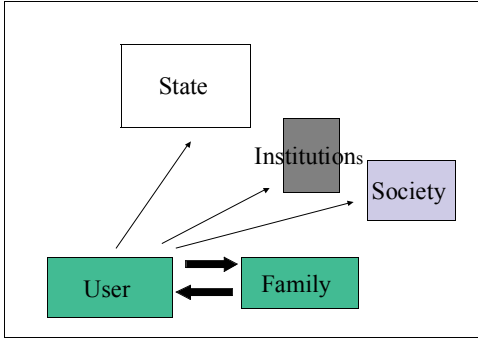
The `User` (a person with personal experience of mental illness) is an integral part of the family. The family is also considered a user (of mental health services). The Family is capable of making decisions on the person’s behalf.

Another extreme position



The independent identity of the user is recognized but at the same time it is recognized that the user is linked and has interdependence with the family.

This position is more appropriate for India





Families are important stakeholders and deserve representation. Such a right should be enshrined in legislation.

The family should have the Right to receive information about the:

- Nature of illness
- Need for treatment and its side effects
- Diagnosis
- Future course of treatment

in the language the caregiver can understand and according to the level of his/her understanding.[educated./non-edu.]

The family should also have the right to

- give any information about the user related to the illness to the service provider.
- seek a second opinion.
- receive education and training for taking proper care of the user.
- decide limits on their time and resources for caring.
- receive assistance for illness related expenses, training, counseling, financial assistance and respite care-UN – CRPD-28 (UN Convention of the Rights of Persons with Disabilities).
- receive help and support arising due to caring responsibilities.
- life.
- live a secured and peaceful life.

Representation

- Families are important stakeholders and deserve representation. Such a right should be enshrined in legislation.

Need for information versus the right to confidentiality

- Families and carers need information about illness and treatment to be better able to take care of their relatives.
- The extent of the right to confidentiality (sometimes called privacy) varies from culture to culture.
- Information should not be refused only on the grounds of confidentiality.
- Legislation should take local cultural realities into account.

Participation in Treatment Planning and Delivery

- Families and carers can play an important role in formulating and implementing treatment plans.
- In many countries due to absence of services
 - relatives and carers frequently are the only providers of long term continuous care.
 - have to implement a treatment and care plan of their own making.



Participation in Legal Aspects

- Families and carers should be involved in legal aspects eg.
 - The right to appeal against involuntary treatment on behalf of the person
 - Applying for discharge on behalf of the person
 - Being represented on review bodies

Participation in Policy Development

Development of

- mental health policy
- Mental health service planning
- Legislation

Guardianship

Mental health tribunals can be appointed which will consist of members of family organizations as well as officials of family organizations along with others.

A Code of Family Caregivers Rights

The first organization to publish a Code of Family Rights was the Schizophrenia Fellowship of New Zealand. In the early nineties the Fellowship drew up an attractive poster, which for many years was front and centre at many exhibits in many parts of the world. The Code is still available in brochure form at: <http://www.sfnat.org.nz/documents/Codeoffamilyrights.pdf>. Many family associations have now developed a code such as this.

Code of Family Rights (SFNZ)

For the family / whanau of a person who either has, or may be developing a major mental illness

People with serious mental illness are not ill in isolation: their families and whanau are almost always involved. When a person with mental illness chooses to involve their family and whanau as partners in care there are improved opportunities for recovery. It is clear that if families are educated and informed about mental illness, they are better able to give support. Some people with mental illness prefer not to involve their family/whanau in their treatment and support, when the family does not have a direct caring role. The extent to which family members are involved in treatment and support is ultimately the decision of the person, and mental health services need to respect his/her wishes. However, family/whanau and primary carers have legal and other rights to information and support. The aim of SFNZ is the best possible care and outcomes for all people affected by mental illness.

The family has the right to:

1. A family-centred approach to treatment and support where these exist

When a person with mental illness chooses to involve their family and whanau as partners in care there are improved opportunities for recovery.



2. Be treated with understanding and respect by mental health professionals
3. Be taken seriously by professionals when expressing concerns about changes in your relative's behaviour.
4. Information about a family member's illness, the diagnosis, treatment and possible side effects of treatment
5. Be consulted about a family member's hospital discharge plan
6. Inclusion in care planning, implementation and review
7. Culturally accepted treatment options which include the family
8. Information on the range of relevant services and supports available in the community
9. Provide relevant information about your family member's history, in confidence
10. Know the names and contact phone numbers of other members of the treatment team to determine such issues. In other places directors of services may be approached
11. A Mental Health service that recognizes the need for families to participate in shaping the service, and invites families to take part
12. A second opinion regarding diagnosis and treatment of their relative
13. Help for problems created or exacerbated by caring for family member with mental illness
14. Make a formal complaint should you or your family member in treatment be badly received or treated. In some jurisdictions there is an ombudsman service planning, implementation and evaluation to determine such issues. In other places directors of services may be approached.
15. A Mental Health service that recognizes the need for families to participate in shaping the service, and invites families to take part in service planning, implementation and evaluation.

Carers recognition act (Australia)

1. Carers must be treated with respect and dignity.
2. The role of carers must be recognized by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
4. Complaints made by carers in relation to services that impact on role of carers must be given due attention and consideration.

You may contact Anil at: avartak@yahoo.com

Anil offers a special thanks to Dr.Soumitra Pathare.

The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.



Comments received by WFSAD about Human Rights and the Rights of those with Mental Illness

On Human Rights

I have seen in so many countries now how families will still chain their loved one in a room, to the side of a building, hide them away from the neighbours.

I have seen in so many countries now how families will still chain their loved one in a room, to the side of a building, hide them away from the neighbours. Yet I am also aware that the doctors/nurses who visit those families do nothing to address the issue. I again visited a hospital in Chennai, It was built by the British during the 1700's and has not changed much. Neither has how the people are dealt with changed much either. I am aware that families try very hard to stop their loved on going into such a place. If they do go in it is because of a court order which is the only way the family can get treatment for the person. So a false charge is laid to cause this event.

A former WFSAD director

WFSAD recently received an email from someone in Turkey claiming to have been given ECT without anaesthetic even though it is against human rights legislation. We reported this to the World Health Organization and the Mental Disability Rights International NGO. We spoke with Canadian government officials, but we were given little hope of making any changes without considerable lobbying efforts.

