



Important WFSAD News:

WFSAD in Merger Discussions with World Federation for Mental Health

After 25 productive years of operation, the Board of Directors of the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) met via the internet recently to discuss how to maximize the future of the organization. WFSAD has grown exponentially in its responsibilities to the developing world in the provision of both formal and informal education, support and advocacy for families and consumers. Our web connections are vast – from Swaziland to Surinam, from Peru to the Philippines.

Thus, we have strong representation on all continents: a growing group of Asian, African, Central and South American family organizations. Our responsibilities grow with every passing month.

Needing a More Developed Infrastructure

We have reached a position where we must consolidate our growth and plan for the delivery of our programs with a more developed infrastructure, something that is increasingly difficult to achieve in our present form.

With this in mind we approached the World Federation for Mental Health (WFMH), an organization with which we have had close relations for the past several years, to inquire whether we could find a significant place under their umbrella. We are delighted to report that the president and the Executive Committee of WFMH welcomed our letter of inquiry.

We have reached a position where we must consolidate our growth and plan for the delivery of our programs with a more developed infrastructure, something that is increasingly difficult to achieve in our present form.

Through our research we found that our organizations share similar visions, missions, and most importantly values. As preliminary discussions progress we are realizing that we will make strong partners and that this will provide a strong basis on which

to work towards a successful merger. We have now engaged in formal discussions which will last through till late 2008.

Benefiting from the Strength of a Combined Organization

WFSAD has presented the idea of incorporating the work of WFSAD within a new section of WFMH: the Centre for Family and Consumers. This Center would represent consumer and family interests and operate very much as WFSAD has operated, but within the strength and infrastructure of a large and well respected organization (WFMH was founded in 1948). Our interests are very much the same, a fact that can be readily seen by looking at the vision and mission of WFMH on their website (<http://wfmh.org>).

We have strong support from our national members who have been invited to give their input on the essential issues that must be raised during discussions. It is clear that what is important to them is WFSAD's unshakable family advocacy. I quote from one member:

WFSAD has become the single most powerful symbol of family empowerment ... it is their iconic status that has inspired caregivers in (the developing world) ... WFSAD has tried to build a movement which goes beyond methodologies and programs.

WFSAD will do its best to ensure that this merger will keep alive the "powerful symbol" that "goes beyond methodologies and programs", through building a new and renewed commitment to consumers and family at the new Center, which will have a set of principles and guidelines of its own as both organizations develop these in our discussions.

This is a very exciting time which we view as a chance to put the strength of both organizations to work on the family/consumer issues in mental health and illness that challenge us both. We have made a very positive beginning. We look forward to a successful fulfilment of the merger plans.

To talk about how the merger will affect you and to give your views contact Diane Froggatt at diane@world-schizophrenia.org. ■

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Effects of Mental Health Law on Recovery from Severe Mental Illness

BY JOHN E. GRAY, PH.D., WFSAD BOARD MEMBER



DR. GRAY, SPEAKING IN CHENNAI, INDIA IN 2004.

Recovery from severe mental illness, especially from the acute or psychotic symptoms, does not start or is grossly delayed if a person does not receive the services needed to promote recovery. Ill people who do not receive services not only continue to suffer, they may harm themselves, end up on the streets, homeless or in jails, unemployed, become the victims or, less frequently, the perpetrators of violence. Their families suffer along with them.

A number of people who initially reject voluntary treatment can be “persuaded” to accept treatment “voluntarily” even though they do not really believe they are ill. That treatment can start them on the road to recovery. However, for the smaller group whose illness is harmful and who completely reject or cannot consent to voluntary treatment there is still hope. Governments throughout the world have passed mental health laws that provide for admission to hospital without the person’s consent. Without these laws, many people, their families and society would suffer the harmful consequences of untreated severe brain illnesses.

Members of the World Fellowship of Schizophrenia and Allied Disorders (WFSAD) are likely to be involved in discussions about reforming the mental health act in their country or state and this paper may be useful to illustrate some of the approaches taken by different governments, which can be more or less helpful in promoting recovery, in the areas outlined below:

1. Who Should Involuntary Hospital Admission Be Limited To?

The challenge for governments is to write an involuntary admission criterion that leads to the fewest number of people being involuntarily hospitalized, but covers those who must be hospitalized and treated or they will not recover from the illness and its serious consequences. In general most governments’ laws

state that the person must meet all the following three criteria to be involuntarily admitted:

- (a) *Must not be admissible as a voluntary patient*
- (b) *Must meet the definition of mental illness or disorder, and*
- (c) *Must meet the dangerousness or harm or deterioration criterion*

In addition, some governments also require either one or both of the following:

- (d) *The person to be treatable*
- (e) *The person to be incapable of making a treatment decision*

Issues Regarding Involuntary Admission Criteria

There are several issues associated with these criteria:

(a) If suitable as a voluntary patient, cannot admit as involuntary

All governments state or imply that the person cannot be involuntarily admitted if they could reasonably be voluntary. (An involuntary patient who recovers to the point that they no longer meet the involuntary criterion may stay in hospital voluntarily if needed), AND

(b) Meets the definition of mental disorder

All governments require the person to have a mental disorder or illness to be committed. Definitions of mental disorder differ with some laws just stating that the person must have a disorder of the mind whereas others specify the type, nature and severity of symptoms in order for the person to qualify no matter what the formal psychiatric diagnosis. Some definitions of mental disorder (or as a separate criterion) require the person to be in need of psychiatric treatment, AND

(c) Meets the “harm” criterion

All governments recognize that in addition to having a mental disorder the person must not be forcibly admitted or treated unless the untreated illness is likely to result in some harm to the person or others. What differs dramatically is how the “harm” is conceptualized. The range is from “imminent serious bodily harm” only, to broadly based “harm”, to prevention of harm through a “likelihood of substantial deterioration” standard. If a person has a severe treatable mental illness, but does not meet the dangerousness/harm/deterioration criterion of their jurisdiction (e.g. country, state, province), they cannot be involuntarily admitted. Therefore they may continue to be psychotic and never recover from their illness because they refuse treatment.

Three types of harm can be seen in different laws.

(i) Only bodily or physical harm to self or others

At its extreme this requirement is very narrow, requiring a history of recent violence, and likely physical bodily (only) harm to a person which is imminent (i.e. will occur in the very near future). Since the only harm recognized is physical harm, a person who

terrifies his family causing great psychological harm and spends all their money because of a treatable manic illness, which will not recover without treatment, cannot be involuntarily admitted and treated under physical harm criteria.

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(ii) Broad harm

In response to lobbying by family groups and others including police, a number of governments have broadened dangerousness "bodily harm laws" to "harm" laws. Governments have recognized that physical danger to self or others applies to a relatively small number of people with severe mental illness. However, they have recognized that untreated illness can cause a number of severe harms for the person, the family and others, such as psychological suffering, financial consequences, emotional harm, etc. A number of governments recognize that untreated severe mental illness in and of itself is harmful and allow the harm to include harm to the person's health. Thus the person described above with a manic illness could be helped under these broad harm criteria even though they were abandoned under physical dangerousness criteria. Persons suffering their first psychotic break – who refuse treatment but are not physically dangerous – can start on the road to recovery under broad harm committal criteria.

(iii) Likelihood of substantial deterioration

Early intervention not only saves the person suffering and possible involuntary hospitalization, it can reduce family, work and social disruption. Where a person has an illness that has repeated episodes it is often clear to family and those close to them that the person is starting to deteriorate but the person does not recognize this and will not seek treatment. Under the broad harm criterion such a person does not qualify and must wait until they are likely to harm themselves or others. To address this issue which is common with relapsing illnesses like schizophrenia, a number of governments have introduced "likelihood of significant mental or physical deterioration" if the disorder is not attended to. This deterioration criterion is also used in some jurisdictions for people to qualify for outpatient involuntary recovery services.

(d) Need for psychiatric treatment

In order to qualify as a mentally disordered person, essential for involuntary admission, some governments require the person to be in need of psychiatric treatment. Other governments have a specific criterion that says that if the person does not need psychiatric treatment they cannot be admitted. This requirement recognizes the "treatment" purpose of the Act and excludes untreatable persons such as those with anti-social personality disorder. However, if such people have symptoms amenable to psychiatric treatment they can be helped.

(e) Incapable of Making an Admission or Treatment Decision

Some governments (e.g. Scotland, Nova Scotia in Canada) have introduced another restriction. The person may qualify on all the above criteria but if they are capable of making an admission and treatment decision they cannot be involuntarily admitted no matter how ill or how dangerous to others. The advantage from a civil rights perspective is that it holds a capable person accountable for the harms that may occur from them knowingly refusing treatment. In addition it addresses the potential legal problem of treating capable people over their objections. The potential problem of this criterion is that with the normal level of capability it may be that some people who are ill and dangerous will be abandoned to the community. For this reason some governments have imposed a higher level of capability to reject involuntary admissions (must be "fully" capable).

2. Procedures for Admission

When the person's recovery process cannot start because their illness makes them refuse voluntary hospitalization, most countries have three methods of addressing this issue. The most common and desirable is where the person can be seen by a physician (or two in some jurisdictions) who applies the criteria in the community and the person is then taken to the hospital for an evaluation. Where this is not possible in some countries the police have authority to take a person with an apparent mental disorder and meeting dangerousness or harm criterion to a physician. That physician then decides if the person should go to hospital for an evaluation. For some families, neither a physician nor the police are possible and they may go to a judge who may order the person be taken to a physician for an examination.

