

World Fellowship of Schizophrenia and Allied Disorders
 First Quarter 2004

Does “employment for all”
 include the mentally ill?

Most people I know start working in their teenage years at part-time or summer jobs. After graduation they apply for and find employment, for the most part, in the field in which they were trained. I have never heard them say how lucky they are to work or how much they appreciate the feeling they get from earning money for a job well done. If, however, they were to lose their opportunity to work, I am sure they would realize how important employment is to them.

The majority of people who suffer from mental illness already know the value of employment and the sense of reward and belonging it creates. Unfortunately, finding and maintaining employment is not an easy task. Employment, the focus of this issue of the WFSAD newsletter, is a topic that needs to be discussed and understood at all levels if we are to empower the mentally ill to find employment, adjust to the work setting and succeed in their communities.

In countries where there is a social safety net, consumers are often afraid of losing health care benefits provided by the government if they work outside of a hospital/clinical employment setting. This is particularly daunting if they are unsure of their capacity to maintain a job. The high cost of medications associated with many mental disorders is another consideration when deciding to take a position and potentially lose the financial assistance they receive to help pay for their medication. Even with improved legislation such as the Work Incentive Improvement Act in the United States, finding

employment is still a scary prospect laden with barriers. If a consumer is prepared to seek employment, there must be jobs available and employers willing to hire them. What incentives do employers have to employ the mentally ill? Some countries use legislation and quotas to ensure that positions are available to the mentally ill. Other countries use tax rebates or grants for employers. Many countries, however, do not do enough to support employment for the mentally ill. The Israeli National Forum of Families of the Mentally Ill has proposed an employers forum to the Parliamentary Economic Committee. Highlights of the proposal can be found on page seven of this newsletter.

Another approach to reinstating the mentally ill in real employment is to create new positions or modify existing ones to better suit a mentally ill person. The Ontario Council of Alternative Business (OCAB) in Canada assists in the development of economic opportunities for people who have been through the mental health system. Removing vocational training from the hospital, providing a professional work environment and paying a real wage are the goals of a variety of alternative businesses. Story on page seven.

The book review on page fourteen of this newsletter also tackles the issue of important issue of employment with specific reference to employment for the severely mentally ill. The method outlined in *A Working Life for People with Severe Mental Illness* by Deborah Becker and Robert Drake moves beyond the traditional approaches to vocational rehabilitation, such as skills training classes, job clubs, and sheltered

(see Employment - page 6)

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

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"I have been pleased to see the rise of the consumer movement, but dismayed to see that it has never included most of the people with serious mental illness. My son, for example, is not a part of it. Nor are the great many people who are in hospitals or group homes, hidden away, out of sight, and out of the minds of policy makers and mental health professionals. I hope WFSAD will speak for these people."

Dale Johnson, WFSAD President-Elect

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

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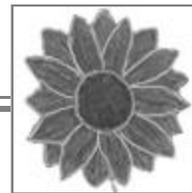
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*WFSAD looks forward to seeing you in Chennai, India
this coming November for our best conference ever
The Power of the Family Movement: Sharing the Knowledge*

Those of you who have an interest in WFSAD biennial conferences will note that we have repeated the title phrase, "The Power of the Family Movement", used in the title of our meeting in Kyoto, Japan 2002. We have also added a second phrase: "Sharing the Knowledge". The key words are "power" and "knowledge" which reflect WFSAD's objectives and those of the emerging Indian family movement. Many people took part in the choice of the name and in the focus that the meeting will take.

The conference will be held over a three-day period starting on November 2, 2004. Prior to the conference (on November 1) there will be sessions for 30 selected trainees on matters of importance to people organizing and running family self-help, support and advocacy groups in India. The training will also be open to those applying from other parts of the world for a nominal fee. Trainees will be asked to implement what they have learned within a set period of time following the training and to give feedback on their experiences. Participants will receive a certificate following completion of this work.

The conference itself will be inaugurated on November 2 and continue through November 4, and is open to anyone from any part of the world. We request qualified persons to submit abstracts on the conference theme for inclusion in the program as soon as possible. For more information on abstract submission, please see the Conference Announcement we have included with your newsletter. Consumers and families will also be participating in the conference. WFSAD believes that families are best equipped to fight the stigma of mental illness.

Our host for the meeting will be AASHA, the family organization in Chennai. AASHA will be celebrating its 15th anniversary this year and will also represent the National Federation for the Mentally Ill, an all-India association of family organizations whose founding will be celebrated officially this month (February 2004) in Delhi.

A significant goal for both the training course and the conference

proper is to give confidence, strength and ability to family organization leaders and families in order to build the family movement. India is a region of the world in which mental health professionals are few and far between and where the development of volunteer mental health workers is essential in order to provide the services that are presently unavailable to the population.