WFSAD learnt indirectly about the situation in Uzbekistan. The news was that medical students are taught that it is the mentally ill who commit all the crimes. No one (among the mentally ill) is officially allowed medical treatment. Families have to sign a release so that the government can imprison their relatives in asylums where they are starved and beaten. No family organization can exist in this atmosphere. Meetings are impossible. In Uzbekistan you cannot make demands upon government. It was even said that psychiatrists were praised for the most number of mentally ill persons they committed to an asylum.

Abuses like cages and tying people to trees we must eradicate with education and alternatives of decent treatment.

A correspondent

Psychiatric treatment must not be portrayed as an abuse of human rights.

A correspondent

On Other Significant Rights

People with SMI (serious mental illness) must have the right to treatment that is up to date and evidence based as described in the documents of professional associations like the American Psychiatric Association Practice Guidelines for Schizophrenia 2004.

An American (US) correspondent

People with SMI should have the right to a disability pension for those whose illness prevents them from doing regular full time work, or the right to unemployment benefits. It is unfair and untrue to proclaim that schizophrenia is curable and that they are all able to work. Doesn't one have the right to be ill?

A correspondent in India

One of the biggest abuses is stigma which dissuades people and their relatives from seeking treatment and that must be addressed.

WFSAD director



A Caregivers' Bill of Rights from WFSAD's Family Education Course Reason to Hope

Families have drawn up a bill of rights to help them recognize their own personal needs and rights.

I Have the Right To:

- Take care of myself. This is not selfishness. It will give me the capacity to take better care of my loved one.
- Seek help from others, even though my loved one may object. I recognize the limits of my own endurance and strength.
- Maintain parts of my own life that do not include the person I provide care for, just as I would if he or she were healthy. I do everything I reasonably can for him/ her and I have the right to do some things just for myself.
- Get angry, be depressed, and express other difficult feelings.
- Reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- Receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- Take pride in what I am accomplishing and applaud the courage it has sometimes taken to meet the needs of my loved one.
- Protect my individuality and my right to make a life for myself.
- Expect and demand that, as new strides are made in finding resources to aid persons living with mental illness in our country, similar strides will be made toward aiding and supporting caregivers.

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The Aasha Employment Project

By Tanya Saieesh

Sundar Raman, Srinivasan, Arjun Prasad, Raman, Murli, K Venkatesan, Ramesh, Jamuna and Ravichandran are just the tip of an iceberg. These are the names of some of those individuals who have been rehabilitated in Aasha and specifically through the Aasha Employment Project. Today they are employed at places elsewhere and potential employers are beginning to look at them with a newer perspective.

Aasha Employment Project was the brainchild of Ratna Chibber, President of Aasha. In 1998 a project report sent to Abilis Foundation in Finland by Dr. Radha Shankar helped Aasha to get financial assistance to start the project. A decision was made to start a retail outlet to sell non-perishable goods where Aasha residents - who were at that time involved in other occupational therapy, would be employed for a few hours in rotating shifts. The first shop became operational in 2003.



World Fellowship for Schizophrenia and Allied Disorders Q4

Any resident who showed a desire to work in the shop was immediately considered and those who didn't want to were in no way pressured to take part in this venture. A supervisor in the form of a care-giver or staff of Aasha was present in the shop at all times to provide assistance. The employees of the Aasha shop were paid a stipend depending on the time spent in the shop. The shop was located close to the rehabilitation home in a fairly busy area. It was stocked with stationery, general household items, and contained beverage facilities –serving tea, coffee & soft drinks. A telephone booth was installed with STD & ISD facilities. The innovative combination of these services in one place proved to be a great selling point and in no time customers were lining up at the shop. It soon became apparent that very few residents wanted to continue with the chalk & detergent making that was being provided as occupational therapy. Most were becoming interested in spending time in the shop and interacting with the customers.

The whole premise of the Aasha Employment Project has been based on this above fact: to be able to capture the interest and create a motivational environment for the residents to thrive under and begin their journey towards rehabilitation.

The whole premise of the Aasha Employment Project has been based on this above fact: to be able to capture the interest and create a motivational environment for the residents to thrive under and begin their journey towards rehabilitation. By the creation of a unique environment that provides no threat, and unlike one they have experienced before, they find themselves more in control of their lives. Now they have a purpose. They want to go out there and make a difference. They want to get better and prove to their families that they can. A few days ago, one of the residents spoke about his experiences in the shop. It was startling and moving since it was the first time I had audibly heard this resident speak in the five years that he had been at Aasha home. It was a day as beautiful as it could be.



Today Aasha Employment is in the process of opening its fourth retail store. Aasha's second store provides photocopying facilities, telephone and beverage facilities and is located in an industrial area. The third shop is also a stationery and general store and the fourth store is engaged in the production of paper cups. All stores were financed through Aasha & other philanthropic organizations.

The Aasha shops have employees from other organizations as well and are not restricted to Aasha residents only. Other NGOs regularly send their members for rehabilitation to Aasha.

Aasha Employment aims to engage, empower, rehabilitate, and relocate as many mentally ill persons as possible.

In the words of Confucius, ***“Give a man a fish; he'll eat for a day, Teach him to fish and he'll eat for the rest of his life.”***

Aasha strives to educate mentally ill persons and their families in recognizing their ability to live as close to normalcy as possible.



Family Members as Case Managers –

Report of an Iranian Study

By Dr. Seyed Kazem Malakouti

Individuals With Schizophrenia Working As Case-Managers to Provide Home-Visit Service for Serious Mentally Ill Patients In Iran

The history of “after-care programs” in Iran is limited to the last 15 years in which some sporadic activities have been carried out as temporary action research projects.

Many kinds of aftercare services and their cost-effectiveness have been evaluated in different societies hitherto. Although provision of aftercare services for patients with serious mental illness (SMI) is among the national mental health programs of the Ministry of Health (MoH) of Iran, few research activities have been carried out so far. The history of “after-care programs” in Iran is limited to the last 15 years in which some sporadic activities have been carried out as temporary action research projects. The current study, carried out by the “Iranian Society Supporting Individuals with Schizophrenia” evaluated the efficacy of a home-visit model corresponding to a case-management service, in which family members of the SMI (FMSMI) were considered as case-managers to provide services. The main objectives of the current study were

- 1) to evaluate the effectiveness of the program
- 2) to examine the feasibility of considering family members of SMI performing as a service provider
- 3) to evaluate the cost-effectiveness of the program

In this study, which was based on non-randomized double blind clinical trial design, the participants received “home-visit” service for 12-months consecutively. The study was carried out in Tehran, the capital, from October 2005 to December 2006.