3. Who Authorizes Admission?

There are two basic models in the world for authorizing the involuntary admission of a person. In the United States and many European countries, it is a magistrate or judge who makes the decision to admit, based on medical advice. The United Kingdom governments, most Canadian jurisdictions and some other countries changed their judge systems to a physician authorization system because of concerns about stigma and a desire to make psychiatric admissions more like other medical admissions that do not involve the legal system. Review tribunals that can overrule the physician were also introduced to protect rights.

4. Authorizing Treatment and Treatment Refusal

In all countries, a person who meets the involuntary criterion can be involuntarily admitted without their consent. In a number of countries, since admission is for the purpose of treatment not social control, the admission automatically authorizes the treatment. In other countries, however, there is a separate process for authorizing treatment. In fact the treatment that the treating physician says is utterly necessary for the recovery of the person so that they can regain their freedom may be refused. This treatment may be refused by the person if they are competent or if they have an advance directive (continued on page 4)



(continued from page 3)

not to be treated, or by a substitute decision-maker such as a relative or judge. Unlike voluntary patients who may discharge themselves if they refuse treatment, the involuntary refuser must be detained indefinitely, obviously affecting their freedom rights. Other consequences of treatment refusal include longer suffering, more seclusion and shackling, more assaults on nurses and other patients, more disruption of other patients' treatment, and higher costs for more nursing supervision.

5. Assisted Community Treatment

Many families including people with serious illnesses are all too familiar with the "revolving door" where a person must be committed to hospital to start the recovery process, does well in hospital but once out ceases to participate in recovery services including taking medication needed to reduce relapses. In the psychotic state the person refuses admission and the door revolves again. To address this issue many governments (e.g. New Zealand, Australia, Scotland, Canada, Israel, Norway, U.S.A) now have involuntary treatment in the community. If the person does not participate in recovery services they may be involuntarily hospitalized. Different forms of assisted community treatment include leave from hospital, community treatment orders and guardianship or committeeship.

Two distinct approaches to assisted community treatment (ACT) exist in the world. In New Zealand, the Australian states and Scotland, for example, ACT can be used as a "least restrictive" option. If the person meets the committal criteria and can safely be treated in the community, that must occur and the person is not detained in hospital. This least restrictive model is particularly relevant for young people and spares them the trauma of being with very ill adult patients in hospital.

In contrast, in most U.S. and Canadian jurisdictions the person must have had multiple or long involuntary inpatient admissions. In other words ACT can only be provided once the person has become "chronic".¹

6. Rights and Protections

Many people's worst nightmare is being forced into a psychiatric hospital because of a mistake or malevolence, and forcibly treated with psychotropic drugs. For those people with an illness who do not believe that they are ill, this is exactly how they feel. What are the rights people have and the protections built into the law to minimize wrongful admission, wrongful treatment and wrongful restriction of rights?

The protections against wrongful admission include the person having to be examined by (usually) two independent physicians against detailed criteria. In some jurisdictions a judge also assesses the person with a lawyer representing the person. In addition, once admitted, the person can request a review from a tribunal or judge and that can be appealed to higher courts. Issues of treatment usually involve meeting specific criteria including that the person's wishes be taken into account, that treatment must be in the person's best interests, authorization by a relative or judge and appeals to the courts.

Most modern mental health acts state or imply that the involuntary patient has the same rights as any citizen except those that are specifically restricted by the legislation. In order to ensure people's rights are not unnecessarily restricted, providing information to the patient and next of kin, using rights advisors, and allowing next of kin to request reviews are often available in mental health laws.

7. Services

A wide range of psychiatric, rehabilitation, family and community services are necessary to assist people with severe mental illnesses experience a full recovery. All groups advocate to governments for nothing less. While mental health acts could require this range of services for the whole population of people with mental health problems, most do not.² Instead, since mental health acts are primarily about assisting people who do not recognize they are ill,

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these acts usually only address services required to get the person well enough to make voluntary decisions. For example, most community treatment order laws state that the services a person is required to participate in must be available or the person cannot be put on the order. The bottom line is that mental health legislation that deprives a person of their freedom but does not provide the treatment and services needed to restore that freedom and start the recovery process is counterproductive.

8. Conclusion

Many families with a relative with schizophrenia or severe bipolar illness have had experience with the involuntary mental health system, not because they wanted to but because their loved one refused treatment and that was the only way there was of starting the recovery process. The alternative to involuntary services can be continued psychosis with its great harms to the person and others. Obviously families, consumers and professionals want involuntary services to be used as little as possible and to be sensitive to the person's needs, wishes and rights. They also want follow-up so that the person who did well in hospital stays well. The different approaches taken by governments with involuntary admission criteria, methods of authorizing admission and treatment, involuntary treatment in the community, protection of rights and provision of services can be more or less "consumer and family friendly" and "recovery oriented". ■

¹ Gray, J.E., Shone, M.A. and Liddle, P.F. *Canadian Mental Health Law and Policy 2nd Edition*, LexisNexis Canada Inc. 2008

² *WHO Resource Book on Mental Health, Human Rights and Legislation*, World Health Organization, 2005



Thinking Differently About Schizophrenia

The following two articles highlight research findings that are expanding our understanding of how to think about schizophrenia. Highlights of the findings include:

- The identification of a new receptor complex in the brain that responds to current antipsychotic medications used to treat schizophrenia. The researchers want to further study this to develop more specific medications for hallucinations and psychosis.
- A new drug from Eli Lilly – in the early stages of testing – that would be the first schizophrenia medication to target glutamate and glutamate receptors rather than the neurotransmitter, dopamine. While early testing shows the new medication to be slightly less effective than the current medication, Zyprexa, it has fewer side effects.

New Glutamate Receptor Discovered

Dr. Stuart Sealfon and colleagues at the Mount Sinai School of Medicine in New York City have identified a new receptor complex in the brain that responds to current antipsychotic medications used to treat schizophrenia.

The study identified two receptors in mice – neurotransmitters glutamate and serotonin – that act together as a hybrid complex. The researchers showed that glutamate receptors interact with serotonin receptors, triggering unique cellular responses when targeted by hallucinogenic drugs, such as phencyclidine (PCP). Activation of the glutamate receptors by antipsychotic medications on the other hand, blocked hallucinogen-specific signals and changed the behaviour in mice.

In people with untreated schizophrenia, serotonin receptors are highly activated and glutamate receptors show very low activation, indicating that this serotonin-glutamate complex may

be involved in the altered brain state found in people with schizophrenia. The researchers are now looking to further study this effect to develop more specific medications for hallucinations and psychosis.

The Role of Glutamate in the Brain

Dr. Darryle Schoepp, neuroscientist at Eli Lilly and Company, has developed a new drug that is in very early stages of testing. If proven effective, it would be the first medication for schizophrenia that did not target the neurotransmitter, dopamine.

Dr. Schoepp and his team had focused their attention on the way glutamate, a neurotransmitter, ties together the brain's most complex circuits. It is crucial in linking circuits involved in memory, learning and perception. Because of this, drugs that target glutamate and glutamate receptors have the potential for addressing both positive and negative symptoms.

The first schizophrenia medicine was developed accidentally about 50 years ago, when Henri Laborit, a French military surgeon, noticed that the anti-nausea drug, chlorpromazine, helped to control hallucinations in psychotic patients by blocking the brain's dopamine receptors. Both first and second generation anti-psychotics target dopamine, and have been somewhat successful in reducing positive symptoms, but not the negative, cognitive symptoms.

In Lilly's early tests, this new medication was found to be slightly less effective than the current medication, Zyprexa. But the new medication had fewer side effects, and also appears to improve cognition.

Researchers report that approval is at least three to four years away, with many large-scale trials still ahead. But so far, glutamate seems to offer a new, more complete picture of schizophrenia. ■

Update on the Investigational Antipsychotic Iloperidone:

An Expert Interview With Andrew J. Cutler, M.D. (Excerpt from Medscape, April 16, 2008)

(Dr. Cutler is a professor of psychiatry and behavioural medicine at the University of South Florida. He is also the founder, president, and medical director of Core Research of Florida Inc., a private facility dedicated to psychopharmacology research.)

Medscape: Second-Generation Antipsychotics (SGAs) have slightly varied pharmacologic profiles. Can you tell us about the pharmacology of iloperidone?

Dr. Cutler: First of all, the property that all SGAs seem to share is blockade of dopamine D2 and serotonin-2A (5HT2A) receptors. One of the theories about what makes these (second generation) antipsychotics special is that the relative affinity for the serotonin receptors is greater than the affinity for the dopamine receptors. Iloperidone is different because of the different serotonin receptors to which it binds.

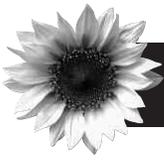
We know of at least seven families of serotonin receptors, and

iloperidone is an antagonist of some (blocking the receptors), and it is a partial agonist (activating the receptor) at others.

Iloperidone also has strong affinity for the adrenergic receptors. Blocking these receptors can cause dizziness or orthostatic hypotension. However, it also appears to contribute to the efficacy of this drug, particularly in mood and cognition.

Finally, iloperidone affects different dopamine receptors. It has little activity at muscarinic cholinergic receptors, so it is not likely to have anticholinergic effects (nervous system side effects). So iloperidone has a unique pharmacologic fingerprint. Whether this translates into unique clinical effects has not yet been studied.

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RESEARCH *cont'd*

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Medscape: You were the lead investigator on one large recent study of iloperidone, the results of which you presented at the 2007 American College of Neuropsychopharmacology meeting in Florida.

Can you tell us about this study and its design?

