

World Fellowship for Schizophrenia and Allied Disorders

Fourth Quarter 2005

**Getting Your Life Back**

By Diane Froggatt

Until recently, it was not part of medical treatment to do more than relieve the positive symptoms of mental illness with the antipsychotic medications available. The job was done when the medications relieved these symptoms. However, for some years, partly as a result of the consumer and family movements, and partly due to an improved understanding of the working and efficacy of medications, a new paradigm has arisen for these conditions.

Many consumers, those who have seen improvement in their condition, have come forward to say that there is more to their lives than disease and symptoms of disease and they want society to have a holistic approach to treating them. They have stressed that even with some symptoms they can function if given the opportunity to develop or regain skills, to develop support networks and regain the self-respect that many of them have lost owing to periods of ill health.

In addition to medication and support, people need something that will uplift the spirit and the mind. This is what people may have in mind when they speak of “recovery”: a revitalization of the spirit, a renewal of the identity of the person. For some this idea may seem cruel, for despite all their struggling, even to get through one day takes all their energy. For others, societal and cultural beliefs may work against them even when they try to move towards a better life.

Rehabilitating people from psychiatric illness can be highly labour intensive. In some mental health services it requires one-on-one support from a mental health worker to motivate the person and direct the process. Even in the developed world such services are not widespread. In other recovery initiatives, the emphasis is on groups of people working together to achieve a common purpose. In some countries, large populations and economic deprivation make it difficult for such help to occur. Nevertheless, efforts are being made. In this article we briefly examine what types of help are available.

**Comprehensive Care**

According to Kim Mueser et. al.,(1) illness management programs have traditionally provided information and taught strategies for adhering to treatment recommendations and minimizing symptoms and relapses. However, many programs go beyond this focus on psychopathology and strive to improve self-efficacy and self-esteem and to foster skills that help people pursue their personal goals. Enhanced coping and the ability to formulate and achieve goals are critical aspects of rehabilitation and are in line with the recent emphasis on recovery in the mental health self-help movement. Common themes of recovery are “the development of self-confidence, of a self-concept beyond the illness, of enjoyment of the world, and of

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a sense of well-being, hope, and optimism”.

The challenges are great. Not least of these is the limited efficacy of medications, which may leave people with many of the symptoms that prevent them from living a normal life. These could be anxieties dealing with people; poverty of expression; misinterpretation of the motives of others; inability to experience pleasure; difficulty coping with authority; extreme excitement or slowness of action. The second generation medications have given hope to many, but are still a long way from returning everyone to a reasonable life. Nevertheless, it is generally accepted that for people who have had more than two or three acute psychotic episodes, no improvement in their condition will occur without the help of regular medications in appropriate doses.

Clinical programs that go beyond medication management, adding other aspects of care like psychoeducation, family psychoeducation, behavioural tailoring; skills training, etc., increase the opportunity for people to function better and to overcome aspects of illness such as poor memory, difficulty initiating activity and social deficits. Recent studies have shown that “cognitive behavioral treatment is more effective than supportive counseling or standard care in reducing the severity of psychotic symptoms. Furthermore, studies that assess negative symptoms, such as social withdrawal and anhedonia (inability to experience pleasure), also report beneficial effects from cognitive-behavioural therapy on these symptoms”. (Ibid.)

Family interventions using family and friends as a resource to help improve outcome for the patient makes good sense for the doctor or team, as well as for the family and consumer. (Members will be familiar with our program to promote family participation: *Families as Partners in Care*, and our booklet *Principles for Family Work*.) Recruiting families for such programs is a necessary component for family work, because families do not always recognize the need to be involved in the care of their unwell relative.

## Peer-to-Peer Initiatives

In the last issue of the WFSAD Newsletter (2005-3), we published excerpts from a booklet *Let us Try and See*, which was developed by the Schizophrenia Awareness Association (SAA) located in Pune,

India. The SAA is a peer-to-peer based organization that also welcomes relatives of its members. Their program gives direction to members about improving their quality of life.

Similar programs that go beyond support have sprung up in many places where people with experience of mental illness get together to develop meaningful work or recreational activities to help them in their journey towards a better life.

## Clubhouse

One of the first peer-to-peer initiatives was the development of Fountain House, New York, from which have sprung more than 400 clubhouses in 32 countries. Fountain House is dedicated to “the recovery of men and women with mental illness by providing opportunities for our members to live, work and learn while contributing their talents through a community of mutual support”. It now employs staff in addition to members to run its substantial business ([www.fountainhouse.org](http://www.fountainhouse.org)). The clubhouse idea has been adopted in many places outside the exact Fountain House model, because each place, each culture, each economy and government system is different. Some clubhouses, for example, provide or manage housing initiatives. In all these clubhouses, there is a spirit of cordiality and each provides education, recreation and work activities for its members.

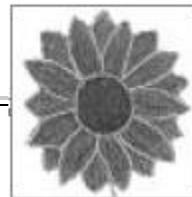
## Consumer Run Businesses

Different from clubhouses, these initiatives are more prevalent in countries where government disability payments are the norm for people with psychiatric illnesses. They provide work for consumers, often on an hourly or daily basis, recognizing not only the need for people to have the self respect that comes from work, but also the limitations that the illness can put on the amount of time they can work. These businesses are usually developed in conjunction with assistance from government sources and charitable foundations.

## Social Firms

Initiatives similar to consumer-run businesses are prevalent in Europe, where they are described as **social firms**. Their purpose is to provide employment at market wages for people with psychiatric disability. If employees require accommodations or modifications to enable them to do the job, these are available. A quarter of the employees of these firms are those with psychi-

(Continued on page 11)



## 120 People Attend Opening of AASHA's Second Shop

I am writing to thank you for the quarter page on AASHA's second shop in the WFSAD Newsletter of the 3<sup>rd</sup> Quarter 2005. The inaugural function of the second shop was held at Hotel Benzz Park on July 25<sup>th</sup>. The function will go down in AASHA's record books as the most well attended AASHA meeting ever. We had over 120 participants. A well-known local TV and stage artist who has consented to becoming AASHA's brand ambassador inaugurated the New Shop. Jim Crowe, who happened to be in Chennai at that time, also attended the function. The highlight of the evening was a skit written, directed and performed by residents of AASHA Halfway Home. If I say that the program contributed towards reducing some of the stigma that we family members ourselves have towards mental illness, I don't think I'll be very much off the mark. And if I say that the program definitely contributed to shattering the myth that mentally challenged people aren't capable of delivering good results, I will be spot on.