Different aspects of the patients and their caregivers’ life were considered to be evaluated as the outcomes of the study. Among these outcomes were:

- “caregivers’ knowledge about schizophrenia”
- life skills and quality of life of the patients
- health status and burden of having a patient with schizophrenia in the family
- positive and negative symptoms of the disease

Thirty naive mental health workers (MHW) with MS degree of psychology and 15 FMSMI with an educational level of high school diploma were selected from the candidates and trained theoretically and practically within separate groups (30 hours for MHW and 60 hours for FMSMI) in a one month period. Three persons of each group were approved and selected as case-managers via oral and written examination.

Allocation of study subjects to two groups was not random, but comparing the demographic and psychological characteristics did not reveal any significant differences between the two groups.

Group-discussion and telephone contact was made to find out the possible reasons for refusing the offered service. These were:

1. Being afraid of unveiling the secrecy of having a family member with mental disorder
2. The offered services do not meet the needs of the patient and the family. They expected financial aid, a general practitioner to visit the patient at home, or rehabilitation and day center to keep the patients out of the house for a while
3. The offered service was not helpful in the emergency occasions and the case-manager was not responsible for finding a place to hospitalize the patient in case of relapse
4. The case-managers were not fully skilled

176 subjects with schizophrenia who gave informed consent participated in this study. They were allocated to each case-manager (CM) according to their residential areas: 98 to FMSMI and 78 to MHW. Forty seven subjects [(34 from family members and 13 subjects from health workers, ($p < 0.05$))] dropped out of the study. The study results showed that the training course was successful in increasing the knowledge of all case-managers about schizophrenia ($P < 0.05$). Statistical analysis showed no significant differences between the two groups before and after training. Allocation of study subjects to two groups was not random, but comparing the demographic and psychological characteristics did not reveal any significant differences between the two groups. Using statistical analysis, the results showed significant differences within groups in caregivers' knowledge, caregivers' burden, patients' quality of life, the severity of patients' psychopathology and social skills of the patients after a year of home-visit intervention ($P < 0.05$), but did not reveal any significant differences between groups.

The result of the current study showed that 0.15 of the study subjects were hospitalized within one year of receiving case-management service, whereas it was 0.45 per year according to their past histories of suffering from Sz. This means that this kind of service succeeded in reducing the hospitalization rate by 67%. The study results show that the family members are capable enough to be trained and perform as a professional career of case manager.

The results showed that even before the training course took place, the FMSMI' knowledge was not different so much from the MHW. This could be due to the familiarity of





The waiting list for being hospitalized even for the patients in acute phase indicates the shortage of facilities for the SMI patients.

the family members with the signs and symptoms of the disease through long term family experience. Concerning the shortage in the budget or for those areas with shortcomings in mental health staff, this could be an important message to the policy makers to use FMSMI of schizophrenia patients as mental health workers in the mental health programs.

Currently, the mental health facilities of Iran are suffering a shortage of available psychiatric beds to serve the patients in case of exacerbation or requirement to be hospitalized for short-term period. With the best estimation, the mental health network provides acute psychiatric beds for only 30 to 50 percent of current need. The waiting list for being hospitalized even for the patients in acute phase indicates the shortage of facilities for the SMI patients. Providing and expanding home-visit services while increasing the patients' quality of life and additionally will reduce the needs of the mental health system for acute psychiatric beds.

As a conclusion, in our socio-cultural situation, case-management services have excellent outcomes on psychological indices and rate of hospitalization. These differences could be attributed to the following reasons:

- 1) In our society most of the SMI patients are dependent on their families for their basic needs. Due to shortage of facilities, paying any attention to them and providing a sort of charge-free service was considered a great virtual support which would reduce their isolation and burden of having a loved one with SMI
- 2) Pharmacotherapy is a cornerstone of treatment of schizophrenia. A home-visit service is able to increase the compliance of the consumers with drug prescription and consequently better control of positive symptoms which are one of the major sources of caregivers' burden and rehospitalization.

Although the results of this study do not mean that the MHWs should be replaced by the FMSMI, the most important practical implication of this study is that the FMSMI are capable enough to rely on to deliver the services, particularly for regions with a shortage of mental health workers, and they could behave as an aid case-manager in the mobile team to provide home-visit services for the SMI patients in the urban areas. In this way, the policy makers provide an opportunity to promote the self-confidence of the consumers and earn a regular income.

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The tale of an Ambulance

By Nirmala Srinivasan, PhD

After attending the NAMI* San Diego convention in 2000, I moved to Sunnyvale, California, where I stayed for six months along with my son. During this stay, we were active participants in the activities of NAMI San José. That was a learning experience that was of immense help in my advocacy initiatives back home in Bangalore, India.

AMEND was set up in 1992 at the initiative of a user and began as a self help group of family carers and users. Lack of emergency help to families ranked foremost among the several problems discussed by the group. A local psychiatric nursing home and also a Senior Citizen NGO came to our help and offered to handle emergencies by shifting the patient to the hospital irrespective of the need for admission. This arrangement continued successfully for a long time. Patients' protests were handled by diplomacy, duplicity or occasional force. Many families could not afford the ambulance charges. Families also felt that a lot of unwanted physical force was used by the staff who were not familiar with psychiatric patients.

Between 1998 and 2000, AMEND participated in international conferences such as the World Association for Psychosocial Rehabilitation Congress (1998), World Congress of Psychiatry (1999) and NAMI at San Diego (2000). In the course of our interaction with the other international family associations and NGOs, we realized the deplorable state of affairs in community support for family care of mental patients in India. I always used to wonder how my city Bangalore got the caption of being the mental health capital of India even without the basic amenity for ensuring that the patients are helped in a crisis to move into a hospital in a dignified and safe manner.