Dr. Cutler: This study had three arms: iloperidone; ziprasidone, an FDA-approved SGA that is well-established to be safe and effective; and a placebo. The 593 participants in the study were adults with schizophrenia having an acute psychotic exacerbation requiring hospitalization. They were randomly assigned to one of the three treatment conditions.

The primary outcome measure was the Positive and Negative Syndrome Scale (PANSS).

Medscape: Can you tell us about results of this study?

Dr. Cutler: At the endpoint, we saw good separation between iloperidone and the placebo. Furthermore, iloperidone worked for both the positive and negative clusters of symptoms. This reflected a robust and broad efficacy across a wide range of symptoms.

Medscape: Pharmacogenetic research has also occurred during the development of iloperidone. Can you comment on this and discuss how pharmacogenetics may influence

the way we treat patients in the years to come and how it may be relevant to iloperidone?

Dr. Cutler: For a number of years, we have been conducting voluntary sub-studies involving genetic analyses of drug response and tolerability. We are trying to identify a common factor in people who respond well, some genetic marker that we can use prospectively to predict who might be likely to respond to iloperidone, because we know that no drug is 100% effective for everyone.

Vanda's research group has developed a panel of markers that may identify patients who are likely to respond to iloperidone. It is not yet commercially available, but clinicians should be aware that in the next few years we are going to have tools like this to help us better match a specific treatment to a specific patient.

Medscape: Can you comment on what niche you think that iloperidone may have if it does gain FDA approval and how this may affect clinical practice?

Dr. Cutler: Iloperidone would be an important new treatment option, although not necessarily a generational shift ahead. Its efficacy will likely be as good as the other SGAs, and I think it has some potential advantages in tolerability and safety. Some of the real excitement may come from the tools to predict response or tolerability to this drug. ■



EXPRESSIONS

Poem BY ANTHONY REID

I am a label, bipolar maybe worse,
They don't know the glue has not stuck.

I am a number
Section 2 or maybe 3
Depends which doctor you see.

I am a prescription,
Collect drugs with names it's hard to say,
But still I am to swallow them each day.

I am a fear,
One of them who hear voices.
The others, the scary ones,
The ones that should be locked away.

I am a survey
Tick the boxes, dot the i's
See it fits
You match the numbers on our sheet.

Don't deny it for it's true,
We have a pigeonhole for you.

In another time, or other place
Would you make your mark upon
my brain?
Would you send a shock through
my skin?
Would you tie me up in your restraints?
Would you throw away the heavy key
and hide your eyes so you don't see?

I am tired
Not a threat,
I hear the whispers, mocks and laughs,
Some real, some I am told imagined.
Never private, never free
I am my illness, never me.

This poem was found in "Carers' Stories" at www.mentalhealthcare.org

Bipolar Diaries

"I'm bipolar, I'm manic depressive, sometimes I'm psychotic, I have severe and enduring mental illness, I had a breakdown/have breakdowns. There are other [labels]. I'm a patient, a client, a mental health service user.

"Mental health, or mental distress, is cluttered up with labels, as we try to define what the issues are and what they mean for us and our relationships with those who help us to deal with them.

...In the meantime, I'm just me".

BBC's Bipolar Diary documents seven days in the life of a woman coming to grips with bipolar disorder. You can read the full story at:

http://www.bbc.co.uk/health/tv_and_radio/secretlife_bipolardiaries1.shtml#day_one:_getting_a_diagnosis



Some Complexities: Mental Illnesses and Medication

BY MONA WASOW, PROFESSOR OF SOCIAL WORK, UNIVERSITY OF WISCONSIN

The author, a social worker in the United States who works in the mental health field, discusses some of the challenges facing physicians and patients with regard to medications. These include:

- *An expectation of quick fixes and turning to the next new thing*
- *A strong pharmaceutical industry promoting medications as the answer to everything*
- *The need for an “holistic” approach to treatment, that includes more than just medications*
- *The difficulty of continuing to take an effective medication in the face of negative side-effects and accepting the ongoing need for medication*
- *Doctors not spending enough time with patients to find the right medication and for ongoing monitoring*

“Medications Cause Mental Fog” read the headline of a recent newspaper article. It got me thinking about a course I taught on aging many years ago. The very first fact I learned while preparing to teach in this area is that the number one cause of illness among the elderly, both physical and mental, was physician-ordered medications! This was probably compounded by patients going to many doctors plus taking over-the-counter medications.

In doing volunteer work in a geriatric clinic, one of my main jobs was to do the “brown bag analysis”.

This consisted of going to new patients’ homes and getting their permission to take all their medications back to the clinic. Step number one at the clinic was to get people off as many medications as was medically responsible, with frequently a subsequent and significant improvement in their health.

Expecting Quick Fixes

In North America, we live in a culture that expects quick fixes to medical problems. There is also a tendency to swing from one extreme to another, often “throwing the baby out with the bath water”. A prime example of this in the serious mental illness (SMI) field is the swing from psychotherapy to “the Medicalization of the Human Condition” (Chodoff, M.D., 2002). Before 1970, most psychiatrists conceptualized SMIs as being caused by bad parenting. From 1970-1986 SMIs were seen as brain diseases, then as neurodevelopmental disorders, and now clinicians are looking more at integrated models of causality. (Taken from a lecture by Dr. Robyn Murray, WAPR meeting in Boston, MA, 4/13/08.)

In North America, we live in a culture that not only pops pills for everything, but there is also the huge influence of a powerful pharmaceutical industry. This industry influences the entire medical profession and the public through massive advertising. Chodoff also points out “that the remedicalization pendulum has

swung too far and that some American psychiatrists...are running the risk of trying to medicalize not only psychiatry but the human condition itself...that are often inescapable aspects of the fate of being human”. (P. 627)¹ This tendency has also downgraded time spent on psychosocial supports.

Holistic Solutions Are Needed

No part of me is saying “do away with medication”. Medications are often helpful, particularly for positive symptoms. But medications alone are seldom enough. Most people with SMIs require a holistic and integrated treatment that pays attention to general health, structure to one’s life, something to do and general psychosocial supports.

When a psychiatrist only has 15 minutes to check a patient’s reaction to medications, he or she is not doing an adequate job. “Each person responds differently to medications and finding the right one at the right dosage can be difficult, exacting work...all medications have some undesirable side effects...” (P. 173)²

There are high rates of non-compliance with prescribed medications among people with SMIs, and there is a tendency for us to “blame the victim” in these cases. We think they are not taking their medications because they are mentally ill and do not know any better. Well, first of all, there are high rates of non-compliance for medication in all illnesses, from all kinds of people

without any SMIs. Secondly, psychotropic medications have many negative side effects. They make most people feel lousy, cause many different illnesses, obesity in some, dull cognitive functioning, sedation, motor side effects, anticholinergic, tardive dyskinesia,

dizziness, and so forth. In addition to all of this, accepting the need for taking medications involves reaching a point of accepting that one has an incurable illness out of one’s self-control. This is not easy to do for any one, let alone accepting SMIs that have so much stigma attached to them.

There is ample evidence in recent research indicating over-medication use in the area of SMIs the world over. This was also spoken of often at the recent WAPR meeting in Boston, April, 2006. One of the best books addressing this issue is *Treatment Collaboration* by Diamond and Scheifler (2007). They emphasize the importance of what the client wants to accomplish and whether/which medication might accomplish that:

“...medications are too often used without enough consideration of what it is hoped the medications will accomplish, and without careful assessment of whether the medication has, in fact, helped...not enough attention is paid to

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Some Complexities: Mental Illnesses and Medications

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the risks and side effects of medication and how the medication can make things worse as well as better". (P. 14)

This is my plea for all concerned: Be more assertive in questioning the issue of psychotropic medications. It often takes a lot of testing, adjusting, and feed-back to know how much, and what

combinations of medication, are working best for any one individual. Also, what may work well for any given person in 2008, may need readjustment in 2009. Clients, families, and professionals all need to be much more aware of the helpful and harmful effects of these powerful medications. It is complicated. ■

¹ Chodoff, Paul, M.D. The Medicalization of the Human Condition. *Psychiatric Services*, May, 2002, Vol. 53, No. 5, pp. 627-628.

² Mueser, Kim T. Ph.D. and Gingrich, S., MSW. *The Complete Family Guide to Schizophrenia*, The Guilford Press, 2006.

³ Diamond, Ronald J., M.D. and Scheifer, Patricia L., MSW. *Treatment Collaboration*, A Norton Professional Book, 2007.



BOOKS

Talk Therapy: Helping to Stay in Touch with Reality

REPORT OF A BOOK REVIEW IN *THE NEW YORK REVIEW OF BOOKS*

The Center Cannot Hold: My Journey Through Madness

By Elyn R. Saks, Hyperion, 340pp. \$24.95

A review in 17th April issue of *The New York Review of Books* entitled "Infiltrating the Enemy of the Mind" by Jay Neugeboren focuses for the most part on the fact that throughout her years with schizophrenia Elyn Saks relied heavily on psychoanalysis or talk therapy to keep her in touch with reality. She is quoted as writing "While medication had kept me alive, it had been psychoanalysis that had helped me find a life worth living". Elyn Saks's exceptional intelligence has allowed her to attend Yale Law School, graduate and become a professor of Law, Psychiatry and the Behavioural Sciences at the University of California Law School. Neugeboren draws attention to the fact that psychoanalysis has been anathema to the treatment of schizophrenia. He describes his own brother, Robert, who also thrived on talk therapy though having a progressively deteriorating course of illness later on. Throughout the review Neugeboren emphasizes Saks's own emphasis on connectivity, with the regular therapies, with friends and the essential to living of "being known". The following quote describes Saks's views about talk therapy:

"Medication has no doubt played a central role in helping me manage my psychosis, but what has allowed me to see the meaning in my struggles – to make sense of everything that happened before and during the course of my illness, and to mobilize what strengths I may possess into a rich and productive life – is talk therapy. People like me with a thought disorder are not supposed to benefit much from this kind of treatment, a talk therapy oriented toward insight and based upon a relationship. But I have. There may be a substitute for the human connection – for two people sitting together in a room, one of them with the freedom to speak her mind, knowing the other is paying careful and thoughtful attention – but I don't know what that substitute might be. It is, at the heart of things, a relationship, and for me it has been the key to every other relationship I hold precious. Often, I'm navigating my life through uncertain, even threatening, waters – I need the people in my life to tell me what's safe, what's real, and what's worth holding on to".

