

**World Fellowship for Schizophrenia and Allied Disorders Q1&2**

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**LAST NEWSLETTER UNDER THE WFSAD BANNER**

This first 2009 newsletter will be the last issue under the WFSAD banner. It is hoped that the newsletter will continue, maybe in a different form, and that its major goals will be pursued under the banner of the World Federation for Mental Health in the proposed Family and Consumer Center for Support and Advocacy.

Nevertheless, this is a nostalgic moment for our members and avid readers some of whom have enjoyed the newsletter from the time that it was first produced in 1987 through the twenty one years of its existence. In those early days WFSAD concentrated on providing information about schizophrenia that families could understand and use to help them in coping with the disorder. It was from these articles that our pamphlets and information papers were developed.

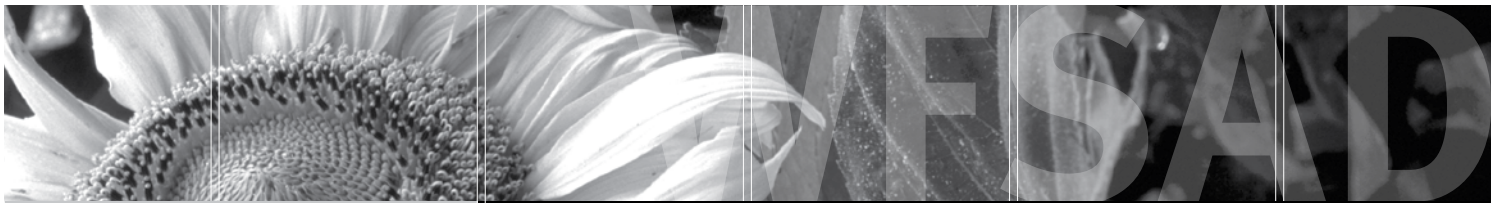
It was not long before we could count mental health professionals among our membership and our newsletter began to have a regular feature highlighting interesting journal articles. We re-published articles from our national member organizations’ newsletters when they were interesting for a global audience, and began a column “News from the Groups” which was popular with smaller groups, encouraging them to learn from others about what they were doing and what they might adopt in their own advocacy and support efforts.

From 8 pages the newsletter became a 16-page publication. It was never a colour publication though it went to a glossy black and white cover. Our board always felt that the content was more important than a “jazzy” presentation.

Recently, we made the big move from a print version to an online version. At first we suspected we would lose a lot of readers who did not have internet connections, but we found that the majority of our members were able to receive notice of the publication and many could download it onto their own computers. Many enjoyed sending it on to yet other networks of people, so our readership was expanded many times over. Now you can read the newsletter online in the Publications Section – just click on Quarterly Newsletter in the left margin. Our website will remain up for some time and when the transition occurs these publications will remain available for our readers.

I have enjoyed being senior editor and would like to thank our editor from 2004 – 2008, Mary Hancock, for her good work.

*Diane Froggatt*



## Personal Story

### Schizophrenia from the inside out

By Patrick W

Since being diagnosed as a chronic paranoid schizophrenic in late February of 1994 I have learned a lot of things about the disease and its effect on people.

My first thought is that it has been a lot more of a problem from a financial standpoint and a social standpoint rather than the disease itself.

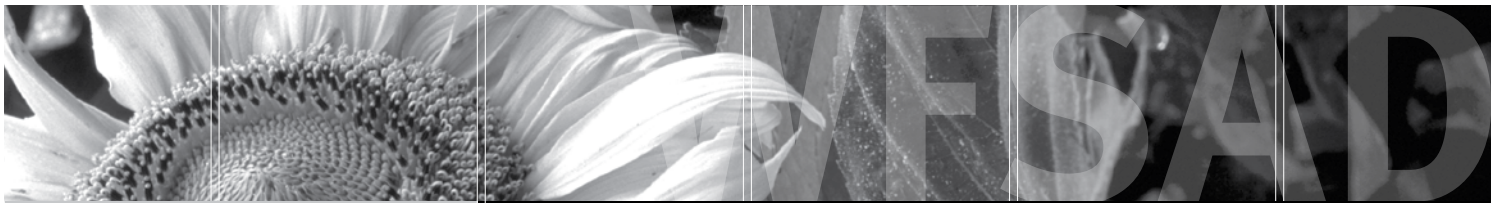
My understanding is that 1% of the population has schizophrenia and 10% of those with schizophrenia have the disorder in as mild a form as I do.

*As far as the disorder is concerned I have not had any audio hallucinations (voices) since 12 hours after being put on medication. My medication, thiothixene, has not changed since day one and now I take 1 mg. every 36 hours. I will admit that it does make one rather tired and lethargic but on this low dose it is not too much of a problem.*

As far as the disorder is concerned I have not had any audio hallucinations (voices) since 12 hours after being put on medication. My medication, thiothixene, has not changed since day one and now I take 1 mg. every 36 hours. I will admit that it does make one rather tired and lethargic but on this low dose it is not too much of a problem. I have been prescribed neurontin and cogentin since that time mainly to deal with muscle cramps. I have felt much better since these have been prescribed and feel very good about my medications at this point, in dealing with the disorder.

I know when I was in the hospital in '94 that many of the staff kept wondering why people would quit taking their medication. The answer is simple: the medication makes you feel bad. Also while you are experiencing symptoms of the disease you are flying about 10 feet off the ground and think you can do and accomplish anything. I was started on a rather high dose of thiothixene to stop the symptoms, and when the medication kicks in you change from flying 10 feet off the ground and thinking very quickly to feeling like you are laying on a hard, cold concrete floor without a blanket and your thought process is terribly slow, and this happens very rapidly. You start to think you may not have much of a future, you wonder how you are going to pay the medical bills and you wonder how many people you have made mad. You also worry about how this will affect your family, your job or business and you hope you do not have any legal problems to deal with. I really believe that if people were given medication in the beginning to help with medication side effects that more people would not stop taking their medication. I also think many people that treat people with schizophrenia don't realize how fast their patients' minds are working.

I have read that it is impossible to think about more than one thing at a time and the human mind can jump from one thought to another very



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*I frankly believe I was confused and irritable more from the physical exhaustion caused by the disorder, rather than from the actual schizophrenia. I have wondered many times what a person with schizophrenia could accomplish if their train of thought could be channeled in a useful direction.*

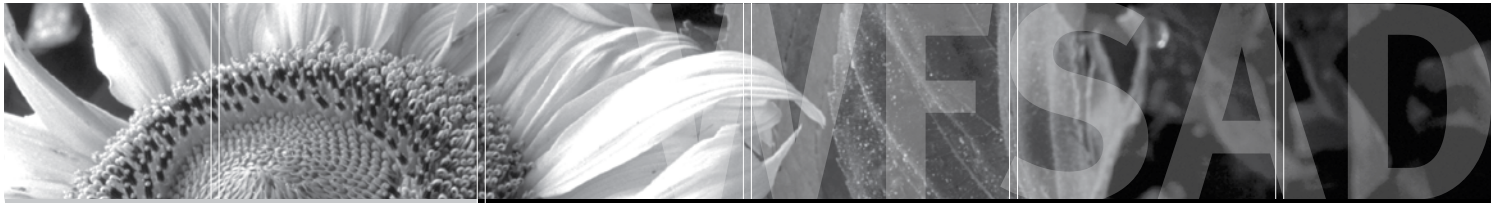
rapidly giving one the impression that he is thinking about more than one thing. I sometimes think maybe a person that is having symptoms can think about more than one thing at a time or at least the mind can jump from one thing to another at an unbelievable rate of speed. Actually I still believe I did some of my best thinking while I was experiencing symptoms.