In 2000, I was made a member of the State Coordinating Committee in the local government under the Persons with Disabilities Act, the precursor to United Nations CRPD (Convention on the Rights of Persons with Disabilities). We shared the problems about mental illness and emergencies and foremost among the issues were lack of ambulance services in India as a whole, including Bangalore. As per the directions given by the Commissioner of Disabilities, we wrote a letter to the State Mental health Authority (SMHA) in 2000. We received a verbal response that the medico-legal clauses of the Mental Health Act do not permit patients to be picked up from home because of possibilities of abuse. Many of us in AMEND felt even more scared to hear of law suits because we were deeply hurt and confused at the perception of the mentally ill as legal cases!

Meanwhile, all emergency calls were directed either to me or to the State Commissioner for Disabilities and in turn, we used to seek the help of private psychiatrists to send the ambulance. This was not always

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successful! One patient committed suicide for lack of timely help; another case wound up with the neighbours sending the family out of the community due to the patient's symptomatic threats. Many harrowing tales of family tragedies, many of which could have been averted by running the Emergency Psychiatric help.

Soon after, we set up ACMI (Action for Mental Illness) in 2003, with the State Sub Committee on mental health, but in vain. In the meantime, the Disability Commissioner and ACMI were receiving calls from patients and families in crisis. The Disability Commissioner played an important role in facilitating police intervention under Sec 23 of the Mental Health Act(MHA). In Aug 2007, a major tragedy occurred in one of the families in the absence of timely help reaching the patient. ACMI took legal opinion from the then Advocate General of our State. He was categorical that the MHA does not have any risks for anyone; in fact, he quoted Sec 3 and Sec 4 that States that the Central and State MHAs were in charge of supervising ambulance services.

Our relentless efforts paid well. Senior officials in the Dept of Health were convinced of the critical need and overruled the views of the mental health professionals that an ambulance can land them up in law suits! Negotiations and deliberations took almost one year to ensure that the legal norms for protection of patients' rights and at the same time provide immunity to the staff.

Shortage of funds became an issue because this Project was not budgeted for in the annual budget of the health department. Recruitment of nurses, salary of the ambulance staff and purchase and maintenance of ambulance necessitated the advent of the PPP (Public Private Partnership) model involving the Government Department of Health, the Rotary Club, Amend, ACMI and private grants from the Corporate sector as well.

On World Mental Health Day, Oct 10th 2008, India got a dedicated service for psychiatric patients. The service is provided completely free of cost. This pilot project operates only in urban Bangalore that has the highest suicide rates in India, 3000 per year!

WE HAVE MADE IT HAPPEN AFTER EIGHT YEARS! Now, I am working with the Ministry of Health in the Government of India to enforce it all over the country. I hope it will happen soon and not take another decade.

Dr. Srinivasan is Director and Trustee, Action for Mental Illness, Bangalore, India.

** National Alliance for Mental Illness, United States national family and consumer advocacy group, a voting member of WFSAD.*



Social Cognition and Schizophrenia: What's Emotion Got to Do with It?

By Diane C Gooding, PhD

Thanks to the advances in both the pharmacological and psychosocial treatment of schizophrenia, more people with schizophrenia are living in and contributing meaningfully to the community than ever before in history. Comprehensive programs such as the Program for Assertive Community Treatment (PACT) [Ed: ACT teams in other areas]... and the Clubhouse movement ... are examples of some of these advances. Despite the considerable strides that have been made, there remains much room for improvement in terms of quality of life for people with severe and persistent mental disorder. Many believe that by improving the social-emotional dysfunction in schizophrenia, we will be better equipped to maximize the community functioning and quality of life of people living with the disease. Objective indicators of quality of life include a person's health status and their access to resources and opportunities, whereas subjective indicators of quality of life include a person's sense of well-being and satisfaction with life.

Negative Symptoms and Schizophrenia

Symptoms in which normal functions are diminished or absent are known as negative or deficit symptoms. One of the most common negative symptoms that schizophrenia individuals have is flat or reduced affect. Flat affect is typically seen by the individual's paucity of expressive gestures, unchanging facial expression, lack of vocal inflection, poor eye-contact, and decrease in spontaneous movements. While most schizophrenia patients show greatly reduced expression of emotion, their experience of emotion can be at normal levels. This has several implications for the person with schizophrenia, as well as for their loved ones. First, the person with schizophrenia may need to be encouraged to verbalize his or her feelings more directly because those feelings may not be readily apparent from his or her facial expression, due to what is known as flat affect. Relatives, friends, and other significant others in the lives of a person with schizophrenia may do well to remember that even if the person does not express sadness in his or her vocal inflection, facial expression, or gesture, that does not mean that the person is not experiencing sadness.

In one study that examined the social cost of flat affect, individuals with schizophrenia discussed an emotionally charged topic with an individual who did not have schizophrenia. The study revealed that the schizophrenia person's inexpressiveness evoked negative reactions, namely, sadness and fear, from their interaction partners. This is significant, because it suggests that healthy individuals are responding

One of the most common negative symptoms that schizophrenia individuals have is flat or reduced affect.



to the lack of facial expressions among individuals with schizophrenia –something that they are doing on purpose---in a negative manner. Clearly there is a need to educate the public in terms of how better to interact with people with schizophrenia.

In addition to the negative symptom of flat affect, many individuals with schizophrenia experience anhedonia, or an inability to experience pleasure. However, more recent developments in the study of anhedonia have provided new insights into the nature of anhedonia in schizophrenia. Researchers such as Dr. Ann Kring at the University of California at Berkeley have emphasized the importance of distinguishing between consummatory pleasure and anticipatory pleasure. Whereas consummatory pleasure is pleasure in the moment, when a person is directly engaged in the enjoyable activity, anticipatory pleasure involves pleasure that is experienced in anticipation of things to come`.

Although people with schizophrenia report as much consummatory pleasure as healthy individuals do, they differ in terms of their experience of anticipatory pleasure. Compared to healthy controls, individuals with schizophrenia experience less pleasure in anticipation of future events. This deficit in anticipatory pleasure can have a negative impact in terms of one`s daily life, as well as in terms of one`s family interactions and general social functioning. For example, many individuals become excited in early December in anticipation of the upcoming holidays, holiday parties and family gatherings. However, if an individual were unable to derive enjoyment from looking forward to those events, he or she would be less likely to agree to participate in them. This might cause family conflict and/or resentment. Moreover, such a deficit in the ability to anticipate pleasure may contribute to limited social engagement with others and/or social isolation. It is presently unclear which neural circuits may underlie this specific type of anhedonia, though dopamine is thought to be involved.