*Ratna Chibber, Chennai, India. (Ratna is President of AASHA.)*



## Film Raises Awareness



On July 31, 2005, the first feature film in India covering all aspects and various phases of schizophrenia was premiered. The film – called Mazi Goshta – was produced by the Schizophrenia Awareness Association to raise awareness of schizophrenia and to

help minimize the stigma associated with this illness.

With input from psychiatrists and professionals, the film tells the story of a music composer suffering from schizophrenia. The film is scheduled to be shown all over India and also abroad. It is available in Marathi, as well as Hindi with English subtitles. If you want to learn more about the film, please contact Vidyadhar Bapat at [vidyadharbapat2002@yahoo.co.in](mailto:vidyadharbapat2002@yahoo.co.in)

## The Steelman

By Celia Soden

Shall I tell you what it's like, Mum,  
Deep down within my soul,  
My mental illness makes me feel  
There's a Steelman in control.

Within and all around me  
He's strong and adamant.  
He's my life's sparring partner  
And escape from him, I can't!

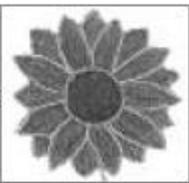
If I box clever, by the rules  
He'll only strengthen me  
But if I pull a fast one  
It's on the floor I'll be!

Each time I hit the canvas  
Bruised and battered I do try  
Not to pull my punches  
But He's there, I wonder why.

A knockdown's my psychosis,  
The rules are few and fair –  
Take medication, lots of rest,  
Walk, don't run, and be aware  
Before a fall comes, if not pride,  
Ambition to regain inside  
My self control, if it hasn't died.

I'd like to think that someday  
I'll give Steelman the blow  
That will send him far away from me –  
If I do, I'll let you know!

*(Inspired by a comment made by John, who knows what it's like.)*



## “Navachetana”

### New Hope for Homeless Mentally Ill Women and Their Families in Ashadeep, India

by Mukul Ch. Goswami



*A resident after rehabilitation*

**G**uwahati, the premiere city in the north eastern states of India – like any other such city in India – has a sizeable population of people who are homeless and live on the streets. Some of them are on the streets because of their mental disorder, while others have developed such disorders because of their homelessness. But in any case, they are perhaps the most vulnerable group amongst the homeless. In addition to the risks for premature death because of poor living conditions, infections, poor personal hygiene, inadequate food, sleep and access to minimum health services, the mentally ill do not receive any help from any form of welfare

activity and are generally avoided by most people because of their inherent symptoms and lack of awareness in the community. Studies have shown that homeless women with schizophrenia are sexually assaulted at an alarming rate which exposes them to all kinds of deprivation and infections, including the HIV virus.

As caregivers of a family member with schizophrenia, and later in trying to help other family caregivers in caring for their wards through Ashadeep’s community-based service facilities, we felt that our relatives were fortunate to have families who were trying their best to improve their situation. But when seeing the homeless mentally ill people lying on the streets, totally unattended by anyone – government agencies, charitable organizations and even consumer groups like us – we felt that it was our moral duty as a caregiver group to help these individuals and whenever possible to re-unite them with their families.

Drawing inspiration from “The Banyan”, Chennai, who have so far rehabilitated over 800 mentally ill women with their families, Ashadeep has initiated activities in this area through “Navachetana”, a new rehabilitation center for homeless mentally ill women at Guwahati. SIR RATAN TATA TRUST, Mumbai, provides financial support towards this project.

#### Success rate of over 60%

When a member of the public or the police inform us of a lady lying on the streets, our rescue team moves in. If the woman shows apparent signs of mental illness, she is brought to our shelter. Cleaning, clothing and food are the initial requirements, after which a thorough psychiatric and medical examination is made.

Since commencing activities in March 2005, 24 women have gone through the rehabilitation process at Navachetana, and amazingly, the families of 12 of them have been located. Out of those, nine women have already been placed back with their families.

All the women treated so far were suffering with schizophrenia or a major mood disorder, and all of them needed continuous medication. In fact, we do not end our responsibility when they are placed back with her family. At the time of discharge, we provide a month’s quota of medication, with a request to attend the psychiatrist after a month. In fact, we will try to supply medications as long as the need is there. We have been provided a fund by the trust to cover the costs of medication and food for a year. Efforts are on to gather more support.

The placement with the family is made by our staff, who have been trained to educate the members of the family on the nature and out-



*Frontal view of Navachetana, where volunteers and staff are slowly developing a poultry farm, a fishery and a small vegetable garden as a workplace for the residents.*

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come of the illness. So far we have received over 60% success with follow-ups. Vocational training and livelihood generation for the patient and family are of prime importance, as poverty is the major cause for people being in the streets.

### Reuniting with family

The story of Joynab provides one example of Navachetana's success. Joynab, who is approximately 45 years old, was diagnosed with schizophrenia; she also has deformed feet. Within two months at Navachetana, Joynab's condition improved rapidly and she could give us her home address. She told us she came to Guwahati to collect a tricycle for herself about six months back, became mentally imbal-

anced and was roaming on the streets. We obtained a tricycle for her from "Alimco" and on May 20, 2005, our volunteers took her home.

### Plans for growth

We are building up the infrastructure to accommodate 20 residents at a time at Navachetana. As we re-integrate women into their families, we hope to bring some light to more and more destitute mentally ill women.