The thing that caused me to seek help and be voluntarily admitted to Doctors Hospital mental unit was physical exhaustion. I only slept about two hours a night, while I was having symptoms, and I was working all day. I was not hungry and lost quite a bit of weight the two weeks I had symptoms. The hospital said on my release papers that I had “knowledge deficit and aggression”. I frankly believe I was confused and irritable more from the physical exhaustion caused by the disorder, rather than from the actual schizophrenia. I have wondered many times what a person with schizophrenia could accomplish if their train of thought could be channeled in a useful direction.

Schizophrenia can be a very boring disease. My doctors have told me that they want me to be on a very even line. I never have a really bad day, and I have had a lot of things happen the last fourteen years, such as selling our farm, a prolonged illness which my father had and financial worries, mainly caused by high insurance premiums, but I don't have those really good days when you feel so good and can accomplish so much. I really miss those mornings when it is bright and sunny and you just can't wait to get outside and start the day. On the other hand dealing with things such as my fathers Parkinson's disease, with almost a year of his being in a nursing home - I am sure even if I didn't have schizophrenia I would have needed psychiatric treatment. I have been extremely fortunate to have very good doctors.

Now I will talk about the worst part of the disease, which is getting health insurance that will cover mental illness. I have been frustrated, infuriated and strapped for money because of insurance companies. The week I was in the hospital was handled by a major insurance company I had a policy which stated that I must pay a deductible and then 80/20 (policy holder to pay 20% of health care charges). That company raised the premiums of their policy holders making premiums very expensive. Then they sold all the remaining policies to another major insurance company which I was to learn did not recognize mental or nervous disorders.

When I called the company and tried to talk about coverage on mental/ nervous disorders they said repeatedly that there was no such thing and would not say anymore. I contacted the Bureau of Insurance in Springfield and they checked into the matter. It turned out that the insurance company's place of business was Juneau Alaska and I would have to deal



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with the Dept. of Insurance in Alaska. It is a little hard to deal with people that far away and too costly to get a lawyer to handle it so I gave up on that. Having a good insurance agent covering my other insurance needs was no help getting private health insurance coverage for mental illness.

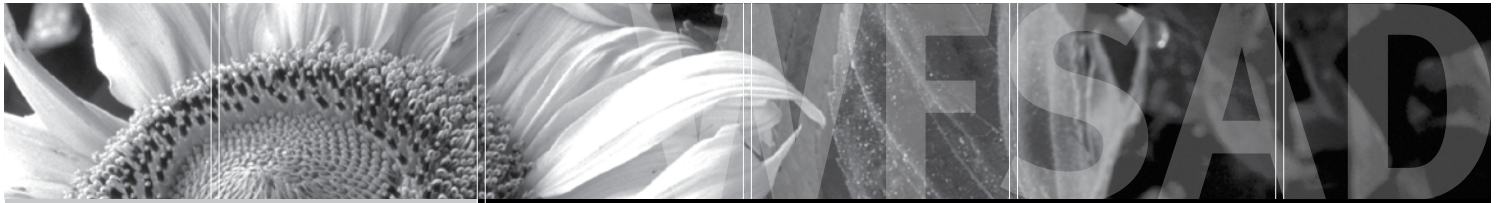
I was lucky to get into the Illinois Comprehensive Insurance Plan which is administered by Blue Cross Blue Shield and it has been a great program other than the premium costs. At this time my premiums have risen to \$699 per month for a \$2500 deductible policy which means I am spending more than half my gross income on health insurance and with my high deductible I have not received a penny in medical expenses from them, other than drugs, since I started with the company more than five years ago.

My parents and I got out of farming in 1994 and my brother and I are now in the storage business with 130 units. I do the renting, maintenance, billing and bookkeeping. I do pay income tax, social security tax and more property tax than I care to think about. I have not sat and felt sorry for myself nor do I want the State or Federal Governments to support me, but there has to be an answer to the insurance problems that I and other people with mental/nervous disorders have.

I have learned over the years that finding a job in a rural area, when you have a mental/nervous disorder is all but impossible. I have not hidden my mental problems and in a town of 2600 everyone knows your business. The people may not know my diagnosis but they know that I have a mental problem and that in turn closes many doors. When we quit farming and moved to town I had no intention of starting a business but wanted to get a job with a decent salary and benefits. I have been very fortunate to have support from my family to get a business going so I can support myself. Really the business has done much better than I ever thought it would but I certainly cannot make enough money to pay for health insurance and have any money left over other than for very basic necessities. I tried working 40 miles away in Peoria but with only a high school education found I could not make enough money to commute back and forth.

The social problems caused by schizophrenia are numerous and complicated. I have found two groups of people that are comfortable with people with a mental disorder. The geriatric people could not care less if you have problems. Most have seen World War 2, the Korean War, the Vietnam War and the mess in the Middle East. They also remember the Depression, working for ten cents an hour and producing your own food. They have a different view of the world and different values. They have seen illness and sickness during their life time and are accustomed to it or at least know better how to cope with illness.

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*I cannot say the disease is all bad because it has made me change some things in my life - it has allowed me to meet some interesting people and I certainly have a lot more understanding and compassion than prior to 1994.*

The other group would be business associates. I have found bankers, lawyers, suppliers, contractors and accountants don't pay any attention to your illness as long as you are able to do your job and meet your obligations.

When I was first diagnosed I learned who my personal friends were very rapidly. Some were not comfortable being around me and others were very supportive. As I got better, the friends, or many of them, gradually went their own way, I very seldom hear from them, and if they are uncomfortable being around a mentally ill person that is probably for the best.

I have thought many times how fortunate I am that my illness is as mild a form as it is but on the other hand it certainly would be better not to have it. I cannot say the disease is all bad because it has made me change some things in my life - it has allowed me to meet some interesting people and I certainly have a lot more understanding and compassion than prior to 1994.