Affective Deficits and Schizophrenia

There is also a large body of studies, including some from my lab, that indicate that schizophrenia patients have a reduced ability to perceive emotion. That is, people with schizophrenia often demonstrate a significant impairment in their ability to identify and accurately interpret emotions from facial expressions. These affective deficits, namely, impairments in emotion perception and emotion processing, have been closely associated with the inability of many people with schizophrenia to interpret various social cues appropriately and in the proper context with respect to a given social situation. This impaired ability to derive accurate social judgments in common everyday situations may present a real-world burden to individuals living in the community.

This impaired ability to derive accurate social judgments in common everyday situations may present a real-world burden to individuals living in the community.



Social Cognition

What is social cognition? Briefly, social cognition can be defined as the ability to perceive, interpret, and respond to social situations and interactions. Social cognition is a multifaceted construct that includes the ability to perceive others' mental states (this is known as Theory of Mind), the ability to recognize affect, and the ability to accurately identify and interpret emotional meanings from the environment. Social cognition can be distinguished from non-social cognitive processes such as memory and general problem solving.

Social cognition is a multifaceted construct that includes the ability to perceive others' mental states (this is known as Theory of Mind), the ability to recognize affect, and the ability to accurately identify and interpret emotional meanings from the environment.

The study of social cognition in schizophrenia is a relatively new and growing area. However, there is some evidence indicating that people with schizophrenia display deficits in social cognition. The ability to take the perspective of the other person as well as to correctly assess another person's likely response based on their facial expressions, are of course very adaptive skills to have for daily social interactions and community living. More research is needed in order to address the following questions: first, what is the nature and extent of the social cognitive impairments seen in schizophrenia? And second, what is the relationship between different aspects of social cognition and community functioning in individuals with schizophrenia? Finally, to what extent, can social cognition deficits be remediated?

At present, it appears the theory of mind deficits displayed by people with schizophrenia are less severe than those displayed by people with autism, another complex neurodevelopmental disease with genetic origins. The neural circuitry underlying social cognition is uncertain, though it is thought to include the temporal cortex and the amygdala, along with the orbitofrontal and medial frontal cortex. Research is in the planning stages; stay tuned.

Improvements in an individual's social cognition may also facilitate one's relationships with siblings and other loved ones. Hopefully, with greater understanding and treatment of the impairments in social cognition, we will be better equipped to assist people with schizophrenia to, as Maya Angelou would say, not simply survive, but to thrive.

Diane C Gooding, PhD, Professor of Psychology and Psychiatry at UW-Madison, teaches courses in Abnormal Psychology, Psychotic Disorders, Schizophrenia, and The Media and Mental Illness. She is a former board member of NAMI Dane County and NAMI Wisconsin. Her area of research specialty is schizophrenia.

Our sincere thanks to Professor Gooding and The Pioneer, the Newsletter of NAMI Dane County, Inc., Madison, Wisconsin for allowing WFSAD to use this article which appears in their December 2008 issue.



Ian Falloon Memorial Award For Implementation Of Family Work

Here Julian Pitt and Lynne Roberts (left and centre) receive the Ian Falloon Memorial Award 2008 from Nancy Falloon



A new biennial award has been established by the Falloon family in memory of their distinguished member, Professor Ian Falloon, who sadly died in 2006. Prof. Falloon worked throughout his career to ensure that those with serious mental illness receive high quality care. He was particularly interested in developing services that would include families, and his evidence-based psychoeducation model of family work is employed worldwide. The award is given for services demonstrating excellence in developing services to families of those with serious mental health difficulties.

Hosting the award ceremonies was the Meriden Family Programme (*West Midlands, U.K.*) during their 10th anniversary celebrations.

The first recipients are Dr. Julian Pitt and Lynne Roberts, Nurse Consultant, from the ACT Service (*Addysg y Chymorth Teulodd*) Education and Support for Families at St. Tydfil's Hospital, Merthyr Tydfil, Wales. They were presented with their award by Nancy Falloon.



US Mental Health Plans to have Same Benefits as Plans for Other Medical Problems

'It took a long time to get Congress to learn that mental illnesses are no-fault illnesses and that people who have them deserve help,' said Carolyn Robinowitz, M.D., immediate past president of APA. She was referring to the new "parity"* act recently passed by the U.S. legislature.

The November 7 issue of *Psychiatric News*, a publication of the American Psychiatric Foundation, reports in an article by Rich Daly, that the US Congress has enacted a landmark federal mental health insurance parity law. We paraphrase and quote from Mr. Daly's text.

The parity measure was passed in a quick and little opposed Congressional vote that was part of the massive financial industry rescue package (HR 1424). It requires health plans that offer mental health coverage to have the same benefits, co-payments and treatment limits as other types of health care. The law will give 113 million people across the U.S. the right to non-discriminatory mental health coverage and will go into effect one year after enactment or on January 1, 2010 for most plans.

The outcome was not as smooth and sudden as it seemed to many



outside the mental health field, but was hard earned through decades of relentless work by American Psychiatric Association members and staff, in alliance with other mental health advocates, to overcome the opposition of insurance and business representatives to parity.

The first federal mental health parity law was passed in 1996 under the guidance of Senators Pete Dominici and Paul Wellstone who both knew personally the devastating impact—financial as well as emotional—on families with a mentally ill relative. Their efforts led sponsors to title the parity bill passed last month the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008.

The next step will be the drawing up of regulations to implement the Act. Among the critical issues that regulators must decide is how to implement the law's provision allowing employers to opt out of providing parity mental health coverage if it becomes too costly.

Future legislation may be necessary if follow-up studies determine that companies are dropping mental health coverage altogether or sharply limiting the psychiatric or substance use conditions they cover.

In addition to the need to educate legislators and the public, the parity battle taught APA leaders that the use of coalitions and partnerships is critical.

'You don't get what you want just because your cause is right and just,' said APA Medical Director James H. Scully Jr., M.D. 'You have to do the hard work of building coalitions and getting allies.'

** The word parity can be defined as equality or equivalence as it refers to equal treatment opportunities for those with mental illness as for those with other illnesses. Up to the present, health insurance companies have often refused to give similar benefits for those with mental illness.*

Future legislation may be necessary if follow-up studies determine that companies are dropping mental health coverage altogether or sharply limiting the psychiatric or substance use conditions they cover.