Neugeboren discusses the various theories and thoughts on talk therapy, but ends by drawing attention to what he feels is most important about the book: the human experience and what makes our lives worth living. DF ■

Diagnosis and Treatment of Mental Disorders Across the Lifespan

JOHN WILEY AND SONS LTD, APRIL 2008, 1152pp.

Diagnosing and Treating Psychopathology Across the Lifespan: An Integrated Approach is both a clinical diagnostic training manual for students and a reference for experienced mental health professionals. It provides all of the essentials of clinical practice, including placement, interviewing, crisis intervention, and diagnosis, treatment, and clinical management of specific disorders. Divided into two sections, the first part of the text presents the foundation of clinical skill development, while the second part emphasizes the application of those skills as they relate to specific client problems. Information is presented at both

basic and advanced levels, making this text valuable for both novices and seasoned clinicians. Unlike other texts, this book takes a lifespan approach to psychopathology, including information on etiology, clinical presentation, diagnosis, and treatment of a wide range of mental health disorders that occur in people of all ages. ■

Order online at:

http://www.researchandmarkets.com/product/97eb20/diagnosis_and_treatment_of_mental_disorders_a

75 Euros -- hard cover



How to Advocate for Policy Change Development

BY TRISH RUEBOTTOM

This article offers advocacy tips to help those with mental illnesses and their families and family organizations, based on the Zimbabwe National Association for Mental Health's (ZimNAMH) workshop at the World Psychiatric Association's Congress in Nairobi, Kenya, February, 2007. It identifies a four-step process to achieving an effective advocacy campaign:

1. *Developing your constituency and finding your supporters*
2. *Understanding the government*
3. *Establishing a clear goal*
4. *Building your case using evidence-based data*

Advocacy in the field of mental illness focuses on promotion of mental health policies, increased resources, greater availability and accessibility of needed services by people with mental illness and their families, and an end to stigma and discrimination.

Often we assume that we understand the opposition – we have heard it already, echoed in the newspapers and throughout society. But always take the time to truly understand your opposition – you will create a much more persuasive response.

Many policy makers hold both conscious and unconscious prejudices, and so advocacy must start at the very beginning – with education about the issues and solutions, backed by the fundamentals of human rights.

By taking a rights-based approach to advocacy, you confirm the obligation of governments to ensure all citizens equally enjoy their rights and freedoms and can participate fully in society. A rights-based approach highlights that people with mental illness are people with rights, not just objects of charity, and gives legal capacity to the fight. The international human rights treaties and national human rights laws of the last few decades contain principles of equality and nondiscrimination that can be used to promote and protect the rights of people with disabilities, specifically including people with mental illness.

1. Develop your Constituency

Effective advocacy starts with having a critical mass. A broad-based, well-organized coalition across sectors will carry more weight than a small, undefined group – no matter how important the issue. Governments respond to numbers, and you must first appeal to them at this level.

You must also have the support of key people who can make things happen. When ZimNAMH began, they targeted women

policy makers, and approached them with an emotional plea, as mothers. Other groups have approached the First Ladies of Mental Health – an influential and already supportive group. Try to approach people from more than just your country's more liberal, socially-minded party – a bipartisan approach will hold more strength, and will cut across the already strained relations between parties.

With this constituency behind you, speak a common message with one voice.

2. Understand the Government

Take time to prepare yourself, reviewing existing legislation, as well as the structures and processes of government's executive and legislative branches. Usually, there will be clearly defined points of access for the public in policy development, and following these can open the doors. Finding an entry point in existing legislation is also important for gaining credibility. For example, "it says here in the government's health legislation 'mental health', so what is your plan to...". If there is no mention of mental health in existing legislation, look to comparative legislation on consumer protection, either in UN documents or in other countries.

Timing is also very important. Current events can turn the government's attention towards or away from issues of health and mental illness, treatment and discrimination. Government cycles are also important – coming into an election period is not a good time for bringing up a controversial issue, one that is not seen by many as "important" enough to get voters' attention. Understanding the political environment to ensure the timing is right will save months of frustration.

3. Establish a Clear Goal

ZimNAMH started out with a realistic and defined goal: to compel debate in parliament. After educating the women policy makers and gathering their support as fellow mothers, the debate was then left in their hands.

The goal must be clear, based on your understanding of policy development, and backed by your constituents. You must have a clear "ask", identifying specific priorities – what you are asking for from the government.

4. Build your Case Using Evidence-Based Data

You will need to educate people in order to build support. You must educate the government on the importance of mental health care, with statistics, cost data and important reports. Use evidence-based data to back your case, but you must specifically address the underlying issues.

It is here that you must seek out the opposition – understand their perspective and arguments, find mutual solutions and directly address their concerns. There is no point

(continued on page 15)



Changing the Name Schizophrenia

Should the name “schizophrenia” be changed? An international survey conducted by The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) recently gathered feedback on this issue. Results:

- The majority of respondents are in favour of changing the name
- Areas of the world where there has been the most reduction in stigma are most against changing the name
- Persons with mental illness were the most strongly in favour of changing the name, while the responses from professionals were more evenly divided
- The primary reason given for the name change was to reduce stigma
- For those against the name change, the main reason was that it would not reduce stigma

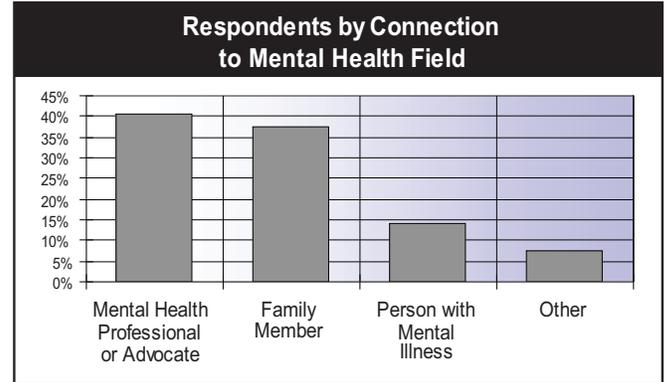
Read on for all the details.

WFSAD recently surveyed our international network of families, professionals and people with mental illness asking whether the name “schizophrenia” should be changed. The issue has been talked about for years and continues to crop up. It is an important time to ask this question, as the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* is being reviewed (the new edition will be released in 2012), and changing the name of schizophrenia is one of the items being considered. While it is a diagnostic and treatment-based decision, the impact is much broader than just diagnosis and treatment. WFSAD wanted to add the voices of our network to the debate, letting the reviewers know how family, people with the illness and other mental health professionals feel.

About the Survey Respondents

Respondents by Country		
	Number of Respondents	Percent of Total
Asia	7	5%
Australasia	31	20%
South Asia/Indian Subcontinent	1	1%
Europe	17	11%
Middle East	1	1%
Africa	10	6%
Central & South America	16	10%
North America	72	46%
Total	155	100%

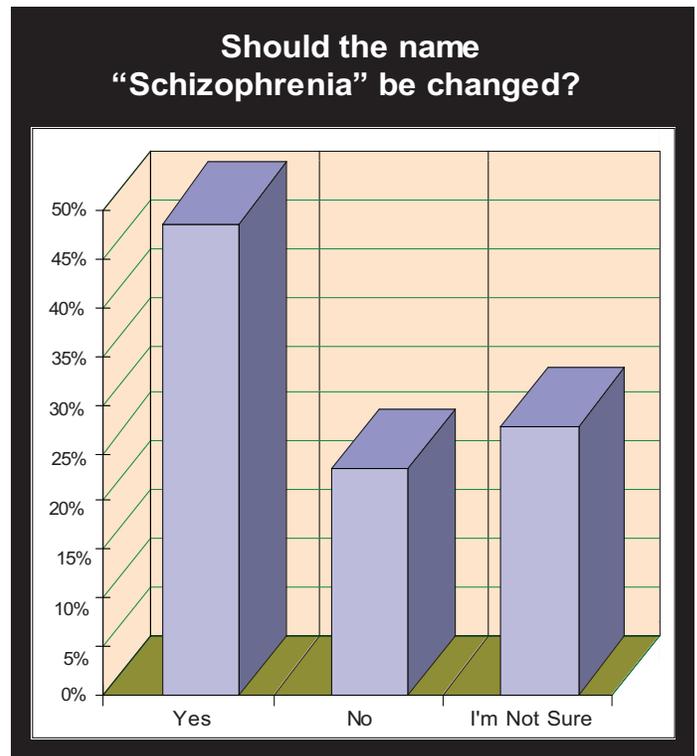
A total of 155 people responded to the survey, representing a cross section of stakeholders from around the world. Several respondents listed more than one connection to the mental health field – many family members and consumers are also advocates – but for the purpose of the reporting, their primary identification with the field was used. (The data has not been tested for statistical significance.)