In designing the program, we have sought information from potential delegates in India, Bangladesh, Sri Lanka, Malaysia, Singapore and other Asian countries, as well as family organization leaders in other parts of the world. Their input on cultural, political and societal issues will help shape the program. The scientific committee, comprising members of the WFSAD board of directors and members of AASHA, will determine which topics from those submitted will be of most interest to delegates.

We are currently examining the following subjects:

Current Ideas in Clinical Care: Models of Comprehensive Care

Background and Philosophy of Families as Partners in Care; Basics of working with families; solving problems; current treatment and support systems.

Conducting Family Support, Self-Help and Education

What should self-help offer to families? Practical programs for families; Emphasis on women and aged.

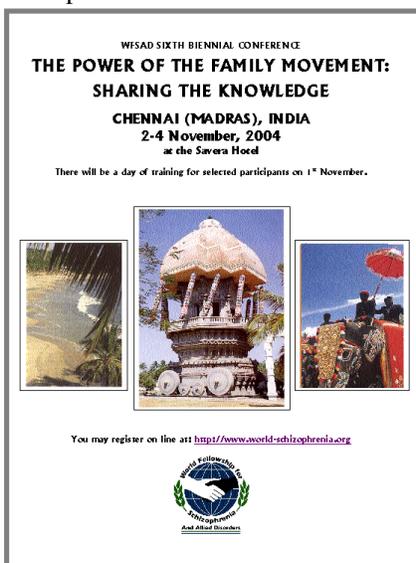
Involving Families in Direct Service Delivery

Employment for people with mental illness; Clubhouse-type activities for patient wellness

Advocacy and Influence

Dealing with media; lobbying government

India is a fascinating place to visit. Please join us in November at WFSAD's 6th Biennial Conference.





PERSONAL STORY

Such an Experience

By Yalcin Eryigit

I am from Turkey and a 45-year-old engineer. Well, sort of...

I was first diagnosed with paranoid schizophrenia at the age of 29 in Australia. Yet, I think my experience of schizophrenia started six years earlier when I was still living in London. As far as I remember, during the last couple of months of my stay in London I had started treating my girlfriend badly. I also remember that a kind of social withdrawal had already begun. London's weather, my conditions, etc. were too much for my Mediterranean nature.

Then another country, another culture, more difficulties and disappointment started forcing me a lot. On the other hand, it was still nice to make friends, to take pictures at political meetings or demonstrations and to get to know new NGOs such as AI, Greenpeace, etc. It was such an historical period during which the world changed a lot. The USSR collapsed, Germany was unified and then the Gulf War.

My paranoia had dramatically increased. I used to think that the CIA and Australia's intelligence services were after me. Of course there were some acceptable reasons to make me think so. I now know I was seriously ill. Then I experienced my first hospitalization and diagnosis with as psychosis. Yet, I still did not know that I was ill. I took medication for a while which was my first experience with conventional antipsychotics and their horrible side effects. At the end of this first psychotic episode I decided to return to my home country.

I was always a happy child and a successful student. My father died when I was an 18-year-old engineering student. When my older brother (two years older) was diagnosed with schizophrenia, I realized that I knew too little about this condition. Because I was living and working in another town, I was not able to help him much. I tried to read every single thing on the illness but there were no guidebooks or institutions like the Schizophrenia Solidarity Association.

Returning to Turkey was quite enjoyable in the beginning. I easily took a good job again. In fact, even during my illness I always

worked for prestigious companies. If I had a psychotic episode I was still successful. It was usually because of my delusions that I left jobs. Soon after returning to Turkey, as a result of an examination, I took an extremely good job that could be considered the dream job of an engineer. Then came the beginning of another episode, leaving the job, moving to another town, joining political activities, supporting Amnesty International's campaigns only to be taken into custody a couple of times because of my political beliefs and activities on human rights and illness. I was penniless in the end.

I tried to resist the conditions for a while but in the end I returned to my hometown where my mother and brother with schizophrenia were still living. One of the worst experiences of my life began here. Because I had no social security at that time, I was taken to a state hospital where I experienced traditional antipsychotics, weight gain and other serious side effects. Then came the end of another episode and the circle continued - giving the medications up, taking another good job and then the beginning of another episode. But this time even my delusions and hallucinations were continuing seriously. Nevertheless I was very productive. I was reading about 600 pages a day, jogging 5 km every day, giving up smoking, eating healthy food, no alcohol, taking part in almost every single cultural event, reading the paper, joining Amnesty International's campaigns, etc.

I was quite experienced and knew that something was going wrong but I cannot say that I was unhappy. Yet I still did not know that I had schizophrenia. Another hospitalization and this time I did not take medication and after a two-month stay, I left hospital ill again. I kept living an extremely productive life but refused every job offer. I had no money. Even

when my mother was trying to give me some money, I did not accept it. My mother was getting old, my brother was ill too and we were all living in the same home. But my mum was experienced, serious and quite stubborn, especially about my illness.