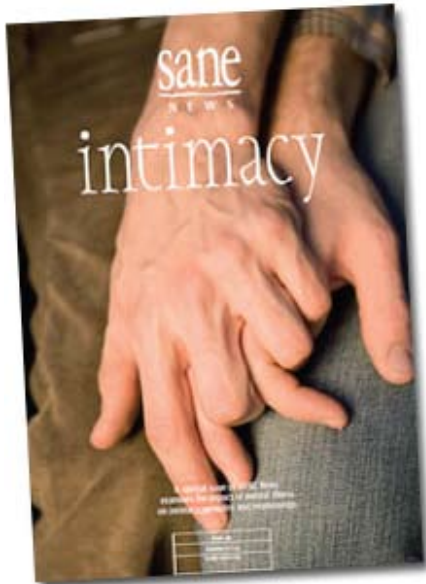
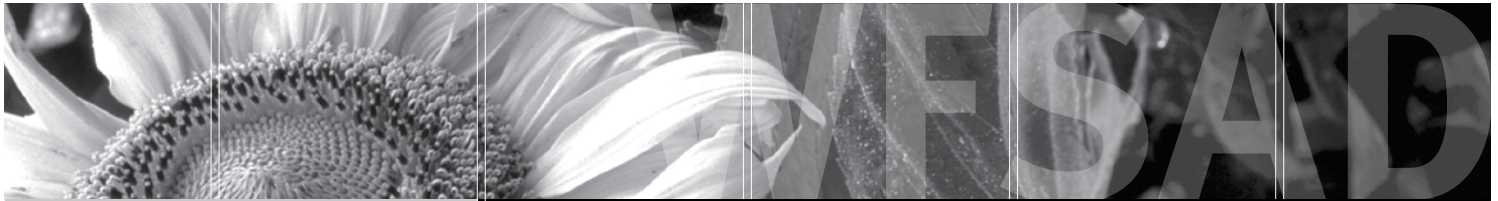
So many people have asked me over the years to explain how you feel and think while you are having a schizophrenic episode and about a year ago I stumbled on the answer. After my father died our pastor sent a booklet dealing with grief every month for several months. I really did not find the books all that helpful but while reading one I found this quote from the Bible: "I have no peace no quietness; I have no rest but only turmoil." I am certainly not a very religious person and from what I can find from others, schizophrenia was not being discussed with this scripture from the Book of Job 3:26 but it certainly encapsulates the disease very well. I have spent many hours trying to explain the disease to others and to find such a simple and eloquent description in such a brief statement allows me to hope maybe others can understand the disease too.



### **New research by SANE Australia: Intimacy and Mental Illness**

A new research study by SANE Australia reveals people affected by mental illness pay a high price when it comes to relationships and social contact, with the study showing half have no close and warm relationship with another person.

The research, conducted in September to December 2008, focuses on the emotional and physical relationships of people living with a mental illness, the consequences of this for their lives and what can be done about it. The most disturbing result is the impact of mental illness on personal relationships, with almost half having no friends, wanting to,



yet struggling to connect with others. Physical intimacy, which includes hugging and touching others, was rare for many. In fact –astonishingly – almost one in six had not touched or been touched by another person for more than 12 months.

The study found the numbers of respondents who had:

- No close relationship 49% (General community with no close relationship 15%)
- Not touched or been touched by another person for 12 months 13%
- No sexual contact in last 12 months 35%

SANE Australia Executive Director Barbara Hocking says extreme social isolation is known to damage mental health, yet it's something many people with mental illness have to endure. 'Not only are many people with mental illness dealing with their symptoms and associated problems such as poverty, they are leading isolated lives and often have no partner or even friends to share their lives,' Ms Hocking said. This impedes their recovery.

*'While governments are promoting social inclusion, these findings highlight the very real need for immediate, specific action to ensure such basic human needs for social contact are not being ignored.'*

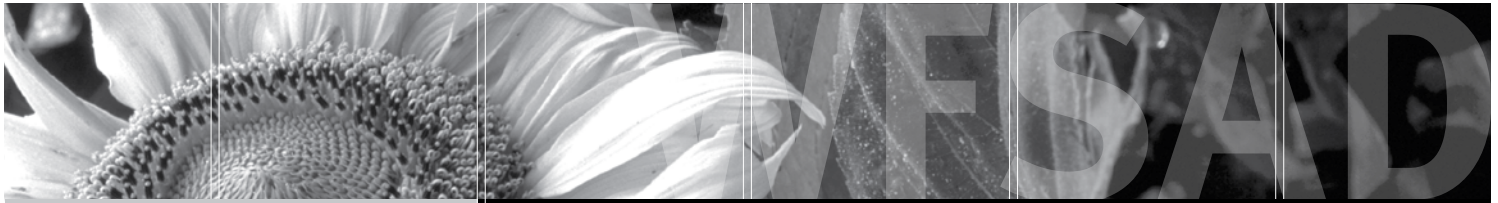
Sexual health and intimacy also emerged as areas of concern for respondents:

- Had not discussed the issue with their doctor or health worker 50%
- Did not know enough about sexual health 65%
- Not receiving routine health checks (e.g. pap tests, prostate checks) 46%

Ms Hocking says these figures reflect the general poor physical health care provided to people regarded all too often as solely "mental Health patients".

SANE is calling on government agencies at all levels to improve opportunities for those affected to improve close relationships with others and improve their capacity for recovery. Recommendations include:

- **Promotion of Social Inclusion Action** is needed by all levels of government to ensure people with a mental illness are genuinely included in their local communities and have opportunities to meet and socialize with others.
- **Support to develop relationships**
- Doctors and other health professionals need improved awareness of the effects of mental illness on social relations, and to understand the profound negative impact this has on quality of life and mental health.



*People with a mental illness are known to be at greater risk of physical health problems than the general population, yet most do not receive regular health checks.*

Education and training is needed in how to discuss the effects of mental illness on emotional, physical and sexual intimacy, and how these issues can be addressed.

- **Improved sex education:** The onset of mental illness often occurs in the late teens, disrupting acquisition of life skills as well as education. Health professionals and recovery-focused rehabilitation programs need to provide practical education for people affected by mental illness about sexuality and related issues.
- **Sexual health checks:** People with a mental illness are known to be at greater risk of physical health problems than the general population, yet most do not receive regular health checks. As this survey indicates, checks of sexual health are also sparsely provided. Family doctors, primary care clinics and other health services need encouragement and incentives to provide regular health checks for people with a mental illness. These need to include pap smears, breast screening, prostate checks and testing for sexually-transmitted disease, as well as other routine tests.

*You may see a more detailed report of Research Bulletin No.8 at:*

*[http://www.sane.org/media/media\\_releases\\_2009/research\\_bulletin\\_8%3a\\_mental\\_illness\\_and\\_intimacy.html](http://www.sane.org/media/media_releases_2009/research_bulletin_8%3a_mental_illness_and_intimacy.html)*

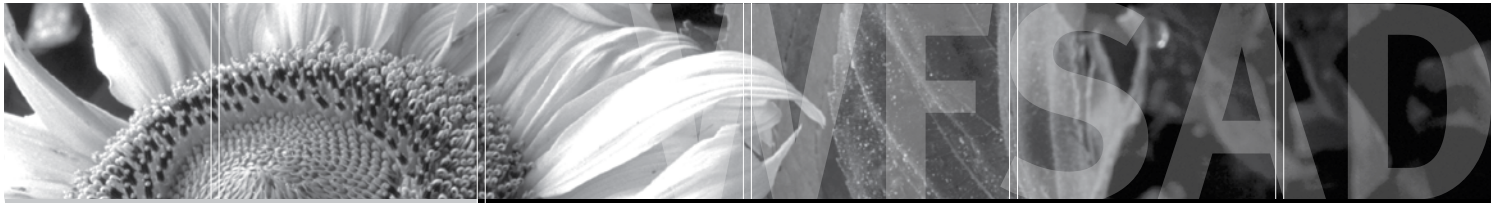


## **Avoiding Deliberate Self Harm - Giving people a Reason to Live**

*By Ishita Sanyal*

*As many of our readers know the World Federation for Mental Health is working on a suicide prevention initiative designed to help families of people with psychiatric disorders, especially those who have thoughts of suicide or deliberate self harm. The program is in its early development and research phase and we continue to be interested in information that may help us in our quest to find ways in which we can help to avert suicide among families/consumers who live with mental illness. The program will not be limited to what we call the First World, but will also include support information for families in the developing world where at present there is little help available.*