We make efforts to provide vocational skills to all the residents after they recover from the acute state of their illness, so that they can return home with a skill and do not become a burden to the family.



## Treatment in India

Psychosocial rehabilitation is a term used to describe services that aim to restore the patient's ability to function in the community. It not only includes the medical and psychosocial treatment, but also ways to foster social interaction, to promote independent living, and to encourage vocational performance (Cook et al., 1996). Psychosocial rehabilitation now aims to integrate patients back into the community rather than segregating them in separate facilities. The goal is to teach skills and provide community supports, so that individuals with mental disabilities can function in social, vocational, educational and familial roles with the least amount of supervision from helping professionals.

Developing countries have a dearth of financial resources, which causes tremendous difficulties in rehabilitation. A study of the status of the mental hospitals by the National Human Rights Commission revealed gross inadequacies in all aspects of care, clinical services and rehabilitation (National Human Right Commission, 1999).

A common problem faced in developing countries is scarcity of financial resources. Developed countries may have a different set of problems. But some of the problems like bureaucratic hurdles, uncooperative attitudes of relatives and societal insensitivity may be seen in both developing as well as the developed countries.

Most of the patients coming into a government institution in the developing world are from lower socio-economic strata and most of them are daily wage earners. They are living a hand to mouth existence. Even patients from "well-to-do families" face financial problems when a family member develops mental illness.

The processes of rehabilitation start with medication. But due to

lack of money, they cannot come for regular follow-up. They cannot afford bus fare or train fare. Sometimes the illness of the earning member of families ensures that they don't even have money for food. Sometimes the hospital will arrange for bus or train fare from the poor patient's fund. So patients cannot come to take medication regularly. They cannot take medicine from outside, because the cost of medicine is high. And medicines have to continue for long time or in some cases for a lifetime. This leads to frequent relapse.

In places where poverty is widespread, many relatives of the patient don't want to take discharge, even when patients have improved completely. This happens in cases in which the patient is admitted into an open ward along with his relative. Sometimes when a doctor has asked them to take discharge, relatives and patients describe fake symptoms. And when one cross checks with the attendants and nursing staff, the said symptoms are absent.

Many relatives are not interested in the treatment or rehabilitation of the patients. Their aim is to get the patient admitted to an institute and get rid of him. However, they are not always at fault because treatment and rehabilitation of psychiatric patients is difficult due to frequent exacerbations and relapses. To get rid of a patient they may give the wrong home address or move after the patient is admitted.

*The above excerpts are from an article by Dr Hitesh C Sheth, 202 Aashrayadeep Apartment Gautamnagar Society, Alwa Naka, Manjalpur, Baroda, Gujarat, India.*

Available at [http://www.psychosocial.com/IJPR\\_10/Common\\_Problems\\_in\\_PSR\\_Sheth.html](http://www.psychosocial.com/IJPR_10/Common_Problems_in_PSR_Sheth.html)



## The Alianza Latina WFSAD

WFSAD first began its outreach into south and central America in 1993/4 shortly after the formation of APEF, Argentina, through its founders Martha Piatigorsky and Diane Trumper. In 1995 WFSAD encouraged APEF to hold a conference, which was very successful. From that time, a strong link was forged between APEF and WFSAD and the knowledge of the family movement spread to different countries in the region. In 2001, a major "Strengthening Families through Empowerment" visit took place in which WFSAD and APEF hosted a symposium at the Argentine Psychiatric Congress and conducted outreach visits to several regions of Argentina. We entered into an agreement with APEF to support their newsletter financially and later to provide our own international pages. This partnership continued until 2004, when financial limitations prevented its continuation. Today our international newsletter (Boletín Internacional) is produced four times a year, and sent out by PDF internet file and in hard copy where necessary. Any member of WFSAD may request a copy of this Spanish news sheet.

Since the visit to Argentina, WFSAD has held three conferences for the groups comprising the Alianza Latina WFSAD, which have grown exponentially since the first meeting in Guatemala.

The first conference was in Guatemala, where a Declaration was ratified. The second was in Caracas, Venezuela, where over 40 family leaders attended the Regional Conference of the World Psychiatric Association. WFSAD conducted educational sessions for the family leaders present, and members addressed the issues raised in the Guatemala Declaration. This conference was extremely successful, particularly in the advocacy work we were able to do with the media and with psychiatrists and psychiatric associations. We are extremely grateful to the Pfizer Foundation and their affiliate in Venezuela for their valuable support.

The third conference, in Punta del Este, Uruguay, was a smaller meeting, owing to distances and the costs involved in travel, so that organizations in the northerly part of South America and Central America were unable to attend.

### The Goals of the Alianza Latina WFSAD

The goals of the Alianza Latina WFSAD are laid out clearly in the document called the **Guatemala Declaration**. Members

of the alliance drew up this document in Guatemala and have revised it twice since then. The document is reproduced here.

### The Future of the Alianza

The 20 organizations of the Alianza Latina WFSAD are led by strong committed men and women. They have the possibility of a successful future. To develop this, it is necessary for us all to keep them interacting with each other and for WFSAD to provide its expertise learned over the 23 years of its existence. To this end we have arranged for visits to three of the Alianza members, in order to provide in depth education, advocacy skills and skills in leadership and training.

Two executives of WFSAD will deliver the "**Strengthening Families through Empowerment Program**" in November 2005, visiting **Alamo, Peru; Fucopez, Costa Rica; and Asfae, El Salvador**. We will meet with families and patients, politicians, journalists, mental health workers and officials of WHO/PAHO during these sessions. There will be discussions surrounding the implementation of the goals and objectives of the Guatemala Declaration.