An Overview of Survey Results

Respondents were asked whether the name should be changed in English, in their own language (if other than English), and whether they felt the issue was important.

As the accompanying chart shows, most respondents thought that the name schizophrenia should be changed:



For those in favour of changing the name, the most common reasons were, in descending order, to:

1. Reduce stigma
2. Improve accuracy – the name “schizophrenia” is scientifically inaccurate and often misunderstood as multiple personality disorder
3. Reduce negative historical connotations – hopeless, without chance of recovery, and the fault of the family

4. *Avoid difficulty in pronouncing and/or spelling*

Those who do not want the name to change offered the following reasons, in descending order:

1. *The name change will not reduce stigma towards the illness – the new word will become equally stigmatized*
2. *It is more important to find effective treatments and educate the community*
3. *We would lose the gains we have made in the past 10-20 years, and confuse people*
4. *No one has put forward a better option*

When the results are broken down further, we find that there are different opinions among family, consumers, and professionals, and also among people from different regions of the world.

How did people with different connections respond?

	Yes	No	Unsure
Family Member	50%	23%	27%
Mental Health Professional	42%	27%	31%
Person with Mental Illness	60%	20%	20%

Not surprisingly, persons with mental illness were the most strongly in favour of changing the name, while the response from professionals was more evenly divided.

How did people from different regions respond?

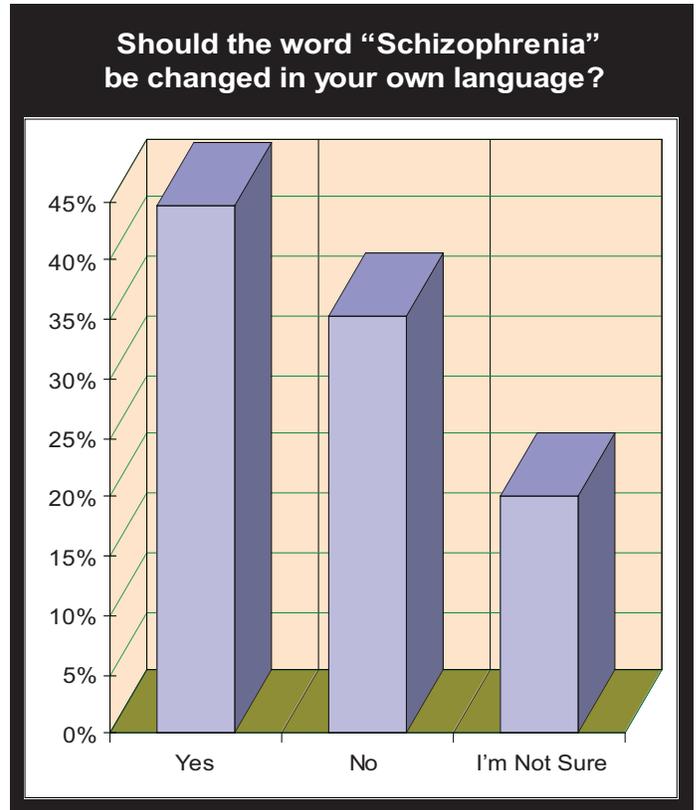
	Yes	No	Unsure
Asia	43%	43%	14%
Australasia	45%	19%	35%
South Asia/Indian Subcontinent	0%	100%	0%
Europe	65%	24%	12%
Middle East	0%	100%	0%
Africa	90%	0%	10%
Central & South America	75%	6%	19%
North America	36%	28%	36%

When the results were compared between people from different regions of the world, the survey showed that:

- *North America was almost evenly split between Yes (36%), No (28%) and Unsure (36%)*
- *Africa is overwhelmingly in favour of changing the name (90%)*
- *Central & South America (75%), and Europe (65%) were heavily in favour*
- *Australasia is closely divided between Yes (45%) and Unsure (35%), although there were only half as many people who do not want the name changed (19%)*

Based on these results, opinions appear to be inversely correlated to the amount of change in societal opinions/stigma – the more people felt stigma had been reduced in their community, the less likely they were to want the name changed.

Surprisingly, the results were somewhat milder when people answered whether the name should be changed in their own language.



6. How important is this issue?

Very important	66	43%
Somewhat important	44	28%
Neutral	18	12%
Not important	12	8%
Really a waste of time	15	10%
Total	155	100%

Finally, most people felt the issue of changing the name was important. Those who did not feel the issue was important, were most likely to not want the name changed.

In the following pages, look for additional articles by Trish Ruebottom and Diane Froggatt, offering perspectives on whether we should be advocating for a name change now. ■

Opinions appear to be inversely correlated to the amount of change in societal opinions/stigma – the more people felt stigma had been reduced in their community, the less likely they were to want the name changed.



What's in a Name?

Perspectives on Changing the Name "Schizophrenia"

The report on pages 10-11 gives the results of WFSAD's recent survey on changing the name of schizophrenia. In the following two articles, Trish Ruebottom and Diane Froggatt provide additional points for consideration on this important issue.

Trish Ruebottom provides several reasons why she is in favour of changing the name as soon as possible, including:

- The negative connotations associated with the word "schizophrenia"
- Name changes have been effective in the past
- Other names that have been suggested more accurately reflect our understanding of this condition

Diane Froggatt, on the other hand, suggests it would be worthwhile to wait longer before changing the name. Describing the focus that scientists and physicians are currently giving to better understanding psychosis and the range of mental illnesses that it may encompass, she suggests: "Rather than fulfilling our emotional need to change a perceived unpleasant name, wouldn't it be better to wait and see what clinical and basic research can tell us about healthy brain function and how this is disrupted by mental illness? We seem to be on the cusp of discovery".

In Favour of Changing the Name – Now

BY TRISH RUEBOTTOM

We must push to change the name of schizophrenia. Now, while revisions are being considered for the DSM-V, we must add our voice to the debate and let the psychiatrists know that families, consumers and other mental health professionals want the name to change.

The word "schizophrenia" is weighed down with fear and misunderstanding; it carries with it the historical context during which it was named, a time when we had no understanding of the illness, treatments had not been developed, and recovery was impossible. It has become one of the most loaded words in our vocabulary. To say that "a rose by any other name..." is an appropriate aphorism in the name-change debate for schizophrenia is like saying that the connotations associated with language are irrelevant – that the language we use is not important. Anyone in the mental health field must agree that the language that we use to talk about mental illness, about *people* with mental illness, is most definitely important, that names can hurt us.

Names Matter

I volunteered on a telephone helpline for many years, and one of the most important things I learned in the training was to choose my words carefully. Especially when people are vulnerable and

seeking help, they are most sensitive to language. Many words can be interpreted as a threat or a challenge that will close the doors to conversation, whereas others come across as supportive and friendly. The wrong words can stop people from seeking help. In Japan, the connotations attached to schizophrenia were preventing doctors – psychiatrists – from giving the diagnosis to their patients. The Japanese word for schizophrenia, "Seishin-bunretsu-byo", literally translated to "split mind disease". Even when patients clearly presented with the identifying symptoms, only 37% were given the diagnosis of schizophrenia by psychiatrists. In 2002, after several years of lobbying by the Japanese family association, the name was changed to "Togoshiccho-sho" or "integration disorder". A few years later in 2006, it was found that 70% of psychiatrists were now giving a diagnosis when symptoms are present.^{1,2} The rationale for the name change was that the original name implied hopelessness, without chance of recovery and described a deteriorating condition, leading to exclusion and inhumane treatment. Does the English word not carry these exact same connotations?

Renaming is a key strategy used by marketing and public relations industries to improve image. Why? Because it works. Labels used in headlines are chosen to create a picture beyond the literal meaning and when a negative label becomes attached to a product or person, the advertising industry will often stage a massive name-change campaign. Labels in other social issues are also changed in order to change societal perception and attitude. In Canada, as in other multi-cultural and post-colonial societies, the names we use to describe groups are always a topic of debate. North American aboriginal communities did not like being labelled "Indian" – it was 1) incorrect and based on old errors, 2) carried negative historical connotations that enforced stigma and discrimination, and 3) was not the choice of the aboriginal people themselves. This last point is important. Labels can be used to disempower or to empower groups of people – the voice behind the label is the distinguishing factor between whether it will empower or not.

Reflecting Current Understanding

The term "mental illness" itself is an example of changing the perception of psychiatric disorders. It makes clear that it is an *illness*, a biological brain disorder, a label that is more scientifically accurate, reduces stigma and educates the public all at the same time. It has not gotten rid of stigma, but it is a helpful tool for educating society. The new word or label for schizophrenia will of course develop stigma, but it will be stigma based on our current understanding of the illness and the possibility for treatment and

¹ Has the informed consent for people with schizophrenia prevailed among Japanese psychiatrists by changing the name?; the outcome of 3-year study. *Psychiatria et Neurology Japonica*, 2006. <http://scielinks.jp/j-east/article/200605/000020060506A0116224.php>

² Renaming Schizophrenia : A Japanese Perspective. *World Psychiatry*. 2006 February; 5(1): 53-55. <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1472254>

recovery, as opposed to a word that carries over 100 years of stigma and misinformation; a word that signifies violence and danger, hopelessness, deterioration, multiple personalities; and that conjures images of insane asylums with catatonic people who shuffle through their days. Changing the name is not the magic bullet that we would love to find, but it gives us a level playing field, a chance to start fresh with public education and campaigns.