Hope House

By Jess Mackintosh

Seven years ago I had a dream – a dream for my daughter and others suffering from schizophrenia - that they could live in a house and enjoy the support and care they deserved, the independence they longed for and the warmth and love we all thrive on. When we opened the doors of Hope House in July 2002 I pinched myself to make sure that I was not still dreaming.

Hope House arose from the need to find a secure home for my daughter and others suffering from mental illness where they would receive the respect and care they deserved. There was no facility in Cape Town at that time which provided what we were seeking.



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Our residents have thrived. They are happy, stable and enjoy life with the independence they had wished for. They have bonded as a family.

I remember the excitement of the first meeting in my lounge, the pages of plans, the thoughts of possible fundraisers, the relief that at last something practical was being done. After months of hard work and fundraising we bought a large property full of potential. The excitement was huge! Six months later after extensive alterations our first female residents moved into Hope House. The time had come to celebrate.

Hope House has exceeded our expectations. Entering Hope House you hear laughter, chatter, teasing, the dog chases the cats, the piano is played and the aromatic smell of a delicious meal comes from the kitchen – everything a home should offer. Our residents have thrived. They are happy, stable and enjoy life with the independence they had wished for. They have bonded as a family. They care for, respect and enjoy the company of each other. They understand each other and often discuss their illness; drawing courage from each other as well as offering support should a member not be feeling well.

What has been our success?

Firstly, the trustees, friends and family worked hard to raise sufficient funds to finance all capital expenditure thereby ensuring that the Trust is free of debt. We achieved this in our first year. We do not have the anxiety of financing interest on loans. We have continued to fundraise in order to improve the property. Over the last six years we have added an extra bedroom wing and converted the carport into an activity room where our skills therapists and volunteers conduct art and music classes and physical activities such as aerobics.



Secondly we chose our residents carefully. The selection committee comprises a psychiatrist, social worker and a trustee who interview prospective applicants, investigate their past medical history and background and endeavour to ensure that successful applicants will relate well with our residents and that the harmony in Hope House will not be disturbed. Our residents were selected as a family with staggered ages. We have made mistakes. Twice we

accepted residents with bi-polar disorder. The other residents suffer from schizophrenia. The differences in the illnesses have different needs for stability which resulted in disruption. Today all our residents suffer from schizophrenia.

Thirdly, with the support of excellent staff we have been able to create a stress-free environment which we find is most important for people suffering from a mental illness, especially schizophrenia. Their days are structured and the residents have a set routine which they enjoy. For five days each week a skills therapist assists the residents with different crafts and activities that fill their days. They enjoy art, music, sewing, aerobics,



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photography and many other forms of activity. Outings are arranged on a regular basis. During the last four years two of the residents have been successful in starting small cottage industries. What joy the first time a large order was placed for a delicious lemon drink – all the residents celebrated! The weekends are less structured and the residents are free to spend this time as they wish. Friends visit, movies are watched, it's a time to relax.



Finally, the residents understand that medication compliance is non-negotiable and substance abuse prohibited.

The dream came true – with much help from so many. Generosity has taken on a new meaning as friends, colleagues and sometimes strangers continue to give financially or of their time.

Hope House is not an institution. It is truly a home. Our residents have commented “I feel privileged to live here”, “I have made such wonderful friends” and “It's such a Lekker Place”.

*Jess Mackintosh is the Chairperson of
Hope House Trust, Cape Town, South Africa.*



Street Play Draws Public Interest

By Namdev Gawas

Mental Health Awareness Programme at Pernem College, Goa

One of the more eye-catching and interesting events on World Mental Health Day was a fifteen minute street play performed by the students of Pernem College which was enacted in a number of places in Goa.

Using the local language, the play, entitled “Aabhas”, depicted a girl suffering from mental illness after she got the shock that her brother was killed in a terrorist attack in front of her. The parents do not accept it, and taking the neighbours' advice, take her to a black magician, which worsens her health. She thinks and feels that her dead brother is with her all the time and she speaks with him. Her parents say that she should have been killed not their son. She wanders on the road, the people make fun of her and she retaliates by attacking people. Finally, her brother's friend comes and take her to the psychiatrist where she gets help to recover. The psychiatrist (during the play) tells the passers-by and the crowd about the illness and at the climax puts the question: if the girl wants to recover isn't it society's duty to also provide support to her? The crowd are asked to respect people with mental illness.

There was a wonderful response to the play in all the places it was performed. In mid-October it was presented at Parsem Bhagvati Mandir,

Using the local language, the play, entitled “Aabhas”, depicted a girl suffering from mental illness after she got the shock that her brother was killed in a terrorist attack in front of her.



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Siolim-Tar, Calangute and Mapusa, at the bus stands; at Colvale, Virnoda, Mandrem and Pernem at crowded places. Later the play was presented in the Hospital Campuses of Asilo Hospital, Mapusa; Institute of Psychiatric & Human behaviour, Bambolim; and Goa Medical college for the medical, para-medical and non-medical staff and the passers-by, increasing local awareness on Mental Health.

The street play was written by Mr. Vinay M. Madgaonkar, Lecturer in Marathi, Govt. College, Pernem and directed by Mr. Manoj Chindarkar, film actor and drama director. Fifteen students from the government college, Pernem, took part. Dr. Peter Castelino, Director of COOJ ("Cause of our Joy"), Ms. Martha and Mr. Augustine; Members of COOJ, accompanied and encouraged the students. Mr. Namdev M. Gawas, Lecturer in Commerce and convenor of medical services cell was the coordinator of the Street Play, assisted by Ms. Neeta Torne, Lecturer in Marathi and Jt. Convenor of the Medical Services Cell, Govt. College, Pernem.



Sponsors of the World Mental Hhe Committee on College-Community Interface and the Medical Services Cell of Govt. College of Arts & Commerce, Virnoda, Pernem in association with COOJ, and Mapusa, a Charitable Trust providing Mental Health Services in Goa.

Note: Namdev Gawas writes more recently that the play is even more significant with the recent terrorist attacks in Mumbai (formerly Bombay).