*Ishita Sanyal who has been a regular contributor to WFSAD newsletters has written this column which we felt would be of interest to our readers. She expressed a lack of experience with actual suicide but plenty of experience in helping to support those who come to Turning Point in a very distressed condition. "Everyday," she said, "we are coming across so many people who are stamped by psychiatrists or us as suffering from severe mental illness, some of whom have experienced severe crisis situations in their lives, but fortunately none of them have committed*



*suicide to date.” Her article continues below:*

At Turning Point<sup>1</sup> everyone is living their life, enjoying life as much as possible and developing gradually. Though some have partially attempted suicide none of them have ever done anything that required immediate medical attention. So, I may appear lacking in experience as regards real suicide. However, many of those who partially attempted may have been suicide prone (suicide tends to run in families). Perhaps it was our techniques or companionship that have made them think again about living.

### **Two Case Histories**

- A. took six tablets of a medication for depression when her husband decided to divorce her. She was crying and told me that though she took six tablets which she had, she didn't manage to kill herself but said that she wants to end her life and needed more pills that would be effective and cause an end to her suffering is a software engineer suffering from paranoid schizophrenia. She is a good-looking young woman who married (love marriage) almost 8 years ago. However, she never lived with her husband. Even after marriage she continued to live with her own parents and as she was economically free she never demanded any economic support from him. Her husband, who knew her prior to falling in love and marriage, thought that he would be able to motivate her someday to come and stay in his house but failed in his attempt. Her paranoid feelings towards her mother in law complicated the situation. A - and her husband would meet regularly, continue their sexual life but live separately. His earnest request failed to make A- bold enough to stay with her mother in law. Her husband's decision to divorce broke her heart. She was unable to bear the reality and had separation anxiety. She pleaded and promised to stay with him but in vain. Her earlier failure to keep her promises made her husband unwilling to listen to her any more. Though economically independent she was emotionally dependant on her husband and as her parents were aged she found herself in a hopeless and helpless situation. She had counselling sessions and consulted a psychiatrist. She also had regular sessions at Turning Point at which she realized through the friendly environment and the self help group ready to help her in a crisis, that she was not alone. Participation in a few group games and exercises made her become involved in the feeling of companionship. In the supportive, trustful environment she learned of the pain of others through their stories. All of these things helped her to come out of her depression and she no longer talks about ending her life.
- B. is a patient with obsessive-compulsive disorder. He used to have severe sexual obsessions centred on everyone including his near

**TURNING POINT<sup>1</sup>** is a voluntary Non Governmental Organization (Registered under Societies Registration Act XXVI of Govt. of West Bengal 1961) engaged in Mental Rehabilitation in a Day-Care Center. The principal aim is to rehabilitate the mentally challenged persons in society and to fight against the stigma of “mad” or “Pagal” associated with mental health, which severely criticizes a person who is but only mentally sick and can recover easily.



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and dear ones. This used to inflict severe guilt feelings in him that made him perform a number of compulsions to get rid of his guilt. But sometimes he was not satisfied with it and used to cut his hand, wrist, and neck with blades. He used to have aggressive outbursts, which often made him beat his own mother or beat himself severely for it.

Fortunately he never used to have such attacks when he was in the group, participating in group games specially designed for the members of Turning Point or even when he used to chat with other participants. He soon became our computer teacher which used to give him a sense of pride and prestige. But even then this condition prevailed for years together and he used to call me when he had a crisis in some odd hours of day. Not only me, he used to call some of his friends, some of the parents at the self-help group and get relief from his crisis. He was prone to suicide attempts and made some futile attempts that had every possibility to be fatal but it never happened in reality. Now he is doing a job. Obsessions are there but he is capable of coping with them.

### The findings

The list is a lot longer. All of these people have unendurable pain but it has never made them commit suicide. They tried, but I think that they were making a cry for help because they really wanted to live. In these situations every family member must be careful as any of these incidents could become a tragedy. I have been lucky not to have to face such realities. What can be the probable cause?

We have two instincts- thanatos and euthanatos (both ancient Greek terms), the death instinct and life instinct. Generally when a person cannot bear the threats that life has in store for him, the person wants to commit suicide. Love and acceptance are the two basic things along with a feeling of companionship that can change the whole environment. Even depressed persons, when in a group and participating and observing (partial participation) the group games, recover from their bouts of depression and anxiety.

Awareness of family members is very important. Sometimes the family members fail to understand how to identify a crisis situation and how to communicate and react. So crisis intervention skills are essential for family members to learn. Joining self-help groups can make them get the needed support during such situations. Most times the last ignition point before a suicide attempt can be avoided with the caring understanding and skills of close family members. The family members themselves need to control the stress and pressure of continuous anxiety and depression in order not to transmit these feelings to the person who is unwell.

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Immediate assistance from the self-help group and community members is essential, as they are the persons who have the best possibility of persuading the person against self harm.

Our most valuable help comes from the fellow members of Turning Point who often narrate their own stories of depression and how they got through these times.

*Ishita Sanyal is the Secretary of Turning Point*

*We thank Ishita for her contribution to our suicide prevention initiative. We also welcome your ideas on any issues we address on our website or in our news bulletins. Write to [dfroggatt@wfmh.com](mailto:dfroggatt@wfmh.com). To read past newsletters go to:*

*<http://www.world-schizophrenia.org/publications/Newsletter.html>*

## World Health Organization

### International Diploma in Mental Health Law and Human Rights

*A letter from Natalie Drew at WHO*

Dear Colleagues,

After the successful launch of first academic year of International Diploma in Mental Health Law and Human Rights at the ILS Law College, (Pune, India), the Indian Law Society and the World Health Organization are pleased to announce admissions for academic year 2009-10.

This innovative new Diploma will be instrumental in building capacity in countries to promote the rights of persons with mental disabilities in line with the UN Convention on the Rights of Persons with Mental Disabilities and other international human rights standards.

The course provides students with the opportunity to develop knowledge and expertise in the area of mental health, human rights and law, and equips them with essential skills to be able to advocate for human rights and actively participate legal and policy reform.

The one year Diploma includes both residential sessions and distance learning and is taught by a faculty of renowned international experts. The course will appeal to a wide range of people interested in this area including health and social workers lawyers, policy makers, legislators, service users/survivors, families of service users/survivors and government officials.

Applications for this academic year (2009-2010) can be submitted online: <http://www.mentalhealthlaw.in/admission.html>



*This innovative new Diploma will be instrumental in building capacity in countries to promote the rights of persons with mental disabilities in line with the UN Convention on the Rights of Persons with Mental Disabilities and other international human rights standards.*



More information about the Diploma is also available at:

[www.mentalhealthlaw.in](http://www.mentalhealthlaw.in)

*Natalie Drew*

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Visit the WHO MIND website:

[http://www.who.int/mental\\_health/policy/en/](http://www.who.int/mental_health/policy/en/)

## Primary Care and Mental Health

A joint report by the World Health Organization and the world Organization of Family Doctors on the integration of mental health in primary care is being launched and is now available.