Scientifically, the word is inaccurate, and “meets none of the criteria for construct validity: there are no specific symptoms, causes, outcomes, or treatments for schizophrenia”. Dr. Jim Van Os

Scientifically, the word is inaccurate, and “meets none of the criteria for construct validity: there are no specific symptoms, causes, outcomes, or treatments for schizophrenia”, said Dr. Jim Van Os, of the Maastricht University, Netherlands, at the International Congress on Schizophrenia Research³ held in March, 2007. Van Os suggested the inclusion of two Axis I categories in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)*: General Affective Syndrome and General Psychotic Syndrome, plus four Axis II dimensions that describe positive, negative, depressed and manic symptoms. This line of thinking best serves treatment – schizophrenia, bipolar and depression can all show affective and psychotic symptoms, none are specific to schizophrenia alone – and treatment is based on the symptoms as opposed to the diagnosis. In other words, antipsychotic medications target psychosis regardless of diagnosis, and response to treatment is common for psychosis in general, across all illnesses.

At the same Congress, Dr. Robin Murray from the Institute of Psychiatry in London put forward two main objections to the term schizophrenia. His first objection is to the idea that there is a binary distinction between schizophrenia and normality – he argues instead for a continuum of psychosis as opposed to a categorical diagnosis of schizophrenia.

Murray’s second objection centred on the distinction between schizophrenia and bipolar disorder, and he again argued for a continuum:

Even excellent clinicians cannot make this distinction, hence the existence in DSM-IV of schizoaffective disorder. Schizophrenia and bipolar disorder show overlap in symptoms and genetic risk, both respond to dopamine D2 receptor blockade, and both arise typically in early adulthood, showing more severe course and/or earlier onset in men than women.

He argues that while there is an obvious difference in patients at the two ends of the schizophrenia-bipolar spectrum, “our insistence that the two are separate entities exposes psychiatry to ridicule”. Dr. Murray proposes the non-derogatory term “dopamine dysregulation disorder” as the DSM-V diagnosis (since government and the insurance industry insist on categorical descriptions), but most importantly, patients would then be

assessed in terms of three dimensions: positive symptoms, affective symptoms and developmental impairment.

Another interesting suggestion came from Dr. Will Carpenter: people should be diagnosed along three dimensions – psychopathology (symptoms); therapeutic target (what we currently call the diagnosis); and recovery goals (such as autonomy, functional outcome, and quality of life). Dimensional diagnosis, such as these suggested by Dr. Van Os, Dr. Murray, and Dr. Carpenter, allows for independent assessment in each area – since not all people with schizophrenia or bipolar show all symptoms in all dimensions – and best informs treatment-based decisions.

To be labelled with a disorder, a chronic illness, is a difficult experience, a shock that no one expects, even if they suspect. But to be labelled with an inaccurate, stigma-laden name that offers only broad and vague therapeutic guidance for both patient and doctor is cruel. To come full circle, the most important reason for changing the name is that most carers and people with schizophrenia find the term unacceptable. In our survey of 155 people, 49% were in favour of changing the name vs. 23% who were opposed. The majority of those in favour were people with the illness themselves, so we must add our voices to the current psychiatric debate, now, while there is still discussion. If we are to change the name, it is the people who must live with the label who should have the final say. It is the difference between empowerment and oppression.

(continued on page 14)

Another Perspective

If we are to think of changing or renaming a mental illness, then why only schizophrenia? Of course the name schizophrenia makes a person feel totally shattered. If a psychiatrist labels a patient as a sufferer of schizophrenia, it almost means a death sentence is being declared to him. He would physically live, but not mentally. All the hopes, all aspirations come to a full stop after labelling a person with schizophrenia. The word “schizophrenia” is something that harms and makes the so-called “patient” both reduced and afraid. So it is needed that we have to take away the word schizophrenia.

But nearly the same feelings happen when a person is suffering from other psychosis. Changing the name would not solve the problem of social stigma. I think first, stigma towards any form of mental illness must be reduced. I often think: why do we need to know what a person is suffering from? Is it only for medication? Similar medicines are given for many psychotic problems. The prognosis and developments of one person can be better than the other with the same diagnosis.

I think all the professionals and psychiatrists must think about renaming and classifying all the mental illnesses.

Ishita Sanyal, Turning Point, Kolkata

³ ICOSR 2007 – DSM-V Stirs Debate and Discussion, <http://www.schizophreniaforum.org/new/detail.asp?id=1333>



Too Soon to Change the Name

BY DIANE FROGGATT

I have been reading the July 2007 issue of the *Schizophrenia Bulletin*. What a shame they didn't put the theme on the front cover. If they had done so, it would have read "Deconstructing Psychosis". What this means is that researchers and clinicians are taking a long, hard and broad look at psychotic disorders "syndromes currently referred to as schizophrenia, bipolar disorder, major depressive psychosis and substance-induced psychosis".ⁱ The purpose of this examination is to find a global consensus on these matters in order to develop a really superior edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) – a manual that has optimal clinical utility. The formal revision process began in 2006, and the manual will be ready in 2012.

Need for Further Understanding

In his introductory article "Time for a Fresh Start? Rethinking Psychosis in DSM-V", Dr. Darrel A. Regier speaks of some of the new approaches:

During the research review key issues emerged that cut across multiple diagnostic categories. These include interest in viewing and classifying mental disorders from a developmental perspective, reflecting growing awareness that many conditions evolve over the life course.

The notion of "disorder spectra" also drew the attention of several planning workgroups. Accumulating information about putative etiological and pathophysiological mechanisms as well as phenomenological features of different conditions raised questions about more informative approaches... "lumping and splitting" disorders in a manner optimally conducive to both clinical utility and future research. Spectra concepts might well also shed light on a necessary distinction between our current notions of co-morbidity as opposed to a possible moderator effect of a given condition on another. Among spectra considered during the review were those of psychotic phenomena associated with several disorders, obsessive-compulsive behaviors that may be common to multiple discrete diagnoses in the current classification, a new grouping of so-called stress and fear circuitry disorders that promise to reveal common neurobiological substrates, and the stew of generalized anxiety and major depressive disorders, to name a few.

A third cross-cutting issue concerns the somatic, or somatoform, features of mental illness, signaling widespread recognition that since the brain is an organ much like – albeit at a greater level of complexity – other bodily organs, our understanding of mental disorders cannot be separated from broader health and medical concerns.

Finally, and in large part due to the emphasis that the research review has placed on the demographic diversity and international representation of participants, attention to the influence of gender and culture on mental disorder has been prominent in our consideration of future mental disorder classifications.

ⁱ Deconstructing Psychosis. Jim van Os and Carol Tamminga. *Schizophrenia Bulletin* 2007;4,861-967.

One is inclined to feel that the more we know, the more we know we don't know. Not everyone fits into the definitions given by DSM-IV or the WHO International Classification of Disease (ICD 10). Symptoms seem to cross apparent borders and some of the definitions – particularly those for schizoaffective disorder – are unclear at best. The many scientists and clinicians working on DSM face an uphill battle and we value their efforts.

In discussing classifications I am reminded of something my son once said after yet another patient "support" meeting at the hospital. "In all the years I have had schizophrenia I have not yet met one person who experiences schizophrenia as I do. Their symptoms are different, their voices are not like mine, they have different fears and their thoughts and emotions are different". It is known that people with schizophrenia are not a homogeneous group, as my son found when he looked around the support group participants. Additionally, the diagnosis doesn't always stay the same in many cases. Families and consumers become frustrated when a diagnosis of schizophrenia becomes one of bipolar or schizoaffective disorder later on. Years ago at a Rethink (U.K. family organization) conference on the Euston Road in London I heard the distinguished schizophrenia scientist, Professor Tim Crow, speak of a continuum of illness: a line along which each of the psychotic disorders could be found, and one which they could travel along. This seems to be very much what scientists are continuing to probe today.

So with all these scientists trying to figure out etiology, nosology and relationships between all these mystifying diseases, should we really be pressing to change the name schizophrenia for the DSM-V? It is apparent that we are not really sure yet what "schizophrenia" is, whether it might turn out to be several disorders, or how it fits in with the other disorders of its kind.

On the Cusp of Discovery

In the recent WFSAD survey a majority of the respondents favoured a name change though families appeared to be less certain (23% against, 27% unsure – see page 11, column one for figures). Most of those voting against felt that a new name would not change the stigma associated with mental illness, and that the gains made in the past 20 years in putting the word schizophrenia out in the open would be lost as people became confused between new and old names. In addition, the new names being offered so far did not provide a better option or a better explanation of the disorder. There was also the question of how schizophrenia was named in different languages.

Rather than fulfilling our emotional need to change a perceived unpleasant name in time for the DSM-V publication, wouldn't it be better to wait as necessary to see what clinical and basic research can tell us about healthy brain function and how this is disrupted by mental illness? We seem to be on the cusp of discovery. Until that time let us do our best to de-mystify these names, clarifying what it means to live with schizophrenia and humanizing the people who bravely deal with the symptoms and the diagnosis. ■



From Social Write-Off to Writer

BY GREG BAUDER *This author, with published novels and other writings to his credit, tells how he fought back from disabling symptoms of schizoaffective disorder to become a writer.*

I have had schizoaffective disorder for 31 years. My first episode was triggered when my mother died a terrifying death of bowel cancer when I was 20. After descending into a mad world of demonic voices where I was hospitalized and medicated with Stelazine and then Haldol, I thought there was no hope left.

It has taken me many years to recover but I consider myself lucky to have survived the terror and isolation of my old, withdrawn and very depressing schizoaffective world. But I still have bad days too, and I know the importance of remaining medication compliant.

I suffered for years, smoking cigarettes and drinking coffee and doing little else. I would stay up for several days at a time hearing demons threatening me and telling me to do bad things. I began watching Christian shows and soon I was a Christian and I started hearing aliens tell me the world would end soon and The Rapture was at hand. It got to the point where the slightest sound would make me think it was beginning.