Then came the final hospitalization of another two months. As

When I was young and my brother was diagnosed with schizophrenia, I realized that I knew too little about this condition. I tried to read every single thing on the illness but there were no guidebooks or institutions like the Schizophrenia Solidarity Association.

a result of my mother's warnings that time, the only way was to take the medications. It was my last psychotic episode. It was 1997. I suddenly realized that I was ill. I was still taking traditional medications. I was shocked and feeling so small, alone and depressed. That was the beginning of another painful period.

Soon after, with a little push from my mother, I was offered an engineering position in another big company. I was now 38 and it would be my last chance, as companies prefer young engineers. It was the worst working experience of my life. I was unsuccessful this time.

I was afraid of being unemployed. The more I was frightened, the worse things went. In the end, after six months I lost my last chance. In fact I was paid quite a low wage but I needed the money. I had nothing. I did not even have a second pair of trousers when I got that job. I was taking a high dose of one of the new generation antipsychotics. I was sort of stoned. Yet, things started getting a bit better. I found a part-time job that offered little money.

During this period, my family supported me a lot. I was playing chess five times a day to keep my mind busy and to make it function better. The more I used my brain, the better I felt. But I was seriously suffering from stigma, discrimination and side effects of the medications. I was ashamed of myself, feeling low and had no friends but family. My doctor was an intellectual guy who was also an author. I kept saying that "I will get better, I will get better." One day my doctor gave me the bulletin of WFSAD. I soon wrote a letter to the organization. Then I joined the Schizophrenia Anonymous' mail group. I started reading every single thing on schizophrenia, including "Schizophrenia: A handbook for families" by Health Canada and the Schizophrenia Society of Canada.

In a short period of time I learned a lot. I also became a member of the Schizophrenia Solidarity Association of my hometown. I kept going to the monthly meetings. The more I learned about schizophrenia, the more confidence I felt. Sometimes I used to make speeches about my experiences and my feelings, which got big applause from the families.

Most of my friends, even my best friends, left me alone during my illness. That was a new beginning. It was time to make new friends. I met some good people and told them about my illness. One of them especially tried to understand me, my feelings, my fears, etc. Because of the stigma, I did not feel like telling everyone about my past. Then I became more social. I made many

new friends. If I trusted someone, I told him/her my story. If I did not trust them, I would say that I suffered from a sort of depression. Then I became a member of an amateur theatre company. That was a sort of turning point. After a long lasting social withdrawal, I was now acting in front of hundreds of people. It was a type of occupational therapy for me.

Last month I left my mother's home and now am living in a small studio flat with my girlfriend. That was another big step for me to take. I am now trying to stand on my own feet. Things have been getting slightly better.

At that time, I started making translations for Amnesty International's Turkish branch. I made hundreds of new friends and finally a girlfriend. I learned how to manage the side effects of the medication I was taking: sexual function disorders, weight gain, etc. Now I was earning more and I was quite good at doing my job. I became more confident and felt much better day after day.

Today I have a 24-year-old girlfriend who is a psychologist. Maybe we will get married and maybe we will have a baby. We know the risks. I have considerable debt and even a risk of losing my job but I am feeling well. Even though I am under serious

stress all the time I am able to handle my problems.

I still regularly take medications. It is quite a low dose. My brother has been taking the same antipsychotics and even he still has some delusions though he is now much, much better. Once during my recovery period I took my brother to the hospital and another time I was able to persuade him to go to the doctor to have his medications adjusted.

Last month I left my mother's home and now am living in a small studio flat with my girlfriend. That was another big step for me to take. I am now trying to stand on my own feet. Things have been getting slightly better.

As I am a human rights defender, the next thing for me will be to be part of the fight against discrimination and stigma of the mentally disordered. I have already tried once to bring some NGOs together to take action against the dramatic deaths of the residents of a home for adults with mental disorder in Dragash Voyvoda, Bulgaria.

I have been through a lot and am beginning to achieve a lot. I think that I deserve your friendship-maybe even your admiration.

Yalcin is a consumer member of Schizophrenia Solidarity, Izmir, Turkey.



COVER STORY - EMPLOYMENT

Employment (continued from cover story)

employment - approaches that have not been successful in helping people with severe mental illness gain competitive employment. Supported employment, in which clients are placed in jobs and then trained by on-site coaches is the approach outlined in this book.

Referring to studies completed by a variety of mental health researchers, William A. Anthony of the Centre for Psychiatric Rehabilitation at Boston University contends that there are many misconceptions about psychiatric vocational rehabilitation. These myths are hampering mental health professionals in the field from improving the success of people with mental illness in finding and maintaining employment. The points below confront some of these misconceptions.