‘Integrating mental health into primary care – a global perspective’ presents the justification for integrating mental health, and advice on how to do so. Drawing on both the latest evidence and on an in-depth analysis of 12 cases examples of successful integration, the report highlights 10 broad principles to guide countries in their efforts to successfully integrate mental health into primary care.

You can read/ download a copy of the report from

[http://www.who.int/mental\\_health/policy/services/en/index.html](http://www.who.int/mental_health/policy/services/en/index.html)

Please put a link to this report on your websites so that it may reach as many people as possible. The WHO also welcomes anyone who would consider translating the report to contact them. You should contact Dr. Michelle Funk, Coordinator, Mental Health Policy and Service Development – [funkm@who.int](mailto:funkm@who.int) or Dr. Gabriel Ivbijaro, Chair, Wonca

Working Party on Mental Health – [gabierl.ivbijaro@gmail.com](mailto:gabierl.ivbijaro@gmail.com)

*‘Integrating mental health into primary care – a global perspective’ presents the justification for integrating mental health, and advice on how to do so.*



## Mental Disorders - making headway in Bangladesh

Support is needed to spur momentum

By *Badrul Mannan*

The Welfare Society for Mental Health and Rehabilitation (WSMH&R) celebrated World Mental Health Day 2008 on 10th October 2008 at Dhaka, the capital city of Bangladesh, with due respect and solemnity. This is the first time in Bangladesh that an NGO celebrated WMHD day.

There were three events

1. Publishing a special supplement in a Leading National Daily (Prothom-Alo) on the theme of the day (Making Mental Health a Global priority : Scaling up Services through Citizen Advocacy and Action)
2. Conducting a round table discussion on the theme of the day at a national level with leading professionals in mental health and other related fields, e.g. law, Government and business.
3. Displaying two new posters on the theme. Round Table meetings had also been held prior to Mental Health Day to launch the plan, and this was announced on the Day at a press conference.

WSMH&R is thankful to ActionAid for financing the events and also to the National Forum of Organizations Working with Disabilities (NFOWD) for their organizational and management support. These events brought mental health issues into the limelight and also put WSMH&R in a lead position in this field. To maintain the momentum is a new challenge for which financial support is essential.

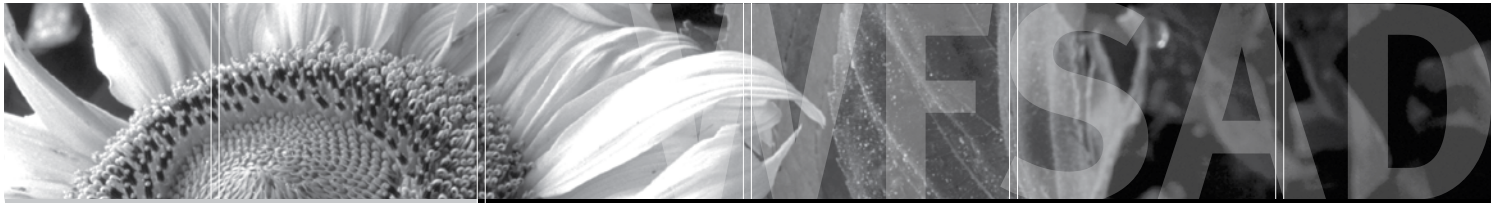
WSMH&R, formerly Society of Welfare for Schizophrenia (SWS), is a voluntary secular and non-political social welfare organization registered with the Bangladesh Department of Social Services since 2000. It is still the only organization in Bangladesh that is working solely for the welfare of persons with schizophrenia – a serious mental illness that causes disability of varying degrees.

Mental disorders and related issues are still little known to the people in Bangladesh. They are often misunderstood as mental retardation. Also mental health is engulfed by Substance Use Disorder. These make the path unpaved and rugged on the one hand and lacking in necessary understanding and support on the other. Still WSMH&R has made substantial (if intangible) progress in this field. This recent event-financing by ActionAid is one of them.

*Speakers at the Assembly:  
(right to left)*

*Mr. Akhil Sukant Paul,  
Director, SENSE International  
(India);Badrul Mannan,  
presenter of the paper on  
psychosocial and invisible  
disability (Mental Health  
and Related Disabilities),  
Bangladesh; Mr. Mosharraf  
Hossain, moderator, Country  
Director, Action on Disabilities  
and Development; Ms.Rabeya  
Sultana, Head, Rights and  
Social Justice, ActionAid  
(Bangladesh); Mr. Sachin Rizal  
of SENSE International, aide of  
a Deafblind participant.*





Disability due to schizophrenia was not known to the lawmakers and even to disability workers and activists until 2005. Thus it was absent in the PWD (Persons With Disability) Act-2001 of Bangladesh. This was probably due to lack of representation at the hearings. WSMH&R has succeeded in making this type of disability accepted by NFOWD and Govt. in turn in 2005. While revision of the Act is awaiting parliamentary action, the type of disability is accepted in principle and also in practice. Consequent upon the acceptance, WSMH&R has not only been a member of NFOWD since 2005, but also the convener of a recently formed thematic group, 'Psychosocial Disabilities' of the National Forum of Organizations Working with Disabilities. NFOWD is the technical support NGO for the Government of Bangladesh in the field of disabilities.

In the recent past WSMH&R participated in the international conference of the Asia Pacific Disability Forum (APDF) held in Dhaka on 27-29th February 2008 with a presentation paper on sub-theme 'Psychosocial and invisible disabilities'.

WSMH&R realizes the importance both of family empowerment and advocacy. It feels that three types of activities are necessary in this field in Bangladesh-

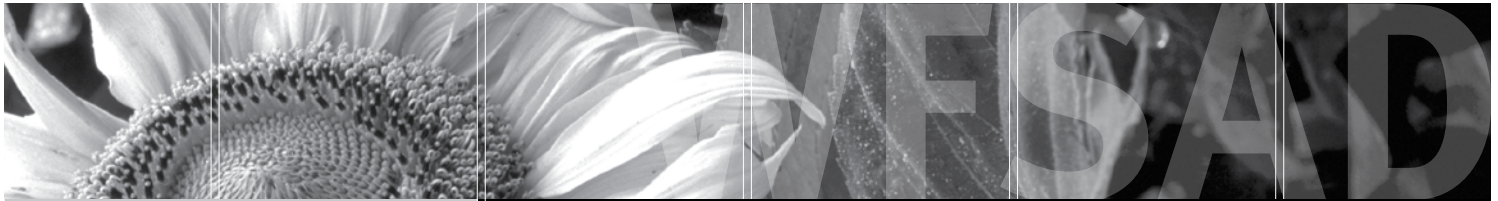
1. Awareness Development
2. Advocacy Activities
3. Rehabilitation

In the absence of financial strength, the Welfare Society for Mental Health and Rehabilitation is concentrating on the first two categories, although a limited amount can be done on awareness development for the same reason. Persistence and determination, however have brought some success e.g. acceptance of the fact that schizophrenia can result in disability, familiarization of the term 'schizophrenia' etc..