**We are very grateful for the generous grant provided by Eli Lilly that has allowed us to continue this work throughout 2005.**



Members of the Alianza Latina WFSAD in Caracas at the World Psychiatric Association Regional meeting

## GUATEMALA DECLARATION

We, Latin American family members of patients with schizophrenia and other mental disorders, meeting in Guatemala and subsequently in Caracas, at workshops convened by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) in 2002 and 2003, affirm the following:

Considering that stigma, discrimination, suffering and misinformation are common factors for all family members of the mentally ill in Latin America, we assume the following commitment:

1. We will advocate for the best mental health care to be accessible and available for our family members with serious mental illness.
2. We will advocate that such care will be given according to the ethics and norms of mental health professionals and will include 1) psychoeducation for families and patients; 2) modern rehabilitation models to improve the possibility of recovery, and 3) the latest effective medications.
3. We will advocate to the governments of Latin America that they:
  - α. develop legislation to protect the human and civil rights of people who suffer with mental disorders, and that through such legislation their civil, political and cultural rights are guaranteed;
  - β. provide financial support for those disabled by serious mental illness;
  - γ. enact licensing and accreditation procedures to ensure that mental health facilities operate using international standards of best practice in mental health care;
  - δ. implement State programs of employment, micro-enterprises, clubhouse models, on-the-job training, etc. to help people with mental disorders re-integrate into their communities;

- ε. make available and accessible to those with serious mental illness the latest effective medications that offer the possibility of reinsertion into social and community life, at affordable cost, and urge them to consider the cost/benefit ratio of investment in effective medications in their budgets.
4. We family members recognize that the participation of the family as caregiver is essential for an improved outcome for the patient.
5. We will encourage recovery within our own family, recognizing that acceptance and positive affection are indispensable elements for the recovery of our sick relative(s).
6. We commit ourselves, as family members, to foster courses, conferences, and talks with professionals so we may learn about the symptoms, management and treatment of mental disorders.
7. We will promote public awareness to reduce fear, stigma and discrimination directed towards the mentally ill.
8. We take as legal framework for these agreements of our Guatemala Declaration the Principles adopted by the General Assembly of ACNUR in Resolution 46/119 of December 17, 1991.
9. We affirm that family members of mentally ill people should continue to organize meetings in order to foster the best outcomes for our relatives through the goals expressed in this agreement.
10. We will undertake these commitments confident that WFSAD will promote and support them with all means at its disposal.

Signed for Alianza Latina WFSAD

Signatories: Martha Piatagorsky, WFSAD Vice President & Diane Froggatt, WFSAD Secretary

Guatemala, 13 July 2002; & Caracas revisions 17th December 2003.

### MEMBERS OF THE ALIANZA LATINA WFSAD

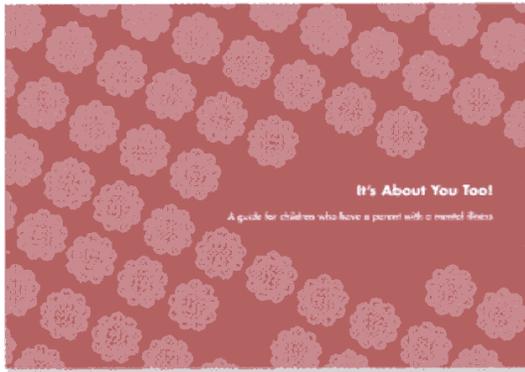
<b>Argentina:</b>	<b>APEF</b> Buenos Aires <b>AJUPEF</b> Jujey <b>ACAPEF</b> Córdoba <b>FUBIPA</b> Bipolar Foundation in Buenos Aires <b>Argentine Alliance</b> Mar del Plata <b>AMFE</b> Mendoza	<b>El Salvador:</b>	<b>ASFAE</b> San Salvador
<b>Bolivia:</b>	<b>FUNSAME</b> Group of professionals helping families in La Paz	<b>Mexico:</b>	<b>ÁMATE</b> Mexican Bipolar Assoc. <b>AFAPE</b> Schizophrenia Assoc. in Mexico <b>INGENIUM</b> Voz pro Salud Mental 5 groups
<b>Brazil:</b>	<b>ABRE</b> Brazilian Schizophrenia Assoc.	<b>Panama:</b>	<b>ANFAPEEM</b>
<b>Chile:</b>	<b>CLINICA SAN CARLOS</b> Clinic's family group	<b>Peru:</b>	<b>ALAMO</b> Lima
<b>Costa Rica:</b>	<b>FUCOPEZ</b> San Jose	<b>Surinam:</b>	<b>Stichting Ypsilon</b> Paramaribo
<b>Ecuador:</b>	<b>FECAPE</b> Schizophrenia Foundation Quito	<b>Uruguay:</b>	<b>Grupo de la Esperanza</b> Montevideo <b>CNRP</b> Psychosocial Rehabilitation Centre, Montevideo
		<b>Venezuela:</b>	<b>CATESFAM</b> Maracaibo

**To contact any of these groups email or write to WFSAD and we will forward your letter. Preferred language: Spanish.**



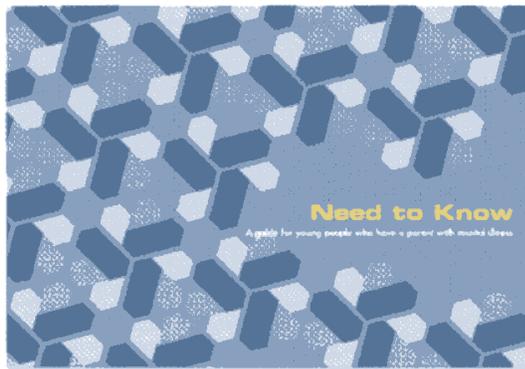
## Booklets for Children and Young People

NSF (Scotland) has produced a series of three booklets addressing the needs of children and young people who live in families where an adult has a mental illness.



Speaking at the booklets' launch in November 2004, Lady Veronica Linklater, Honorary Patron of NSF (Scotland) said, "The new booklets break down barriers by providing a holistic approach to promoting open communication. They provide meaningful advice and guidance to parents, children and professionals alike and hence encourage a more honest dialogue in families affected by mental illness".