People with mental illness want to work

There is a common misconception that people with mental illness are not interested in working. This is not the case. A survey conducted at the Boston University Centre for Psychiatric Rehabilitation found that 70% of people currently unemployed wanted to work and were able to cite a preference for a specific

work situation (Rogers, Danley & Anthony 1992).

People with mental illness want further education

Similarly to wanting to work, people with mental illness are interested in improving their skills and knowledge by furthering their education. The same survey noted that 62% wanted to continue learning in more than the sheltered workshops that are often the only training provided for them.

Psychiatric symptoms do not predict a person's capacity to work

A variety of studies have been conducting examining the correlation between psychiatric diagnosis and future employment. The results showed that there is no relationship, which, again, is contrary to the common belief. This belief has hindered the development and improvement of vocational rehabilitation.

Vocational performance in the hospital does not predict performance in the community

Many clinicians believe that if a patient is able to work successfully in a hospital environment, they will also be able to live and work successfully in the community. This is not necessarily the case.



Working Like Crazy

A film about working in survivor-run businesses

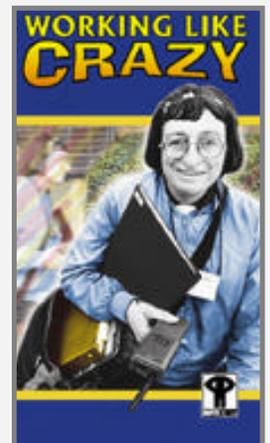
Working Like Crazy examines the struggles and victories of some former mental health patients who work in businesses owned and run by other psychiatric survivors. Labelled "unemployable," they have given themselves a safe space among peers - a place where they can earn an income and rebuild their lives.

Laurie spent years in psychiatric isolation and now runs a courier business; Diana has transformed rage and family violence into work for the Ontario Council of Alternative Businesses; since Graham has a job at Fresh Start Cleaning, his plan is "to get back to being a man"; now that Susan works as a courier, she can afford to care of her pets and the neighbourhood kids don't think she's so crazy anymore.

Illuminating the tears and laughter, the isolation and friendship, the rejection and acceptance, these and other stories reveal a rare glimpse of this complex community.

Produced by Sally Bochner, Laura Sky, Gwynne Basen and Adam Symansky in 1999, *Working Like Crazy* is about alternatives to conventional community mental health and economic development. It portrays work as a human process that rebuilds people's connections with each other. In the end, this is a film about hope.

Available from the National Film Board of Canada Web: www.nfb.ca ID NO. 113C9199228



People with mental illness do not lose their jobs because they are unable to perform tasks

It is rarely the inability to complete tasks that forces an employee to leave a position. Typically job loss is due to a person's work adjustment skills - getting along with other employees and supervisors.

It is often when we are unable to do something or when something is taken away from us that we value it most. It is inspiring to see that people all over the world are actively and inexorably working to create opportunities for people with mental illness and empowering them find and maintain meaningful employment.

Employers Forum and Incentives Proposal, Israel

Encouraging the return of the mentally ill to the community is the primary goal of a proposal put forward to the Israeli Economic Parliamentary Committee by Otzma and the Israeli National Forum of Families of the Mentally Ill. The importance of the proposal is supported by data from the Research Division of the National Insurance Institute that shows that under 7% of the 49,300 mentally ill (eligible for and receiving government allowances) in Israel are employed.

Providing employers with incentives to employ the mentally ill will have a direct impact on reducing allowances, give those able to work vocational training, prevent the deterioration of the illness, reduce the rate and cost of repeated hospitalizations, decrease homelessness as well as other positive effects including giving a sense of being an ordinary citizen to those who were previously unable to find employment.

The following are several proposals to support and reinstate mentally ill people in the labour force and present incentives to employers willing.

1. Tax relief (currently employers tax is 4%; wage tax is 9%)
2. National Insurance concession (currently 5.35% of income)
3. Municipal rate exemptions or discounts for businesses with an increasing involvement of local authorities in the entire process.
4. Grants or benefits to employers who will train employees on the job with the cooperation of the Ministry of Labor's vocational training programs.
5. Benefits such as "Approved Industry" status that were once given to industrial initiatives in Israel's periphery.
6. Redressing discrimination or allowing for quota preference in public tenders.

7. Establishing a forum of employers in association with NGOs involved in rehabilitating mentally ill patients, the rehabilitation department at the Ministry of Health and the Ministry of Labor and Welfare. A good example of such an initiative is the employers' forum in the U.K. established in 1986. The forum also acts as a lobby in parliament for both employers and employees on national and local levels.

8. Another useful example can be drawn from the American Medicaid medical insurance program. Under this program, employees do not forgo their allowance for the first eight years of employment. After eight years or after reaching a certain level of income, recipients are required to contribute a certain percentage towards their own health schemes.