After the necessary inclusion in the draft revision of People With Disabilities (PWD) Act and formation of the new thematic group, the Welfare Society for MH & Rehabilitation is concentrating on establishing 'Priority of Mental Health', the theme of WMHD-2008. National Health Policy of Bangladesh is under the process of revision now. We are trying to intervene - this time with the support of NFOWD, with much more hope. GO-NGO collaboration is also an objective.

Community Based Rehabilitation for consumers is an ideal prescription for the future. It is an objective that will only be achieved after much awareness development and radical change of mindset in people at all levels. That is a Herculean task of several decades, if not a century. For the present generation of consumers and for a few more generations to come, the practical short term solution is 'caregiver-owned rehabilitation

*Disability due to schizophrenia was not known to the lawmakers and even to disability workers and activists until 2005. Thus it was absent in the PWD (Persons With Disability) Act-2001 of Bangladesh.*



*While we are determined to keep moving toward our target, inching forward gradually, we need support to boost the momentum of these activities in Bangladesh and globally as well. WSMH&R seeks for those who cannot seek for themselves.*

centres' - with life-long residential facilities, half-way home, respite care and day care facility in addition to hospital/treatment facility- all combined together. Supported employment also is an item, that can be run by government, NGOs and family groups. [ED. Note: this can be seen in the shops run by AASHA, Chennai, India – see last issue of the newsletter]

While it is possible to conduct small advocacy and awareness activities on the level of the individual, tasks of rehabilitation are not so easily accomplished. Our Welfare Society is seeking financial support for this too.

While we are determined to keep moving toward our target, inching forward gradually, we need support to boost the momentum of these activities in Bangladesh and globally as well. WSMH&R seeks for those who cannot seek for themselves.

*Badrul Mannan is General Secretary of WSMH&R and an activist caregiver. He is the father of a consumer son from Bangladesh. He (62) took early retirement from his employment in 2003 to seek the answer to his 'Million Dollar' question- "WHO WILL LOOK AFTER MY SON AFTER I DIE?" Community Based Rehabilitation is too distant a target for his son (and millions of consumers like him in western/developed countries as well).*

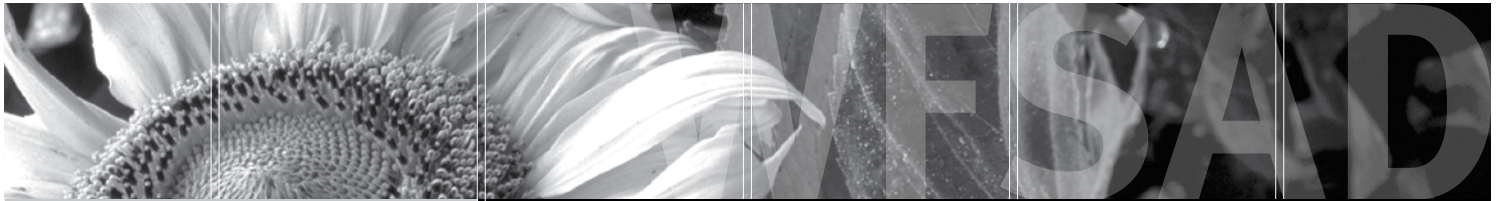


## **Between Reason and Illusion: Demistifying Madness**

The Brazilian Schizophrenia Association (ABRE), member of the WFSAD Latin Alliance, has just edited a book called "Entre a Razao e Llusao: Desmistificando a Loucura" (Between Reason and Illusion: Demistifying Madness). The book grew out of a project of six booklets on schizophrenia written by a person with schizophrenia, an occupational therapist, and a psychiatrist who is also a family member.

The "booklets project" originated from accounts collected over the years, of an important gap between the professional discourse/ practice and the discourse/ experience of people who have schizophrenia. Assuming both as legitimate thoughts and ideas that usually fail to acknowledge each other as valid and useful, we devised a story involving three main characters, approaching every step of the illness, from prodromal signs to full manifestation, treatment, relapse and recovery.

Instead of communicating psychiatric knowledge to consumers, the aim of the material was to bring different perspectives through the narrative of three main characters, aiming to express the complexity of schizophrenia with a realistic hope.



### The 6 booklets

1. How does it Occur focuses on the prodrome symptoms and the first psychotic episode
2. The Construction of a Diagnosis focuses on the issues related to the diagnostic criteria
3. The Relevance of Treatment focuses on the treatment challenges
4. Stigma – How people perceive it focuses on perception of stigma in real life
5. Family Environment focuses on the families' perspectives
6. Recovery and New Perspectives shows the different aspects of recovery and the new scientific advances.

By giving multiple perspectives for every piece of information we aimed at promoting a dialogue that might help people with schizophrenia and their families to listen and trust each other and to aid clinicians in establishing better rapport with “difficult patients”, thus increasing treatment adherence and contributing to the dissemination of the concept of recovery.

The “booklets project” (30,000 copies of each issue) developed as a partnership initiative between ABRE and PROESQ (Schizophrenia Program of Sao Paulo Federal University) and was sponsored by AstraZeneca Brazil. The material was distributed in most mental health centers all over Brazil by AstraZeneca’s representatives every two months over an eighteen month period.

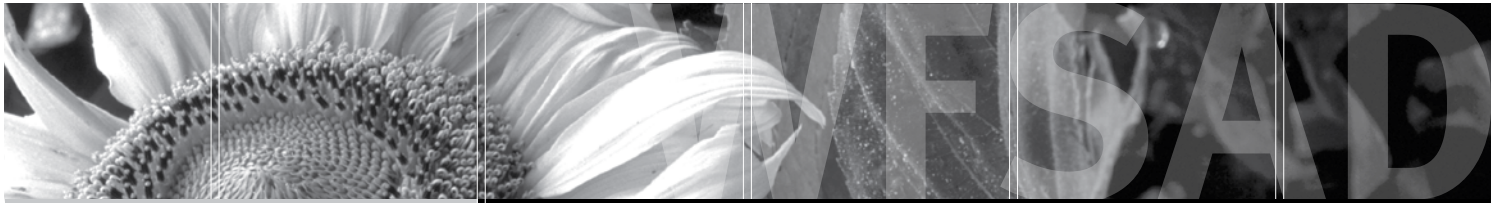
The booklets were extremely well accepted by patients and families with several reprint requests. Psychiatrists also evaluated the material very positively, some clinicians use the materials at their regular appointments. A website was recently developed and is being widely accessed by patients and families. The booklets can be downloaded for free at: <http://proesq.institucional.ws/psicoeducacao>



### Family Groups in Nigeria and Ghana

Under the auspices of RETHINK the British mental illness charity, RETHINK groups have been established in both Ghana and Nigeria. Emails from Emmanuel Eseine tell us that the groups are established and that through contacts with the executive arm of the government they are trying to involve more government officials “in this noble fight for people with mental disorder”.

During the World Drug Day in June 2008, the Nigeria Rethink Group organised a programme for secondary school students as well as



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university students to let them know the effect of the usage of hard drugs. Photos were taken and we hope to reproduce a selection in the next newsletter.

The programme was well attended and sponsorships were obtained from the National Drug Law Enforcement Agency (NDLEA). Some participants from Ghana Rethink Group were also in attendance.

it also proved to be an opportunity for RETHINK Nigeria to receive more memberships from professionals and other volunteers. "People like what we are doing in Nigeria and really want to Identify with us", said Emmanuel.