The support needs of these young people are often left unaddressed. It can be very difficult for them to understand what is happening, and distressing to try to explain to others why the adult in their family behaves in certain ways.



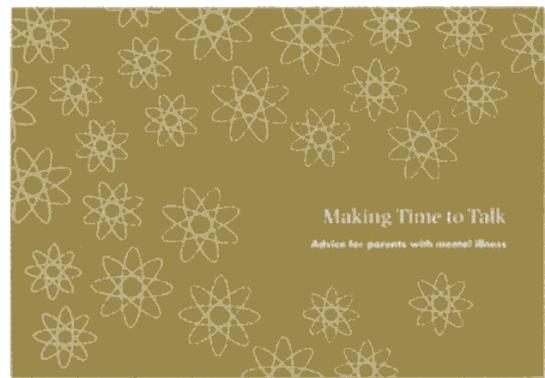
The young people may suffer stigma, as pointed out by Linda Dunion, Director of the *See Me* campaign. "The stigma surrounding mental ill health does not just affect adults", she stated at the launch. "Children and young people can also

find themselves isolated or bullied as a result of a parent's mental ill health. The booklets are a valuable source of information, support and help for young people facing that kind of challenge".

The new booklets are intended to break down barriers to communication for families. They explain what mental illness is, terminology and how mental illness can affect people.

The first booklet – called *It's About You Too!* – is intended to be particularly helpful for children aged eight to 10 years. The booklet uses straightforward language and illustrations to assist children in understanding the nature and causes of mental illness. It also suggests people who children can talk to if they need more information.

The second booklet is intended to be particularly helpful to

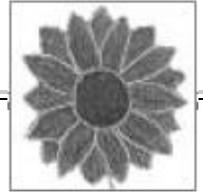


young people aged 11 to 14 years and is titled *Need to Know*. The text and illustrations explain what mental illness is, and how it is caused. There is also a section discussing the impact on the young people themselves, with suggestions about other sources of help.

The third booklet is for parents with a mental illness and is called *Making Time to Talk*. This booklet explains the importance of talking to the children and young people about mental illness, with suggestions about how best to do this. There are also some commonly asked questions.

The booklets are also intended to assist professionals who are working with – and providing support for – families with mental health problems.

You can download copies of the booklets the NSF Scotland web site at [www.nsfscot.org.uk](http://www.nsfscot.org.uk)



## Study Finds Little Advantage in New Schizophrenia Drugs

*(excerpted from article by Benedict Carey,  
New York Times, Sept. 20, 2005)*

A landmark government-financed study that compared drugs used to treat schizophrenia has confirmed what many psychiatrists long suspected: newer drugs that are highly promoted and widely prescribed offer few – if any – benefits over older medicines that sell for a fraction of the cost.

The study, which looked at four new-generation drugs, called atypical antipsychotics, and one older drug, found that all five blunted the symptoms of schizophrenia, a disabling disorder that affects three million Americans. But almost three-quarters of the patients who participated stopped taking the drugs they were on because of discomfort or specific side effects.

One of the newer drugs, Zyprexa, from Eli Lilly, helped more patients control symptoms for significantly longer than the other drugs. But Zyprexa also had a higher risk of serious side effects – like weight gain – that increase the risk of diabetes.

The study was widely anticipated because it is by far the largest, most rigorous head-to-head trial of the newer antipsychotics conducted without significant drug industry financing. The new drugs account for \$10 billion in annual sales and 90 percent of the national market for antipsychotics.

The government study set out to judge each drug by how long patients and their doctors continued the therapy, a criterion rarely used in studies by drug makers but crucial in real-world practice. People with schizophrenia struggle with delusional thoughts, private voices, blunted emotions and other symptoms, and most try multiple drugs in trying to avoid severe side effects.

The researchers, led by psychiatrist Dr. Jeffrey Lieberman, then at the University of North Carolina and now at Columbia University, recruited 1,493 people with the disorder and assigned them to receive one of five drugs: Risperdal, from Johnson & Johnson; Seroquel from AstraZeneca; Geodon from Pfizer; Zyprexa; and an older drug, perphenazine.

After 18 months, the researchers found 64 percent of the patients taking Zyprexa had stopped, and at least 74 percent had quit each of the other medications. The most common reasons were that the drug was not effective, the patient could not tolerate taking it, side effects like sleepiness and weight gain or neurological symptoms like stiffness or tremors.

Doctors' concerns about neurological side effects in particular have sped the switch to newer schizophrenia drugs over the last decade. Studies have shown that these medications carry a lower risk than the

older drugs of tardive dyskinesia, a disorder that causes tics, lip-smacking and other involuntary movements.

But the study found that at more modest doses, the older drug, perphenazine, while just as effective, was not significantly more likely to cause neurological symptoms. Dr. Lieberman said that there was no reason to believe that modest doses of other older drugs, like Haldol, would perform differently.

The patients on Zyprexa were less likely to be hospitalized because their condition worsened than those taking the other drugs, the study found. But these patients also gained the most weight, adding an average of two pounds a month while on the drug, and their lipid levels increased more than those of people on the other drugs. Weight gain and elevated lipids are risk factors for diabetes.

In the doses used in the study, a month's supply of perphenazine costs about \$60, compared with \$520 for Zyprexa, \$450 for Seroquel, \$250 for Risperdal and \$290 for Geodon, according to Drugstore.com.

"Probably the biggest surprise of all was that the older medications produced about as good an effect as newer medications, three of them anyway, and did not produce neurological side effects at greater rates than any of the other drugs," said Dr. Lieberman in an interview.

Dr. Robert Baker, who directs the neuroscience group at Eli Lilly, said that he was pleased with the findings. He said the weight gain and other side effects of Zyprexa were "very consistent with what we've seen in our studies" and that the company tells doctors about these symptoms. "I think what we can conclude from this study is that there is not one-size-fits-all treatment for schizophrenia," Dr. Baker said.