Assessments for Schizophrenia

We reproduce here, thanks to the Schizophrenia Society of Canada (SSC), a useful table on medical assessments for schizophrenia contained in the booklet Schizophrenia: The Journey to Recovery - A Consumer and Family Guide to Assessment and Treatment. The booklet is available on the SSC website: www.schizophrenia.ca

Not all of the assessments which follow are necessary for every person. * Also some tests may not be available in every community or clinical setting. Some of the assessments which may be done include:

Type of Assessment	Purpose
Blood Work <ul style="list-style-type: none"> Blood Chemistries Blood Sugar Hematology Toxicology screen Lipids 	<ul style="list-style-type: none"> Check kidney, liver and thyroid function Screen for diabetes and when there is weight gain Complete blood count (CBC) Screen for substance use or abuse Cholesterol tests; total cholesterol, low density and high density lipoproteins, triglycerides
Body Mass Index (BMI)	<ul style="list-style-type: none"> Monitoring for healthy waist circumference when changing medications and every three months when stable. General measure recommended for all adults
Cognitive function <ul style="list-style-type: none"> Neuropsychological testing 	<ul style="list-style-type: none"> Testing could include working memory, attention, visual learning and memory, reasoning and problem solving, etc. These tests are not about “right” or “wrong” answers; the objective is to find out how the brain is working
Cardiovascular	<ul style="list-style-type: none"> Pulse and blood pressure Monitor when changing medications
Endocrine and sexual	<ul style="list-style-type: none"> Lack of sexual interest or drive or lack of sexual function; functioning such as inability to get an erection or have an orgasm can be caused by a number of social or physical reasons including medications. If a person has concerns in this area they should speak with their physician. Identify any behavioural risk factors for sexually transmitted diseases or HIV
Extrapyramidal symptoms and signs	<ul style="list-style-type: none"> Side effects caused by too much dopamine blockade due to antipsychotic medication. They can be stopped by adjusting the dose or type of medication. Symptoms include Parkinsonism (rigidity, tremor), uncontrollable movement in the face, arms and legs, etc.
Genetic	<ul style="list-style-type: none"> Only needed if these are physical signs suggestive of a genetic abnormality Screen for chromosome deletion syndrome
Infectious diseases	<ul style="list-style-type: none"> Screen for syphilis, hepatitis or HIV is a behavioural risk factor has been identified
Level of function	<ul style="list-style-type: none"> Ongoing assessment of social, occupational or vocational and living situation
Psychopathology	<ul style="list-style-type: none"> Monitor positive and negative symptoms; disorganization; mood; suicide, aggression or impulsivity.
Substance use / abuse	<ul style="list-style-type: none"> Alcohol Tobacco Street drugs Prescription / over the counter
Structural brain	<p>CT or MRI if it is considered necessary. Helps to rule out brain damage and supports the diagnosis of schizophrenia as an illness.</p>

**** The range of assessment may depend on available resources in the community or nearby.***



News from Korea of Amendments to the Mental Health Act

For Members of the Asia-Pacific Patient/ Family Forum

By Choon-Jin Kim of the Korea National Assembly

By attending the Asia-Pacific Advocacy Skills Workshop of 2006 and 2007 I was able to understand the pain and suffering of families with relatives with mental disorders in Asia-Pacific countries and who share the wisdom and technology to overcome the difficulties by relying on each other.

At the last workshop I spoke of the seven revised bills of the pending Mental Health Act. These were finally passed as amended on the February 19th 2008.

I want to share this good news and introduce the content of the amendment.

First, *A National, City-Province-regional mental health Business Plan shall be established to systematically carry out the mental health business.*

Second, *Civil rights education shall be required for people engaged in implementation and management as well as employees of mental health institutions and professionals of such institutions, so that infringement of the human rights of patients by the employees of such institutions or the patients themselves shall be prevented.*

Third, *Rehabilitation facilities are to become diversified so that the patients with mental disease can return to society after being discharged from the mental health institution.*

Fourth, *the Minister of Health and Welfare shall evaluate the mental health institutions every 3 years to manage the quality of the institutions and the service.*

Fifth, *until now volunteer patients did not have to go through continuous hospitalization evaluations, hence they faced problems about their long term hospitalization. In order to solve this the heads of mental health institutions and such shall have the authority to confirm the intention to be discharged at least once a year for the volunteer patients, so that a system platform for volunteer patients being able to be discharged from long term is provided.*

Sixth, *in order to go back to regional society after being discharged from the mental health hospital, a variety of services*

At the last workshop I spoke of the seven revised bills of the pending Mental Health Act. These were finally passed as amended on the February 19th 2008.



in regional society is necessary. Hence, the heads of the mental health institutions, at the consent of oneself or the guardian, shall notify the mental health centre or public health centre of the discharge so that the means for connecting the mental health facility service to the regional service is provided.

Seventh, *Regional Mental Health Deliberation Committee shall be divided by metropolitan mental health deliberation committee and basic mental health deliberation committee. Hence the long-term hospitalization deliberation shall be activated and substantiated.*

Eighth, *An outpatient system shall be implemented so that patients shall not be limited to being treated in the hospital and institution but also be able to be treated in their region as well.*

Ninth, *it was stipulated that mental patients who have been hospitalized long term shall not be forced with inappropriate labor or abuse.*

Patients and family, there's no guarantee that these amendments will all be carried out. However, I will try my best to see that these amendments are carried out as stipulated.



News and Info in Brief

World Congress of Mental Health

To be held in Athens, Greece from 2 to 6 September 2009. The Congress will be organized by the World Federation for Mental Health in collaboration with the Hellenic Psychiatric Association and the Society of Preventive Psychiatry. The first announcement and Call for Abstracts was just received by WFSAD. Deadline for Abstract Submission is February 2nd 2009. The Congress President is Prof. George Christodoulou. Congress email: info@era.gr. Website: <http://www.era.gr/>

International Journal Now on the Web

Developing Mental Health is an International Journal for Mental Health Care that is published quarterly by Icthes World Care. There are few medical publications directed towards the developing world where few text books or journals are available. This journal is for physicians and all those in a position to treat patients with mental health issues. The issue we received recently (Volume 5 Issue No. 7 2007) is devoted to adolescent depression, bipolar Affective Disorder and Late Life Depression. There are also case studies in HIV and Psychiatry in Zambia.



We thoroughly recommend this publication which you may be able to find on the Ichthes website: www.ichthesworldcare.com. We quote from part of the Adolescent Depression article:

Families need encouragement to understand what is over-burdening their teenager. A 'generation gap' can create misunderstandings.