To contact Emmanuel or his volunteers here are the addresses and emails.

*Rethink Nigeria, C/o National Youth Council Secretariat (Youth House)  
Attention. Mr. Emmanuel Eseine  
120 Akpakpava Street, Benin City, Edo State, Nigeria.*

*eseine emmanuel [eseineschatz@yahoo.com]*

*Rethink Group Ghana, C/o Rethink Coordinators;  
Miss Happy & Miss Gloria  
27a Akanteng Tawn, Lower West Akim,  
Under Eastern Region, Ghana.*

*blessingigunbor@yahoo.com*



### A request for information on programs

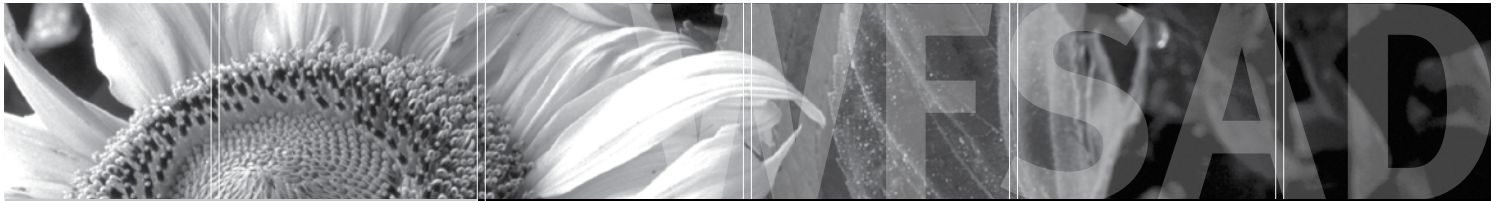
Joanne Pollard, Project Officer, Partners in Respite, Western Australia Association for Mental Health, is working on a project for respite and support for the Carers of a person with a mental illness. They have done a scoping exercise in Western Australia and have identified a gap for the following areas.

She would like to know of any programs that provide respite and support for the Carers for the following groups:

- Young adults, 18 – 25 years old, who are the carers of a person with a mental illness – we find that this group no longer fits into the 'young carers' group, and sometimes not really into the older groups;
- Parents of children who have a mental illness and are in hospital and when they leave hospital – if you have any programs that offer respite and support to the parents while the child is in hospital, or when the child returns home from hospital; and
- Young Carers
- Parents of children who have a mental illness generally

*If you have any information  
please contact Joanne at:  
Western Australia Association  
for Mental Health, City West  
Lotteries House  
2 Delhi Street,  
West Perth 6005*

*Tel: +08 9420 7277  
Fax: +08 9420 7280  
Web: [www.waamh.org.au](http://www.waamh.org.au);  
[respitoe2@waamh.org.au](mailto:respitoe2@waamh.org.au)*



## 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](mailto:info@era.gr).*

*Website: <http://www.era.gr/>*



## Congratulations to Mental Disability Rights International (MDRI) Recipient of American Psychiatric Association's 2009 Human Rights Award

**Arlington, VA** – The American Psychiatric Association (APA) announced this week that MDRI is the recipient of their 2009 Human Rights Award, bestowed by the Council on Global Psychiatry, a component of the APA. Established in 1990, the award is given to “individuals and organizations whose efforts exemplify the capacity of human beings to act courageously and effectively to prevent human rights violations, to protect others from human rights violations and their psychiatric consequences, or help victims recover from human rights abuses.”

According to Lawrence Hartmann, MD, and Chairperson of the Council on Global Psychiatry, the award is being given to MDRI for “your overall career and life achievement as a champion of human rights.”

Past recipients of the APA Human Rights Award include President Jimmy Carter and Roselyn Carter, Senators Paul Wellstone and Pete Domenici, Justice Richard Goldstone and Physicians for Human Rights.

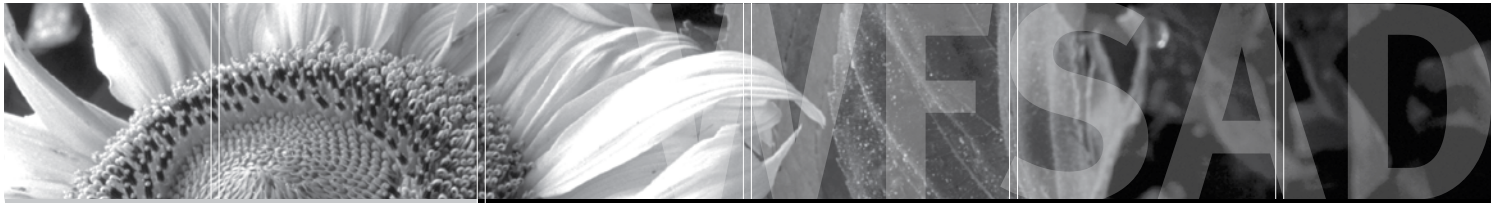
The award will be presented to MDRI at the APA's annual meeting, to be held in San Francisco May 16 through 21, 2009.



## From the Journals

In the January 18, 2008 issue of Schizophrenia Bulletin, Professors Assen Jablensky and Norman Sartorius take issue with an article in a previous Bulletin by Cohen, A. Patel, V. et al. which challenges the findings of the WHO International Study of Schizophrenia (IsoS). Jablensky and Sartorius refute their observations in this short article which ends with the following paragraph:

*“individuals and organizations whose efforts exemplify the capacity of human beings to act courageously and effectively to prevent human rights violations, to protect others from human rights violations and their psychiatric consequences, or help victims recover from human rights abuses.”*



We do not argue that the prognosis of schizophrenia in developing countries is groupwise uniformly milder or that the existing huge gaps in mental health service provision between high- and low-income countries are irrelevant to the lives of millions of people affected by this disorder. On the contrary, the erosion of social support systems, likely to be associated with the processes of globalization, should be a matter of grave concern. The sobering experience of high rates of chronic disability and dependency associated with schizophrenia in high-income countries, despite access to costly biomedical treatment, suggests that something essential to recovery is missing in the social fabric. Thus, the existence of outcome differentials between populations and cultures is not “presumed wisdom” but a real complex issue which should be addressed with standards of precision and rigor that are customary in scientific research and discourse.

*<http://schizophreniabulletin.oxfordjournals.org/cgi/content/full/sbm151v1>*



## Media

### New York Times

#### To Fight Stigmas, Start with Treatment

In the NYT column ‘Mind’ Sally Satel, M.D, a psychiatrist and a resident scholar at the American Enterprise Institute, poses the question: Do campaigns to fight the stigmas surrounding mental illnesses work?

Taking a British reality show called “How Mad are You” as her catalyst for the article Satel makes the point that, when treated, people with bipolar disorder seem no different from the general population, but that the real point is that when left untreated they are not the same. The “soothing fiction” provided by the reality show provides an unrealistic view. The article discusses the limited value of antistigma programs and ends with the following:

“Antistigma campaigns are well-meaning but they lack a crucial element. No matter how sympathetic the public may be, attitudes about people with mental illness will inevitably rest upon how much or how little their symptoms set them apart.”