Spokesmen for Johnson & Johnson and AstraZeneca said that the study supported their drugs and the importance of tailoring treatment to individual patients. "The efficacy results for Risperdal did not demonstrate the full efficacy of Risperdal because many patients in the trial received doses that were too low", Dr. Ramy Mahmoud, of Janssen Pharmaceutica, the unit of Johnson & Johnson that makes Risperdal, said in an e-mail message.

One thing that all agreed on was that the current state of schizophrenia treatment leaves a lot to be desired, and that the field longs for new and different drugs.



## A Place of Healing

### Thanks to David

David Pienaar once had a dream of helping people with severe psychiatric illnesses. Today he is doing just that and with great success because he understands the difficulties they face – he has schizophrenia.

David, 39, from Observatory, South Africa, was diagnosed with the illness when he was 21, but he fought back and today he is the manager of The Welcome Club.

The club, which David joined in 2001, is situated at the Old Stores Building on the Valkenberg Hospital Estate in Observatory.

It is a social rehabilitation center for adults suffering from severe psychiatric disabilities and it's here where they can be themselves, call on David if they need a friend or a share a quick smoke with someone.

Many just sit and watch television or listen to the radio, while others enjoy and game of pool or PacMan. And then there are those who release the artist in themselves by creating pieces of art and jewelry.

"I try to assist where I can and encourage people to get well. I am a helping hand," David says.

Everybody at the club either comes from homes, the hospital or from the ComCare residential complex situated on the premises. All of them are on medication.

David says that when he was diagnosed "it was difficult time for me – I am independent now, but it is difficult to go into society because we are abused and misunderstood by everybody."

The club is not only a support system for patients, but also for David.

"Every day is a challenge and at the club I can escape and do art, like wall hanging and other pieces.

"I offer encouragement but it's up to the person to get well – all I can do is lend a helping hand".

The club is open weekdays from 9 a.m. to 1 p.m. and David opens up every morning and gets the radio and television going.

Since he had been club manager, it has grown to about 40 people coming in daily, compared to only 4 visitors in 2000.

Everybody at the club has a duty, whether it is making tea, washing the dishes, cleaning up or cooking.

"This is not a military camp, but I usually get the ball rolling and everybody follows suit", David says.

For most of the people who come to the club, David says it is a huge challenge for them to get out of bed, so just coming there is a battle they have already won.

He says that with the help of ComCare, a non-government organization, they have managed to keep the club going with a small subsidy provided by government and donations from the Community Chest and national lottery.

They also do their own fundraising by selling the things they've made at the Obz Festival and at flea markets.

Paula Sellmeyer, a social worker with ComCare, says David is able to make more progress with the patients than occupational therapists and social workers because he can relate to them.

"They are going through a hard time and I have been through it, so I understand them better", says David.

He says he phoned a friend eight years ago and told him of a dream he had about starting a club like this one and giving back to people like himself.

"This is my true calling. It is difficult living with my illness, but together we can beat it and deal with it.

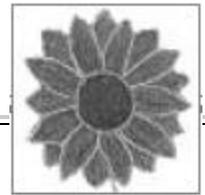
"Sometimes I smoke or sit and watch TV. Just as long as I have something to do".

Besides being club manager, David enjoys art, listens to music, and swims. He also intends playing tennis when the weather warms up.

Does he ever feel like giving it up and staying in bed? "No, I love my work and it's what I do.

"A dream of mine has come true and I have ComCare to thank for giving me the opportunity", he says.

*(Article by Cindy Mathys; reprinted from The Cape Argus, Tuesday, August 24, 2004)*



(Continued from page 2)

atric disabilities or other difficulties. Social firms usually have a two-pronged direction. They must fulfil the social as well as the trading and economic aspect of the enterprise. Thus the business must be viable in order to succeed. More than 50% of income must be derived from sales, according to Social Firms UK ([www.socialfirms.co.uk](http://www.socialfirms.co.uk)). They must compete in the marketplace. Social firms are usually led by people with business and social sector know-how.

Areas in which these firms have been successful are services in gardening; horticulture; cleaning; printing/print finishing; graphic design, catering and restaurant ownership. It must be emphasized that developing these enterprises takes considerable time (3-5 years) and skill.

### Vocational Training/ Supported Employment

“A majority of seriously mentally ill people would like to work and there are compelling ethical, social and clinical reasons for helping them achieve this goal. Pre-vocational training and supported employment are two different approaches to helping people obtain employment. The key principle of pre-vocational training is that a period of preparation is necessary before entering competitive employment. In contrast, a key principle of supported employment is that placement in competitive employment should occur as quickly as possible, followed by support and training on the job. Supported employment is more effective than pre-vocational training in helping people to obtain competitive employment”.(2)

This view has been current for some time. One of the reasons that supportive employment is favoured is that transferring skills taught in one location and applying these same skills to a job in another location does not seem to work very well, particularly for people with schizophrenia. With supported employment, consumers receive training at the location where they will be working.

The goal of supported employment is to help those with serious mental illness (who have shown an interest in working) find and keep competitive jobs. Supported employment usually involves a person who acts as an intermediary between the person starting the job and the new workplace. Research suggests that the new employee needs this person to smooth out social issues with co-workers rather than to give further instruction in the job process. In the last issue of the WFSAD Newsletter (2005-3, p.8) we briefly described a “Toolkit for Supported Employment” offered on the web by the US government’s Mental Health Services Administration (SAMSHA) Center for Mental Health Services. The booklet

was designed to introduce strategies needed to be an effective “employment specialist” – a job that is directly linked to the treatment team. Specialists help people look for work and continue to support the consumer as long as they want assistance. Another manual in the same vein is *A Working Life for People with Severe Mental Illness* by Deborah R. Becker and Robert E. Drake, reviewed in the WFSAD Newsletter 2004-1, p.14.