The concluding remarks of the proposal reinforce the importance of a fundamental conceptual change for both employers and for those responsible for rehabilitating mentally ill people. Both these groups, the proposal suggests, are obligated to actively endorse equal opportunity for the mentally ill and to guarantee their training and employment in the community.

Alternative Businesses

The Ontario Council of Alternative Businesses (OCAB) assists in the development of economic opportunities for people who have been through the mental health system. OCAB believes that these economic opportunities or alternative businesses are a form of affirmative action. Created to employ survivors of mental illness, the businesses are operated through peer training and support with connections to the local community for technical and organizational expertise.

The businesses range from cabinet making to office cleaning and current employ over 600 psychiatric survivors. Most positions allow for flexible hours of work with an environment that makes employees feel secure enough to ask for time off without the risk of losing their job or being judged as irresponsible.

Parkdale Green Thumb Enterprises (PGTE) is one example of an OCAB alternative business success story. Started in 2001, PGTE is a landscaping company that provides services to Business Improvement Associations, home owners and businesses in Toronto. The benefits to the community and the 43 employees are immeasurable.

Some of the suggestions OCAB makes for policy makers:

- Increase the funding allocated for survivor business development.
- Institute a public education campaign to reduce stigma and discrimination.
- Reduce the disincentives to work by raising limits on allowable earnings for people on a disability pension.



Silver Linings - From there to here

Schizophrenia Fellowship New Zealand Celebratory 25 Year Anniversary Conference

In September 2003, participants gathered in Christchurch, New Zealand for the 25th celebratory anniversary National Conference of the Schizophrenia Fellowship New Zealand Inc. The two day conference was an opportunity to network, catch-up with old friends, learn, inform and celebrate 25 years of Schizophrenia Fellowship in New Zealand.

Since its start in 1977 in Christchurch, the Fellowship has grown to a network of 21 branches and sub-branches throughout New Zealand.

National President, Max Kerr, paid tribute to SF family volunteers nominated by each branch for their contributions over the years. The original founding members from Christchurch were also celebrated and were delighted to see that the organization that they had started in a living-room a quarter century ago had grown considerable and is continuing to make a difference to the lives of others.

Participants left the conference tired but brimming with new found knowledge and happy with making many new friends.

Highlights of conference speakers

Professor Charles Rapp from the United States outlined the concepts of the Strengths Model which says that it is crucial for the focus of the helping process to be on the consumer's strengths, interests and abilities and not on their weaknesses, deficits or the pathology of their illness. Julie Kneebone described the interaction between recovery and the Strengths Model.

Dr Graham Mellsop reviewed outcome assessments in mental health services around the world and also highlighted evidence based gains from integrating community and patient services.

Robert Miller told about the nature and history of the New Zealand Schizophrenia Research Group.

Delegates also heard about some New Zealand research being carried out by David King and Barry Welsh called *Knowing the*

People Planning. Their research is concerned with finding out the essential qualities of community services required to satisfy consumers and their families/whanau.

Phyllis Tangitu (NZ), speaking as a family member, stated that in order to be able to make a difference we need to get informed about the legislation, documentation and structure of our health service.

David Lui (Samoa/NZ) gave a presentation about the Samoan perspective of health and the Samoan concept of family. David indicated that mental health systems should have the flexibility to embrace paradigms other than the Western one.

A number of presentations were given by Deaf mental health services which raised awareness of the huge obstacles this group face when needing to access mental health services. 50% of Deaf people in New Zealand are at risk of developing mental illness. (Deaf is spelt with a capital "D" to denote Deaf culture) Dr. Peter Hindley, Clinical Director of National Deaf Services (U.K.) spoke of the severe social consequences of deafness. He gave the example that a lack of access to early conversation could be detrimental to the child's development and associated leaning and can lead to delays in emotional development, understanding and vocabulary.

Judith Maloney (NZ) talked about the unique set of challenges that families/whanau face, including their need for specialized training.

Some of the things that can help families are: information, other families/friends and the Schizophrenia Fellowship.

Dr Catherine Wiltshire (Australia) gave a good understanding of the developmental stages of childhood and the mental health issues that often go along with them. Sonia Worthington, a Child and Adult Resource Worker from the West Coast of New Zealand brought attention to the reality that children can be the caregiver in families where there is a mental illness. Mental health services do not always take the role of children into account in their procedures.



Founding Members of the Schizophrenia Fellowship New Zealand Alan Burlton (left) and Anne Noonan (right) with Piripi Rikiti.

Asian mental health was another topic discussed with speakers focusing on Asian students from overseas studying in Christchurch and some of the mental health problems they face, Chinese gambling as a mental health problem and access to services and best practice in delivery for the Asian culture.

Those interested in learning more about particular speakers are welcome to visit the Schizophrenia Fellowship of New Zealand website at www.sfnat.org.nz.