*[http://www.nytimes.com/2009/04/21/health/21mind.html?\\_r=1&emc=eta1](http://www.nytimes.com/2009/04/21/health/21mind.html?_r=1&emc=eta1)*

*“...when treated, people with bipolar disorder seem no different from the general population, but that the real point is that when left untreated they are not the same.”*



CNN

### **Teen tries to quiet the voices caused by schizophrenia**

An article by Madison Park tells the story of a young man of 18 who has developed schizophrenia. His (positive) symptoms are described – threatening voices, delusional beliefs about his body rotting – and how he is relatively well now that he is under treatment. The story is linked to that of Nathaniel Ayers, a promising musician reduced to playing a broken violin on the streets, which is told in the newly released (in the U.S. & Canada) film *The Soloist*. As interesting as the article are readers' comments at the end.

<http://www.cnn.com/2009/HEALTH/04/24/schizophrenia.soloist.brain/index.html>

BBC Website

### **Revolution in Egypt's mental health care**

Radical reforms are being made to a system in which mentally ill patients have been shut away in 19th Century asylums for decades.

[http://news.bbc.co.uk/2/hi/middle\\_east/8034504.stm?utm\\_source=Ode+Newsletters&utm\\_campaign=e717fbe61c-daily-rss&utm\\_medium=email](http://news.bbc.co.uk/2/hi/middle_east/8034504.stm?utm_source=Ode+Newsletters&utm_campaign=e717fbe61c-daily-rss&utm_medium=email)

## **Announcement**

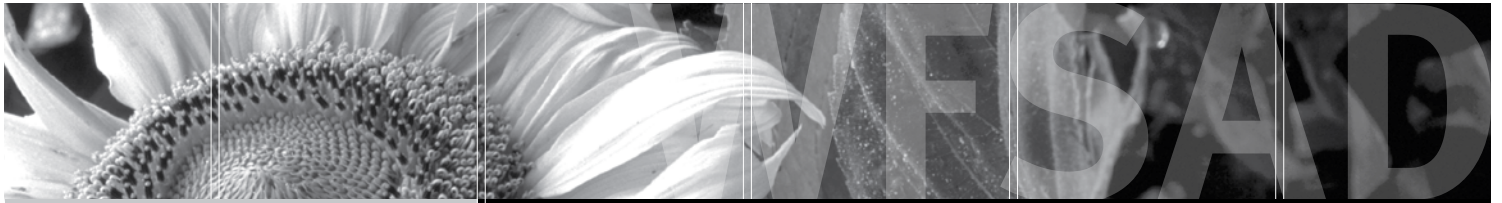
The Association for the Improvement of Mental Health Programmes (AIMHP)

### **Small Grants Programme**

Problems of breaking through the bureaucracy of low income countries with any projects - even the most ingenious ones - are severe. The delays and official chicanery discourage even the most motivated people who, after a while, give up trying.

To support community initiatives aiming to help people with mental illness and their families, the AIMHP is announcing a new programme aiming to provide help to the establishment and functioning of community projects developed to support people with mental illness and their families – such as the creation or strengthening of patient or family self-help and mutual help groups - as well as other initiatives sharing the same goal, particularly in the least developed countries (LDCs).

*Problems of breaking through the bureaucracy of low income countries with any projects - even the most ingenious ones - are severe. The delays and official chicanery discourage even the most motivated people who, after a while, give up trying.*



## World Fellowship for Schizophrenia and Allied Disorders Q1&2

*Successful candidates will receive a grant that has to be used for the project submitted to the AIMHP and found worthwhile by an international committee composed of experts in the relevant fields who, in addition to their expertise, have a good knowledge of the situation in the LDCs, and of representatives of patient and family organizations.*

The AIMHP launched this programme in 2006 with the support of an unrestricted grant by the Eli Lilly Company.

Applications should be in English, presented in typed-written form and be no longer than two pages. Applications should describe what has been done already, and for what specific purpose the support is requested. They should also include a list of individuals involved in the development of the project as well as the address of the person with whom the AIMHP should correspond, and a budget expressed in USD or Euros. Additional material can be provided in annexes. Proposals from developing countries and in particular from the least developed countries will be given priority consideration.

Successful candidates will receive a grant that has to be used for the project submitted to the AIMHP and found worthwhile by an international committee composed of experts in the relevant fields who, in addition to their expertise, have a good knowledge of the situation in the LDCs, and of representatives of patient and family organizations. The grants are limited to a maximum of USD 5,000. The support is intended as a one-time-only grant and will not be repeated. The grants provided are not meant to cover or contribute to the normal functioning of an institution or project, i.e., costs of personnel, hiring of buildings and other recurrent expenses. A report of what has been achieved will be requested and will be published in an appropriate manner.

Applications should be sent by email, fax or in hard copy to the following address:

**Action for Mental Health**

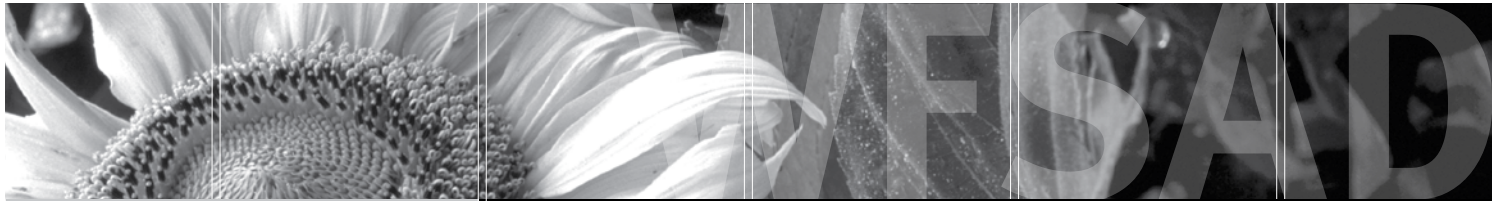
*Association for the Improvement of Mental Health Programmes  
c/o Professor Norman Sartorius, President*

*14, chemin Colladon, 1209 Geneva, Switzerland*

*E-mail: sartorius@normansartorius.com*

**Solos somos invisibles, unidos somos invencibles**  
**Alone we are invisible, united we are invincible**

*This slogan was invented by Voz Pro Salud Mental in Mexico.*



## 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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[www.world-schizophrenia.org](http://www.world-schizophrenia.org)

## Families as Partners in Mental Health Care

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

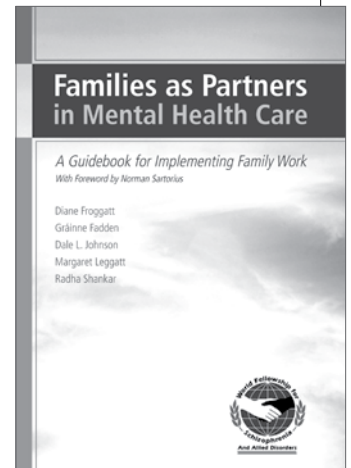
- • A collaborative project by leading experts in family work from around the world
- • Based on Ian Falloon's pioneering work on family psychoeducation
- • Edited by Diane Froggatt, Gráinne Fadden, Dale L. Johnson, Margaret Leggatt and Radha Shankar

**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.**

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I am paying by credit card:  Visa  Mastercard

Card Number: \_\_\_\_\_ Expiry Date: (m) \_\_\_\_\_ (y) \_\_\_\_\_

Name as it appears on card: \_\_\_\_\_