### Work Opportunities Provided by Voluntary Organizations

In this issue Ratna Chibber gives a short report on the opening of a second shop at AASHA (support organization in Chennai, India—see page 3). The second shop, like the first, will employ people with psychiatric disorders whose training will be conducted “on the job” by AASHA members. For the longer article on the first shop see WFSAD Newsletter 2003-4, p11. In the case of AASHA, the family organization developed the means of employing its consumers and then employed them.

It is not always possible to offer work paid at market rates, but an equally important factor is giving people meaningful things to do in a friendly atmosphere. At Turning Point, a Calcutta mental health agency, the goal is to build self-esteem through daily activities such as making handicrafts, painting and doing other work around the agency. One parent said of her daughter: “Slowly we noticed a challenging and winning attitude in her. She started doing more and more work. In the cultural programme, she was motivated to perform on stage.”

### Talent Development

Learning a language takes on greater meaning and interest when it is done through a secondary medium, e.g., taking a photography course in the language you are learning. In the same way rehabilitation can be better achieved while doing something that has a purpose beyond the notion of rehabilitation. Using this technique, many recreational or learning activities have been developed.

Such an initiative is the dance troupe of people (who had experienced mental illness) in Istanbul, Turkey. They were so successful that they have toured in several countries. The group was initiated by the Schizophrenia Society in Istanbul. Similarly, various acting, theatre and even film groups have sprung up giving opportunities to consumers to prepare scripts, build scenery, act, produce and more.

Rehabilitation is a vast field of endeavour in which we can all take part, whether it is befriending a person who has a mental illness, or providing a service. This article has only scratched the surface.

(1) “Illness Management and Recovery” A Review of the Research. Kim T. Mueser, Patrick W. Corrigan, David W. Hilton et al. *Psychiatric Services* October 2002 Vol.53 No.10

(2) R. Crowther, M. Marshall and G. Bond and P. Huxley from a Cochrane Review of Vocational Rehabilitation for People with Severe Mental Illness (2000). (*Cochrane Library, Issue 2, 2005*. Chichester, UK: John Wiley & Sons, Ltd. All rights reserved.)



## Dr. Amador Talks about Insight

Dr. Xavier Amador described himself as a family member, a patient and a mental health professional in a talk he gave recently at a conference in Niagara Falls, Ontario, organized by the Mood Disorders Association of Ontario and the Ontario Schizophrenia Society. His brother has schizophrenia. He went into hospital scared and angry and came out less delusional. Dr. Amador had mixed feelings at this point – he was happy his brother was somewhat better. But he was still angry that his brother believed that there was nothing wrong with him while holding delusional beliefs about their mother. They became estranged for a while during this period.

He wants to help people to get into treatment, but he pointed out the challenges. For example, he mentioned Margaret Ray, the woman who had the delusion that talk show host David Letterman was her husband. She never believed that she was ill, nor did her daughter understand that her mother had a mental illness. When Ms Ray died of suicide, she really died from her illness rather than by choice, as you might think of suicide. Dr. Amador prefers to talk in terms of dying from this disease. He pointed out that Ms Ray got jail time rather than treatment.

Another example: Theodore Kaczynski became the “unibomber” in the United States. Yet his family had worked hard to get him treatment without success. Were his defense team allies or adversaries? Experts evaluated him and found he had schizophrenia. He fired his lawyers.

Schizophrenia can turn allies into enemies. How many of us have been fired by their sick relatives? People become “revolving door” patients. Therapists work hard, but people slip through the cracks. Schizophrenia impairs your common sense so that you do not believe you are ill. If you don’t have an illness why would you take medicine? No, this response is not crazy. It’s not crazy to refuse treatment if you’re not sick. The trouble is that people never learn. There is a word for this impaired awareness of severe mental illness – it is called anosognosia.

Results of a study conducted by Dr. Amador revealed that 60% of schizophrenic patients are moderately to severely unaware. Patients participating in the Hamilton Depression Interview did not forget or deny awareness, but they never seemed to learn. This behaviour has clinical significance. Poor

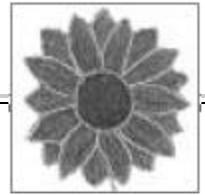
insight is associated with non compliance, involuntary commitment, poor course of illness, and criminalization of the mentally ill. Awareness of being ill is among the top two predictions of medication adherence. It is therefore important that the clinical relationship should be based on trust and that clinicians respect the person’s point of view and listen to what the patient has to say as they attempt to influence the patient about taking medication.

Programs to increase adherence to medications have been largely ineffective. Clinicians and families need to listen to the fears, the frustrations and the desires of their sick relatives and work with their desires to achieve common goals.

Dr. Amador described some of the techniques used to gain the trust of a patient and help him/her into treatment while being persuasive about your own goals and avoiding colluding in delusional thinking. The techniques were akin to those used in cognitive therapy for schizophrenia. He went on to describe the role of the family in interventions with patients new to treatment. Families needed to maximize their adaptive functioning and minimize disruption. They needed to explore the impact of mental illness on everyone, and to minimize family disruption. Education would demystify the illness; diagnosis would usually be helpful to validate what the family was thinking about the situation. Families needed to learn how to manage a crisis because there would no doubt be one.

What Dr. Amador described very much reflected the 15 principles developed by the Families as Partners in Care strategy initiative. These were principles to be followed by mental health professionals in the treatment of mental illness. Professionals needed to engage with the family and form a fair working relationship; assess the needs of family and patient and help in the management of crisis. Psychosis would be explained and families at high risk of a dysfunctional outcome due to mental illness would be identified. There would follow further education and problem solving particularly for high risk families.

Typically these programs are called Early Intervention and usually last about three years. Dr. Amador posed the pertinent question: what happens then? The WFSAD principles recommend continuing – but reduced – contact with the clinicians or family worker.



## Carer Education in Ireland

By Peter Woodhams

The Meriden (the West Midlands, UK family programme) training team was commissioned to deliver a carer-related training programme in Enniskillen in Northern Ireland in June 2005. I was privileged to be a member of the Meriden training team, along with Dr. Grainne Fadden and Steven Cox.