Acknowledgements

The conference committee sincerely thanks a number of generous conference sponsors including the principal sponsor Janssen-Cilag.

WFSAD and APEF Argentina to expand Hispanic bulletin

For several years WFSAD has had an agreement with APEF Argentina to support the production of a Hispanic bulletin for family members in Argentina and in the surrounding nations. With the development of the Alianza Latina WFSAD (see Regional News, Page 6, 4th quarter issue of the WFSAD Newsletter), WFSAD's outreach to families in Central and South America has widened considerably. Current plans are to expand the present letter published by APEF by adding a four-page international section. The first issue of this bulletin will be edited in Toronto and published and mailed by APEF in Buenos Aires. All Alianza members and colleagues will receive a copy by April of this year. WFSAD would like to thank the volunteers both in Toronto and in Buenos Aires for working on this joint venture. If you have a short article in Spanish (500 words) that you wish to submit, please send it to the WFSAD office and mark the envelope "WFSAD Boletin Internacional".

WFSAD to offer workshops in Moscow soon

WFSAD has been planning to hold international workshops in Moscow for many months. These plans are still moving forward and it is hoped that the workshops will take place this year. The tentative dates are May 19-21, 2004. All those interested in taking part should contact the WFSAD office in order to keep abreast of the plans.

Ypsilon's Laughing Night raises money for a hospital garden project

Ypsilon Surinam celebrated World Mental Health Day with their own event - *Lafu Neti* or *Laughing Night* on October 18 of this past year. The theatrical presentation by Ypsilon family members, clients and nurses from a psychiatric hospital included dances, songs, poems and the telling of jokes and sweet memories about their illness.

Tickets were sold out for the performance with all proceeds going towards a garden project next to the hospital in which clients will be able to work and learn about growing a variety of plants and vegetables. The money raised is expected to pay for the pillars and roof for a garden structure.

Folk Dancing in Istanbul, Turkey

Folk dancing is turning out to be a great method of therapy for patients in a hospital in Istanbul, Turkey. Nine patients and three nurses make up the troupe which is pictured below performing in Hamm, Germany this past July. The professional training and interaction has helped the patients with their self-confidence levels.





FEATURE

The Dream of Hope House

By Jess Mackintosh, Cape Town

We all have dreams. Some are big, some are small and many are impossible. It's the same with wishes - we wish many things and usually those wishes are for those we love. Sometimes when the dreams and wishes become one and materialize, it's almost too much to believe - that this dream, this wish has come true!

I have a daughter, Lindsay. She is my third and much loved youngest child. Her story is sadly so typical. Lindsay was very bright, attractive, a high academic and athletic achiever, well liked by her colleagues and a graduate in physiotherapy when she became ill with schizophrenia. Like other families who have experienced similar adversity, we were devastated. We knew nothing of mental illness, there had been no family history, we asked ourselves "why us?"

Lindsay was in and out of the local mental hospital. Sadly she was resistant to the medication and her stays became longer and longer. Her last admission was for 18 months. After a high security hospitalization of over a year, the team of doctors caring for her suggested a one on one companion to break the pattern of being surrounded consistently by the very ill. After receiving permission from the Department of Health, I found Zainab, a young ex-teacher who felt she had a calling to look after those incapable of looking after themselves. This was the start of Lindsay's new life.

Three months later, she was moved to a less secure ward of the hospital and Zainab started teaching her handcrafts. This became her saviour. By using the crafts, Lindsay learnt a tool. This tool would help Lindsay with one of the most debilitating symptoms of schizophrenia - auditory hallucinations. Another three months later Lindsay was discharged on the strong recommendation that she should stay in a secure environment with 24-hour care. Cape Town offered nothing suitable for the care Lindsay needed. I

heard that a former social worker in Port Elizabeth was running a group home where the residents were occupied productively during the day. I flew to meet with him and came back motivated and knew that this was what Cape Town, my daughter and so many young sufferers of schizophrenia needed.

I can remember the first meeting in my lounge at which a group of concerned people discussed how we were going to make this happen. I remember us choosing the name "Hope House Trust" for our organization, working on the business plan and eventually the fundraising. I felt so proud of the group - two of

us the mothers of sufferers, the rest wonderful friends wanting to help - a teacher, a lawyer, an accountant, friends of different ages, different walks of life. We had immediate support from the psychiatric hospital and their psychiatrists. At many of our fundraisers we spoke about mental illness, educating the public and making them aware of the high percentage of people suffering from mental illness. Not only were we raising money for our dream but we were also hoping to make the audience understand and not fear the mentally ill.