...Most teenage depression is reactive to psychosocial adversities and deprivations. Management requires counselling or social work, as much as medications. Families need encouragement to understand what is over-burdening their teenager. A 'generation gap' can create misunderstandings. For instance, the Brain Fog Syndrome in Africa is an anxiety/depressive state related to the overexpectations of education by the older generation (Guinness, 1992). However, it occurs in many developing countries. A good description of how to manage it is given in Vikram Patel's book, Where There is No Psychiatrist (Patel 2003). More difficult to manage is family breakdown, abuse or deprivation. Coping with the tragedy of AIDS orphans and street children, without adequate Social Services is even harder. Young people may have to take on adult tasks before they are ready.

Letters from Uganda Schizophrenia Fellowship

Jinja

I wish to applaud WFSAD and WFMH for exploring the merger. We have a saying that "It is only when both the upper and lower teeth join together that they can bite and chew the meat". So Unity is Strength.

USF Jinja Branch is currently involved in Drama on Mental Health to reduce stigma for people with psychiatric conditions. They are engaging in crafts for sale and mixed farming, but users lack a market. We also run weekly radio talk shows on mental health. However, the radio management wants us to get a sponsor for the talk shows since we have only been sampling for the past two months. Each talk show costs 800,000 Ugandan Shillings for an hour once weekly and we intend to sensitize the public on mental health issues for at least six months.

I would very much appreciate more information on prevention of suicide. [Ed. WFSAD called on its members to provide any practical information they might have as a resource for the upcoming Suicide Prevention shared initiative between WFMH and WFSAD.]

Anyone willing to support us in any of the above priority areas would be very much appreciated.

Emmanuel Mufumba, Jinja Schizophrenia Fellowship.

Kampala

Uganda Schizophrenia Fellowship needs soccer (football) uniforms for their patient/family recreational teams. If you know of uniforms that are no longer used by adult or teenage teams perhaps you could post them to Thomas Walunguba. Uganda Schizophrenia Fellowship, P.O. Box 27321, Kampala, Uganda. Email Thomas at thomaswalunguba@yahoo.com

Photos from the recent Mental Health Rally held by USF in August.



New Supportive Website

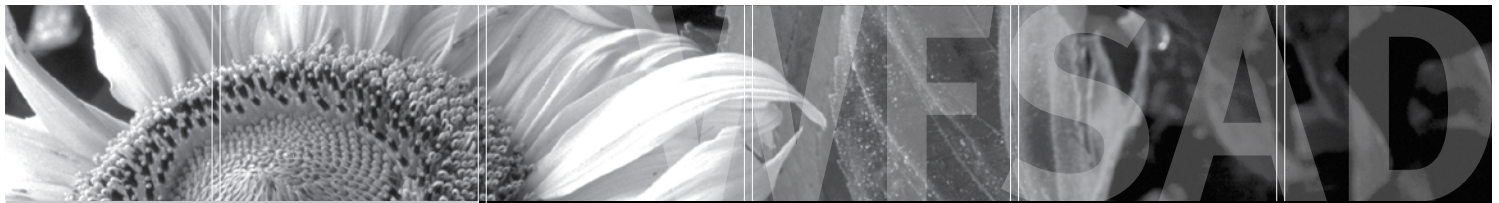
Learning to Care Learning to Live Again is the motto of a new website organized by WFSAD Member and Jeffrey Breslaw, who delivers Family Supportive Training in England. Go to this interesting site at:

<http://www.caring4carers.org.uk>

Speaking Books

The South African Depression and Anxiety Group, have launched an innovative tool called "Speaking Books" which is a interactive book with colourful pictures, text and a soundtrack which guides young people through a step by step journey to recovery. The product complements the service delivery of building capacity for home based care givers, community leaders, teachers, social workers, church leaders, traditional healers, patients and their families. The speaking books and community based workshops contribute to the wellness of the community by offering a service and invaluable product for free to a rural, under resourced area: communities in the North West Province where there is a population of 3.8 million there is only one psychiatrist for the population.

<http://www.sadag.co.za/index.php/Events-Announcements/Press-Release-Mental-Health-Speaking-Books.html>



Announcing WFSAD's New Guidebook!



This newsletter is an international bulletin published by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD).

Our goal is to provide 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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Families as Partners in Mental Health Care

A Guidebook for Implementing Family Work \$29.50 (CAD) + S&H

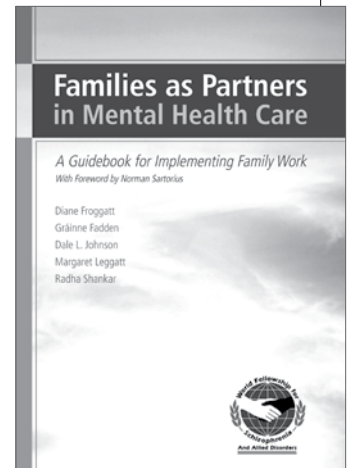
- A collaborative project by leading experts in family work from around the world
- Based on Ian Falloon's pioneering work on family psychoeducation
- Edited by Diane Froggatt, Gráinne Fadden, Dale L. Johnson, Margaret Leggatt and Radha Shankar

Why? The aim of the book is to inform and motivate more people and mental health services to adopt and implement family work as part of basic care.

How? In a down-to-earth way the guidebook describes how professionals can involve themselves in working with the families/carers of their clients for better relationships and superior outcome.

What? Terms such as psychoeducational, family interventions, etc. are not well understood even in the mental health field, despite decades of positive research. Learn from the experiences gained by family services already in place and from detailed examples from various locations around the world.

Who? The guidebook is for anyone involved in the care of people with serious mental illness: psychiatrists, nurses, social workers, occupational therapists, as well as policy makers, service managers, families/carers and people with mental health problems themselves.



To purchase the Guidebook from WFSAD, fill in this form and mail to:

World Fellowship for Schizophrenia and Allied Disorders

19 MacPherson Avenue, Toronto, ON M5R1W7 Canada

In addition to the price of the book, \$30.00 the cost of shipping and handling is \$5.00 per copy in Canada, \$7.00 in the U.S. and \$14.00 overseas.

Please supply the following – print clearly

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Address: _____ Apt: _____

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☐ My cheque (U.S., Canadian, Euro or equivalent) money order made payable to WFSAD is enclosed.

☐ I am paying by credit card: ☐ Visa ☐ Mastercard

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