My family and mental health residents said I sat by the windows waiting for Christ to come. My Dad was especially worried and pushed for me to socialize more. In a successful effort to get me to socialize more, I was moved from a single room in my first psychiatric boarding home into a shared room with a wise, spiritual, but depressed man.

My roommate soon became my best friend and encouraged me to go back to the classics and read books on mysticism. I reread Milton, Blake, Byron, Yeats and the gnostic gospels as well as Joseph Campbell. We would talk for months about literature until I got to the point where I finished the final two courses of my Bachelor of Arts in English Literature by correspondence from the University of British Columbia (UBC).

Unfortunately, my friend passed away of cancer which made me suicidal. I went for grief counselling at the hospital and then I was given a medication that would lead me out of my shell. It was olanzapine and since I've been on it I've had part-time jobs and I have taken creative writing courses at UBC.

I worked with very supportive professors and students and I have had two novels published and another accepted for publication soon. In addition, I have had short stories, poems, plays and reviews published. My first novel *The Temptress Ariel* was loosely based on my boarding home/hospital experiences and it has received good to rave reviews so far. One critic called it "startlingly realistic".

I have never lived on my own and I have been a resident of four psychiatric boarding homes (the first one for 9 years). My dream is to one day get my own place by making a living with my writing.

I still have problems with the negative symptoms of schizophrenia, but I am more self-confident, determined to grow and less paranoid. I no longer hear voices or have delusions of people reading my mind and broadcasting my thoughts. I have even been on radio shows and did public readings in the last few years, and although I was nervous I wanted to share my experiences. ■



(continued from page 9)

How to Advocate for Policy Change Development

building an entire case around the importance of mental health to society (which assumes that your opposition simply does not believe it is important), when really the opposition's argument is much more practical: they do not know where to direct the small resources that exist to address such a large need. These two scenarios would require very different arguments and proposed solutions.

Often we assume that we understand the opposition – we have heard it already, echoed in the newspapers and throughout society. But always take the time to truly understand your opposition – you will create a much more persuasive response.

Once you have built your case, create a platform: a brief, and precise document that presents your case.

In Conclusion:

Creating change is a long process. Pace yourself and ensure you motivate your group along the way. Be prepared – don't underestimate the time and money it will cost to launch an advocacy campaign. Even once the legislation has been changed, or a bill has passed, the work is not done. It must be followed up with interpretation of the the law, assigning a budget, and implementation. To be effective in monitoring the implementation phase, advocates must quickly assume different roles, acquire new skills and use them in a completely new environment. ■



Stigma, Social Support and Recovery

Diane Froggatt, Secretary and Development Officer at WFSAD, was recently interviewed by Shauna Martine Graf, a Grade 12 Sociology student at Catholic Central High School in London, Ontario, Canada for her course: Individuals and Families in a Diverse Society.

Shauna: What is your opinion on schizophrenia being labelled as “youth’s greatest disabler”?

Diane: I believe it is. Schizophrenia has an incidence of 1 in 100 over the life span. Since it usually strikes people between 15 and 30 this 1 in a 100 mostly refers to young people. If there are 100 people in your year at school one of them is going to be affected. That means their family will be affected, maybe five or more people. Many diseases in the world are terrible, and some can kill you. With schizophrenia, it is mostly the case that people live with it. People didn’t used to think about the disability associated with a disease that could last a long time, perhaps all one’s life, and the costs to society, until the World Health Organization did a study that put figures to “Days Lived with a Disability” (DALYs). When looked at this way, schizophrenia and other serious mental illnesses like major depression came out on top of the list for suffering and disability.

Shauna: In your opinion does stigma exist about this mental health issue?

Diane: There is a great deal of stigma everywhere. It usually exists when people are facing the unknown and/or something they fear. I have seen people on the street, and particularly children, laugh and make fun of someone because they were behaving in a bizarre way. My son was one night returning to his home, from a party at my place very late at night. A police car pulled up beside him and asked him where he was going and where he lived. He told them, and he also said “I have schizophrenia”, so that they would understand if he behaved a bit differently from ordinary people. They jumped out of the car and made him put his arms up on the top of the car while they frisked him. They put him in the police car and took him to his home. Could you call that stigma?

In some countries a person cannot get a visa or passport if they have schizophrenia. Airlines have been known to refuse to carry persons with schizophrenia. In Japan, until recently, a person who was mentally ill could not become a hairdresser – and there was a whole list of other proscribed occupations.

Shauna: Are people who suffer from schizophrenia more vulnerable to stress?

Diane: I believe that schizophrenia has something intrinsic in its cause that has to do with stress. We are all under pressure to do well in school, to pass exams, to do the right thing and so on. But that is normal – it is expected that everyone can have mild anxiety about these things that happen in everyday life. People with anxiety disorders and people with schizophrenia have anxiety over everything they do. To go outside and get on a bus, for my son several years ago, was something he could not do for fear of –

WHAT? Upsetting the driver? Feeling people were looking at him? Well I don’t think we can readily explain his extreme anxiety. He told me once that when he walked down our street, if someone was coming towards him, it would feel as though a huge, vicious dog were approaching rather than an ordinary person. This is the kind of thing stress is to people with schizophrenia. This is why my son likes to stick to mixing with the small circle of people he knows well and going to places he knows well where he has gained some degree of comfort.

Shauna: Which symptoms do you consider more severe?

Diane: I believe families consider the behavioural symptoms the most discomfiting for everyone. As to doctors, because the medications have only worked on the psychotic symptoms like hearing voices or having delusional beliefs, these are the symptoms that they have concentrated on – and ask their patients “Are you hearing voices still”? as a measure of how well or “stabilized” they consider their patients. When patients are identified as stabilized, frequently all that has happened is that the psychotic symptoms have been dunned down, and probably the patient has been dunned down too! But schizophrenia is a lot more than psychotic symptoms. The symptoms that give people no motivation, lack of ability to feel pleasure, inability to determine facial expressions and moods in others, and most importantly the cognitive deficits that are common to a percentage of people, all these receive no treatment at all because there is no medication that will change them. (To date, clozapine is the only one that has achieved this in some patients.) Thus, for me, these symptoms are the most important because these are the ones left after people have been treated. As to their severity, it depends on the patient.

Shauna: How are relationships within the family affected (such as parent-child or sibling relationships)?

Diane: Relationships at the best of times can be difficult between people, as you probably know from disagreements with your parents, friends, and so on. A lot depends, at the beginning of the illness, on whether the sibling relationship was good before schizophrenia began. If it was, siblings are usually helpful and understanding – so long as they know what is going on.

The onset of schizophrenia is traumatic for the family and should not be underestimated. At first there is bewilderment – for the person and the family – and when they find out what it might be, quite often a shaft of fear and pain goes through all of them. They just don’t know what the future holds. Siblings often feel neglected when parents are occupied with the sick person. Siblings might also feel guilt that they are well and their brother or sister is not. In all, there are a lot of mixed emotions constantly turning over inside everyone. Arguments can occur about what to

do. Some of the family may deny it is happening: "He's just plain lazy, sitting there all day staring into space". Mothers are usually the ones who keep the family going and seek help from support groups. Though fathers go to support groups too, they are in the minority. Sometimes the person becomes so changed by the illness that you feel you don't know them any more and this can be devastating. Fortunately, when people get early treatment to control the worst of the psychotic symptoms, which happens more frequently nowadays, this doesn't happen quite so often.

Shauna: Are patterns of either the patient binding very close to their family, or the patient completely expelling family relationships regular?

Diane: This question is difficult. If people don't get treatment early it is possible that they may expel their family, due to their psychosis. Many people with psychosis think their family is plotting against them so that they have to defend themselves against their family. In rare cases they threaten members of their

workplace, and do not belong to any social group (team, club, etc.) might be lonely and even unhappy. For many with schizophrenia this is their situation, and without these supports, recovery is extremely unlikely. At this point I would say that "natural" supports are much better than case workers or people paid to come and see you. This is why the consumer movement of people themselves with experience of mental illness has been so successful. They have been instrumental in developing social and business opportunities to help people get out from their lonely apartments and meet people like themselves who know what might be their limitations and what their possibilities. But for this to happen, government support is needed.

Shauna: What is – or has been – the most difficult aspect of recovery?

Diane: For many people this new idea about recovery from schizophrenia is nothing more than a cruel hoax. Where are the necessary adjuncts to recovery? As I have already said, there need

to be opportunities for people with schizophrenia that are geared to what they can achieve – that will support their development and transference to the work force, if possible – but right now there are not. Also,

There is a great deal of stigma everywhere. It usually exists when people are facing the unknown and/or something they fear ... My son was one night returning to his home, from a party at my place very late at night. A police car pulled up beside him and asked him where he was going and where he lived. He told them, and he also said "I have schizophrenia", so that they would understand if he behaved a bit differently from ordinary people. They jumped out of the car and made him put his arms up on the top of the car while they frisked him. They put him in the police car and took him to his home. Could you call that stigma?

family. You can imagine this might result in alienation, especially when the family is fearful and does not understand what is causing this. When a family learns early on about the illness, they want to help their relative get better. As friends drop away, family becomes friend, counsellor, secretary – many roles – so that this person can continue some kind of life. When you join a family self-help organization and work as a volunteer you see this side of the coin, families working hard to maintain a good relationship, while wanting to let go a bit, yet not being able to, for fear of something bad happening to the person.

Shauna: Does society's perception of this disease play a role in recovery?