Everything started falling into place in October 2000 when Hope House Trust was

registered as a charitable trust and thereafter as a non-profit organization. In January 2002 we received government approval as a public benefit organization. We continued fundraising. We commenced our search for an ideal house and faced many disappointments. In December 2001 we finally purchased 32 Peak Drive, Pinelands-our first Hope House! Despite not having enough money, we completed extensive renovations knowing that somehow we would find the money. On the 15th of July our first female residents moved in. It was a very emotional day.

We are very blessed with Hope House. The old family home on

the property is home to our four female residents and a substantial cottage accommodates our three male residents. The property also has a lovely large peaceful garden. Domino, the resident dalmatian, adds to the family feel, as does Lady, the mother of six adorable kittens and the budgie, Blue Boy. Our full time housemother, Gill, stays in the cottage and, in her mothering way, ensures that the residents are cared for and supported. Zainab comes in daily to assist the residents with handicrafts and other forms of occupational therapy. We are putting her through her diploma in auxiliary social work and she loves her studies. Her work is very important as she keeps the residents motivated and busy.

The house is run on a strict but simple routine. Residents are encouraged to assist in the household chores, as well as in the garden. We have encouraged the residents to feel that this is their home. There is a wonderfully happy atmosphere - the girls in the activity room sewing, laughing, with the radio blaring the latest musical hits and the male residents working in the garden or cleaning the pool.

Recently we asked the residents what their feelings were about Hope House. Here are a few replies:

Maurice: "I enjoy the company and being cared for."

Rene: "I enjoy living in Hope House and I have learnt a lot - sewing."

Bekki: "It's a lovely place to stay and the people are very special."

And my Lindsay: "I feel very privileged and lucky to stay in Hope House, and I want to say thank you, and I also feel I have grown from the experience."

And so it has happened. The dream of having a home where people suffering from chronic schizophrenia live in harmony, support each other and are treated with the respect they deserve has come true. With the help and generosity of so many people, Hope House is now a reality. I visit Hope House a few times each week and always have a humbling and wonderful feeling - the kind that makes you want to shout from the rooftops:

"IT HAS HAPPENED, IT WORKS, THANK YOU!!"

By writing this, I sincerely hope that those of you who are still dreaming will be encouraged to pursue your dream and make it come true.

You can write to Jess Mackintosh, Chairperson, Hope House Trust, c/o WFSAD or email her at: hopehouse@kingsley.co.za.



WORLD FELLOWSHIP
FOR SCHIZOPHRENIA
AND ALLIED DISORDERS

5TH BIENNIAL CONFERENCE
*The Power of the Family Movement:
Catalyst for Change*

HOSTED BY ZENKAREN
(Japanese Alliance with the Mentally Ill)

October 9-11, 2002
Kyoto International Conference Hall
Kyoto, Japan

PROCEEDINGS

家族のパワーが
未来を拓く



The proceedings of the WFSAD 5th Biennial Conference in Kyoto, Japan, 2002 are in their final stages of publication.

If you would like a copy mailed to you, please send \$10(Canadian) for each copy ordered. This covers printing and mailing costs only.

Please mail your order and payment to:

World Fellowship for Schizophrenia
and Allied Disorders
124 Merton Street, Suite 507
Toronto, Ontario M4S 2Z2
Canada



WHO Mental Health Global Action Programme documents published

The cover story for our last issue highlighted the World Health Organization's Mental Health Global Action Programme (mhGAP) and gave some details of the part played by the World Fellowship for Schizophrenia and Allied Disorders in reviewing the draft modules. We are pleased to let you know that these have now been published. We have received a set of seven books under the broad title Mental Health Policy and Service Guidance Package. Each book is journal-size and covers a different topic. You may request these documents from the WHO. The following are the topics of each book.

- The Mental Health Context
- Mental Health Policy, Plans and Programmes
- Mental Health Financing
- Mental Health Legislation & Human Rights
- Advocacy and Mental Health
- Organization of Services for Mental Health
- Quality Improvement for Mental Health
- Planning & Budgeting to Deliver Services for Mental Health

In the preface to "The Mental Health Context", Dr. Michelle Funk and Dr. Benedetto Saraceno describe the purpose of the guidance package as follows;

To assist planners to:

- Develop policies and comprehensive strategies for improving the mental health of populations;
- Use existing resources to achieve the greatest possible benefits;
- Provide effective services to those in need;
- Assist the reintegration of persons with mental disorders in all aspects of community life, thus improving their overall quality of life.

Withdrawal reactions for SSRIs

Selective serotonin reuptake inhibitors (SSRIs), now widely prescribed for depression, are again in the news. Health Canada, in its April issue of Canadian Adverse Reaction Newsletter (Volume 13 Issue 2 April 2003), brings to attention withdrawal reactions with this class of drug. These can be common and may lead to inappropriate treatment and may affect compliance with treatment.

The withdrawal symptoms may occur after treatment is stopped; dose reduced; switching treatment, and missed doses. The symptoms can be either physical or psychological including dizziness, nausea and vomiting, fatigue, and vivid dreams along

with anxiety, agitation and confusion.