Delegates from both the Republic of Ireland and Northern Ireland came to this pioneering programme, which was funded by the European Union programme for Peace and Reconciliation as a cross-border approach. It was also an essential requirement of the funding that a carer was included in the training team.

The concept was to deliver a training programme based on the Meriden approach to training trainers, in order to give the delegates the skills and knowledge to be able to deliver a 12-module carer education programme called "Caring for Carers" which had been developed by Grainne and the Meriden team as part of the commission. The fact that this carer education programme was then to be rolled out by the delegates to carers on both sides of the border was the really rewarding part of the project to me and the other members of team as it was clear that no such carer education opportunities had been offered to carers before on either side of the border.

The course went really well, with each of the 13 delegates (including 5 carers) fully participating in all the component parts of the course. As a result we were satisfied that by the end of the course nearly all the delegates had developed the necessary skills and knowledge (supplemented by their own homework) to be able to co-facilitate the devolved Caring for Carers programme.

The first run of this programme is currently in progress with completion scheduled by the end of October, so some carers on both sides of the border are already benefiting from this initiative. The modules on the programme include: the experience of mental health problems in a family; experiences of caring; education and information sharing; diagnosis and treatments; communicating in families; communicating with professionals; problem solving; dealing with crisis and relapse management; recovery and hope; and taking care of your own health.



Peter Woodhams and Marie Crofts, a project worker in the Meriden. (This photo was taken at the 2004 WFSAD Conference in India.)

Being a member of the team delivering the training trainers' programme was for me both challenging and emotionally demanding, but working with the group as a whole and the carers in particular was highly rewarding. It was interesting to hear the delegates comment at the conclusion of the course that they really valued the different inputs of the training team, recognising the professionalism and expert knowledge of Grainne, the vitality, humour and enthusiasm of Steven and the contribution I was able to make as a carer. In particular the delegates commented on how well we had worked as a team (as a model of partnership working), and they were impressed with the extent of the carer contribution to the training.

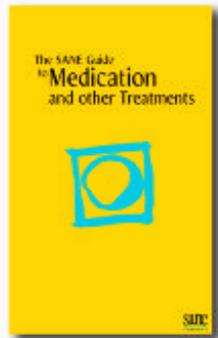
It was an additional bonus to me that as part of the 'winding down' process after the course, I was able to experience some of the views, bars and restaurants of Sligo on the delightful west coast of Ireland!!

The development by Meriden of this Carer Education program is an innovation that may prove to be of significant interest to others who are seeking to develop the education and support services they offer to carers. A program such as this goes a long way towards meeting the needs of carers.

*Peter Woodhams, Carer, is Chair of the Meriden Advisory Group, West Midlands, UK*



### SANE Australia Draws on “Dare to Care” to Advocate for Mentally Ill



One of SANE's informative booklets

For some years now Australia has been seen as supposedly setting a high standard in the provision of good mental health services. Families and other mental health advocates in Australia have not always shared this view, and recent events have highlighted that Australia's mental health services are now at crisis point. One reason given is that Australia spends a far smaller proportion of its health budget on mental health than comparable OECD countries such as Canada, the UK and New Zealand.

SANE Australia, along with other mental health groups, has presented vigorous submissions to the three national inquiries that are currently under way, drawing on the wealth of evidence, personal stories and recommendations in *Dare to Care, the SANE Mental Health Report 2004*.

“Inquiries don't automatically mean things will improve, of course”, says Barbara Hocking, Executive Director of SANE Australia, “but it's up to all of us to ensure we use them to get messages across to decision-makers, and then keep up the pressure to make sure recommendations are implemented”. One of the major issues highlighted in the SANE Report is the lack of commitment by governments for evidence-based family interventions that are proven to reduce the frequency and severity of psychotic episodes as well as reduce stress in family members.

Some important family work is happening, however, in parts of Australia, if on an 'ad hoc' basis, and is usually conducted by non-government organisations such as the Association of Relatives and Friends of the Mentally Ill (ARAFMI). A recent national conference for Carers of People with a Mental Illness was held in Melbourne in April 2005, successfully exploring ways family carers, consumers and clinicians could better work together. This was organised by the Network for Carers of People with a Mental Illness.

For more information visit [www.carersnetwork.org](http://www.carersnetwork.org)

#### Supported Housing

A study on two types of supported housing operating in parts of the United States compared the two on how the housing reflected on the wellness of the consumers involved. The study reported that the more recent *supported housing model* emphasizes the importance of normalized housing that is independent of the mental health system (Ridgeway & Zippelle, 1990). The housing stock is:

- Owned and managed by routine landlords rather than mental health care providers, and mental health consumers are considered routine renters rather than clients
- Consumers live independently rather than with other persons with disabilities
- Decisions regarding housing are made by landlords and renters rather than by mental health providers
- Housing is considered permanent rather than transitional.

Several projects have demonstrated the appropriateness of supported housing for a large proportion of mental health consumers (Carlinhg 1993).

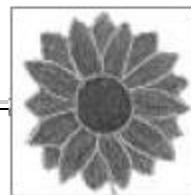
*A randomized controlled Trial of Integrated Versus Parallel Housing Services for Homeless Adults with Severe Mental Illness* by Gregory J. McHugo, Richard R. Bebout et al. *Schizophrenia Bulletin* Vol 30 No.4 2004 pp 969-982

#### World Health Organization

The World Health Organization (WHO) is launching the first ever global forum about community-based psychosocial rehabilitation services. As part of its first phase, WHO has invited people to write in about community-based psychosocial rehabilitation projects that have worked well and about those that have not been successful.

WHO will publish selected submissions in a report that will highlight issues, concerns and successful projects in developing community psychosocial rehabilitation services. For more information, visit [www.who.int/mediacentre/news/releases/2005/pr21/en/](http://www.who.int/mediacentre/news/releases/2005/pr21/en/)

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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 local organizations, individuals coping with illness and friends and professionals.

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