Diane: I think society's perception hampers recovery. If there were no stigma then people would probably seek help like they do for any other illness and there would probably be more services available. Society's perception of mental illness has to change. Government needs to provide appropriate recovery opportunities. So support, self-help and advocacy organizations are essential.

Shauna: How can a person's support system affect their recovery?

Diane: In general, ordinary people who have few friends, do not see their parents or family often, have no friends in the

because the medications do not have any effect upon people's cognition, motivation and initiative a good percentage of people cannot hold down any meaningful job for long. The figures say that 25% of people followed over a 10-year period have recovered. This is not due to anything other than they have just not had any more episodes after having one or two. Who knows why? There are also 25% who don't get better and remain pretty much cared for by family or institutions. The middle 50% are a heterogeneous mixture of partially improved or recovered people. We need more effective treatments.

There remain people who have had schizophrenia for many years living on the fringes of society, who, through support and encouragement do "come along" and do surprising things. One example is a man of 50 I know of who as a young man was an extremely talented artist who never reached his potential because of schizophrenia. He takes his medication regularly. His parents have helped him to get back to his painting, in a slow easy-going way (the only way for people with schizophrenia). He now has his own apartment, which he looks after well. He paints on a regular basis and shows his work at community art shows. He has taken over his mother's old car and drives about to art shows, etc. He makes a small living doing portraits at fairs. I think this is a success story. ■



The Many Roles of Carers' Support Groups

BY HAZEL RUANE

The following article provides some excerpts from an article on Carers' Support Groups. The author highlights the help carers' support groups can offer the families of people with mental illnesses, including:

- *Providing empathy and information about mental illness, its symptoms and where you can turn to for help*
- *Improving coping skills, while also relieving the burden*
- *Providing access to information on recent developments, and opportunities to influence mental health policy*

Providing Empathy and Information

Carers' groups can help to fulfil a niche in the lives of people who are struggling to cope with mental illness in the family. They can provide opportunities to empathise and act as centres of information about the illness, its treatment and the network of services in the area. They are primarily there to help carers come to terms with the everyday problems they face. One of the most important services they provide is information about mental illness, its symptoms, the various medications and access to telephone help lines. When relatives understand what is happening to their loved one they are much more sympathetic and able to cope. It is important to know that not everyone who experiences a psychotic episode will have repeated relapses. Some

people only have one incident and make a marvellous recovery but, in all cases, early intervention is known to make a significant contribution to a successful outcome.

Improving Coping Skills

... access to information is not the only issue facing carers. They need help to improve their coping skills. They may also have to set boundaries while also hoping to retain the trust of their relative. Carers who have to support someone with a severe and enduring mental illness have to come to terms with the loss of the person they knew. They have to learn to adjust to new commitments and at the same time they have to empower the service user to be as independent as possible. It is little wonder that they need a secure environment in which to talk about their anxieties and the social exclusion that mental health service users and their families' experience. Carers' groups can help to relieve the burden that often accompanies the role of a carer.

Providing Access and Opportunity

... membership of a national network of carers' support groups ensures access to information about the most recent developments in treatment, services, benefits and the opportunity to influence future government policy. ■

How I Look After My Own Mental and Physical Health

BY ROSALIND SMITH

One of the biggest challenges facing a family member looking after a person with severe mental illness is balancing the needs of their ill relative with their own needs for maintaining mental and physical health. In the article, one caregiver tells how she does it:

- *Practising meditation*
- *Taking time for herself in karate and tai chi classes*
- *Communing with nature*
- *Obtaining part-time employment outside the home*
- *Having a support system of friends*

When I realised that my daughter's schizophrenia was going to be permanent, I started to force myself to go out. I could no longer work from home because my daughter had become increasingly violent and abusive towards me.

I started going on volunteering holidays, and it was on one of these that I found out about meditation. I started attending classes near my home, and found that in all but the most difficult of circumstances I could keep fairly calm inside. This had a big impact on the emotional "temperature" of our home.

I had been practising karate for a number of years, and this became my evening "away" time, time I was determined to hang on to, no matter how bad things became. Sometimes I just could not escape from what was going on at home, but my instructor was very understanding. I would often ring up to say that I just could not come, only to burst into tears from the tremendous strain. But, when I did have a good class, oh, the elation of being me again!

Next came tai chi: the benefits of feeling so calm inside were tremendous. Together with the meditation, they have an enormous impact on my mental well being. I can even go to bed with a smile on my face!

I try to be as positive as I can be in the circumstances, but some days, the only good thing I can find to say is that the clouds are beautiful, or a bird sings in the garden. Nature usually brings something to lift my spirits, and walking in the fresh air always helps.

I have also started working in an office one day a week. The people are lovely and it makes me feel really good inside.

(continued on page 19)



MEMBERS' UPDATE

Update from the Uganda Schizophrenia Fellowship

BY WALUNGUBA THOMAS

The Uganda Schizophrenia Fellowship (USF) had a student from Douglas College in British Columbia, Canada, doing a two-month practicum placement in Masaka. At that time, USF ran a Reason to Hope Family Training in which the student participated. During that same time, a student from Leeds University in the U.K. visited, attending the monthly meeting. Now, they are launching their new Outreach Program to great success.

It is a very exciting and motivating time for USF! ■

Promoting Rehabilitation Awareness in India



MANASA (Mentally and Neurologically Ailing Persons Self-help Association) of Thiruvananthapuram, Kerala, India, held a public awareness program on rehabilitation in April. During the program, Namdev Gawas of Carers' Hope

in Goa spoke on the need and sustainability of self help groups for mentally ill. Shown are two participants at the meeting. ■

Upcoming Conferences

Mark your calendars for the upcoming conferences:

SF New Zealand National Mental Illness Summit in Wellington on September 6 and 7, 2008. The Summit theme – "Families, Meeting the Challenge of Mental Illness" – focuses on the family/whānau/agai role in the recovery process of people with mental illness. (SF New Zealand uses the terms "family", "whānau" and "aiga" – the latter two are Maori terms – to describe anyone who cares for or supports a person experiencing serious mental illness.) Keynote speakers include:

- Dr. Margaret Leggatt (Aus) – Founder of leading Australian mental health advocacy organisation SANE
- Prof. Xavier Amador (US) – Internationally sought-after speaker, clinical psychologist, professor at Columbia University, Teachers College, New York City
- Paraire Huata (NZ) – Trainer, instigator, teacher, mentor – passionate about mental health and drug and alcohol issues

The Summit line-up also features practical workshops, run by leaders in New Zealand mental health. Online Summit registration is now open. For more information, please visit www.sfnat.org.nz.

The 16th Annual Conference of the Indian Association for Social Psychiatry will be held in New Delhi from November 28-30, 2008. The theme of the conference is "Social Psychiatry and Clinical Practice". ■

Visit <http://www.wpanet.org/> for more information.

Getting Funding By Changing Minds: Share Your Ideas with Turning Point, India

Ishita Sanyal writes from Turning Point in Kolkata that she was planning to write a letter to WFSAD telling of the success of a social integration initiative, but sadly funding for the program through a competition did not materialize. She describes the initiative as "an entrepreneurship project" where Turning Point would start a cyber café.

They applied for funding through a competition. "We were short listed too", she says, "but the local inspector told us that a mentally ill person can never learn computer. It

When we showed him that our people have learnt it and are doing well, he said that maybe they wouldn't be able to run the cyber café.

can be learned by blind people or mentally delayed persons, but not those who are mentally ill. When we showed him that our people have learnt it and are doing well, he said that maybe they wouldn't be able to run the cyber café. He was rigid in his approach and even with all our efforts, we failed to convince him".

Members, please email Ishita if you have similar projects to the one described above. Give her details and website addresses so that she can show the man judging the competition and help him realize that his view is absolutely incorrect. Maybe next time the competition is run Turning Point will be successful. ■

Email to: ishitasanyal@hotmail.com.



CARERS

How I Look After My Own Mental and Physical Health

(continued from page 18)

I force myself to go no matter how bad things are; one Christmas, on being given a present from everyone, I just burst into tears. Quite what they made of that, I do not know. I feel appreciated once more. Because I gave up work to care for my daughter, this new self-esteem is very important to me.

I no longer feel angry about my daughter's behaviour. In fact I feel almost grateful that it has brought me such a lot of interesting things to do. My new interests have brought me so many new friends, too, which, together with my old friends make up my "support system", another important aspect of my life. ■

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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Uncommon Heroes. Common Good.

The Skoll Foundation has funded the last four issues of our newsletter. A sincere thank you for their support.

Announcing WFSAD's New Guidebook!

- 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 a 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, psychologists, nurses, social workers, as well as policy makers, service managers, families/carers and people with mental health problems themselves.

The guidebook can be purchased online at www.world-schizophrenia.org.

Families as Partners in Mental Health Care

A Guidebook for Implementing Family Work
With Foreword by Norman Sartorius

Diane Froggatt
Gráinne Fadden
Dale L. Johnson
Margaret Leggatt
Radha Shankar



\$29.50 (CAD) + S&H



REGIONAL NEWS

Schizophrenia Society of Nova Scotia



The Schizophrenia Society of Nova Scotia's 20th Annual Conference entitled Families as Partners in Mental Health Care took place at Dalhousie University in Halifax on 30th May. As a result of her presentation at the WFSAD International Conference – Lighting the Path – last September, Professor Gráinne Fadden of the University of Birmingham and Meriden Family Service in the U.K., was a keynote speaker. As many of our readers know, Gráinne has spearheaded family work not only in England but in Australia where she has conducted many training sessions. She is also one of the authors of the WFSAD publication *Families as Partners in Mental Health Care*. ■