Withdrawal symptoms can be misdiagnosed as a recurrence of depression, evidence of ineffectiveness of the drug in a non-compliant patient, or adverse reactions of the new anti-depressant following a switch in medication. Most withdrawal reactions are mild and transient but some can be severe.

Clinicians should be aware that the use of an antidepressant with a short half-life* may be an important risk factor for withdrawal reactions. Patients should be informed of the risk of withdrawal reactions to prevent unguided cessation of treatment. Proper diagnosis of withdrawal reactions may prevent unnecessary reinstatement of treatment, unnecessary tests and an undesirable escalation of dose.

* Half-life is the time taken (hours or days) for 50% of the drug to be eliminated from the body

WARNING

Health Canada is advising Canadians that patients under 18 who are currently being treated with a newer anti-depressant -- Selective Serotonin Re-uptake Inhibitors (SSRIs) or Serotonin Noradrenaline Re-uptake Inhibitors (SNRIs) -- should consult their treating physician to confirm that the benefits of the drug still outweigh the potential risks in light of recent safety concerns.

Cost of depression among adults in England in 2000

A report of a study in The British Journal of Psychiatry (2003) 183: 514-519 by Christine M. Thomas, MSc of Organon Laboratories Ltd, Cambridge, and Stephen Morris, PhD of Imperial College Management School, London, UK estimates the total cost of adult depression at over £9 billion, indicating a great increase in estimates made a decade ago of £3.5 billion. "£370 million represents direct treatment costs. There were 109.7 million working days lost and 2615 deaths due to depression in 2000." Recorded data on health service use by patients with depression were analyzed and the cost of treating patients was calculated. The cost of working life lost was estimated from sickness benefit claims and the number of registered deaths of patients with depression. The study concludes: "Despite awareness campaigns and the availability of effective treatments, depression remains a considerable burden on both society and the individual, especially in terms of incapacity to work."

WPA's International Guidelines for Diagnostic Assessment

A British Journal of Psychiatry Supplement (Column 182, Supplement 45) is devoted to the essentials of the World Psychiatric Association's International Guidelines for Diagnostic Assessment. The Supplement is edited by J. E. Mezzich, C. E. Berganza, M. Von Cranach, M. R. Jorge, M. C. Kastrup, R. S. Murthy, A. Okasha, C. Pull, N. Sartorius, A. Skodol and M. Zaudig and contains the following papers:

1. Conceptual bases - historical, cultural and clinical perspectives
2. Interviewing the patient
3. Use of extended sources of information
4. Evaluation of symptoms and mental state
5. Supplementary assessment procedures - psychopathological, neuropsychological and physical aspects
6. Supplementary assessment procedures - functioning, social context, cultural framework and quality of life
7. Standardized multi-axial diagnostic formulation
8. Idiographic (personalized) diagnostic formulation
9. Linking diagnosis to care - treatment planning
10. Organizing the clinical chart
11. Illustrative clinical case

New Imaging Technique Shows White Matter Changes in Early-Onset Schizophrenia

Researchers presented information at the Radiological Society of North America annual meeting about using diffusion tensor imaging (DTI) to examine white matter in the frontal regions of the brains of 12 adolescents with early-onset schizophrenia and nine normal volunteers. Contiguous imaging slices were obtained at levels from 25 mm above to 5 mm below the anterior commissure-posterior commissure (AC-PC) plane.

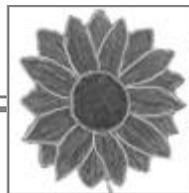
The studies demonstrated clear differences between the schizophrenia patients and the controls. Dr. Manzar Ashtari of Albert Einstein College of Medicine, New York, stated "the results might point to new therapeutic targets for research", and that the "research suggests that schizophrenia has its origins early in life."

Asked about a possible clinical role for DTI, Dr. Manzar said it is too early in the research process to say that DTI could be used as a diagnostic tool "although we hope that is the case."

Source: Peggy Peck, Reuters Health Information

Embracing Traditional Healers

A British Journal of Psychiatry article stated that in Tanzania, Ngoma et al (pp. 349-355) found the prevalence of common mental disorders to be twice as high among patients attending traditional healers than among those attending primary health clinics. Such patients usually presented with chronic symptoms and had previously consulted several doctors. The overwhelmingly somatic presentations may have militated against recognition by clinicians. It is suggested that the formal health system might usefully be aided by indigenous practitioners in improving the mental health of the community, by providing a better understanding of the prevailing indigenous models and idioms of expression for common mental disorders.



OBITUARY

Philip Wilmot died last October after a considerable battle with cancer. He was to have been WFSAD's president - a post he would have held with dignity, efficiency, warmth and good humour. But it was not to be. Philip joined the WFSAD board in 1989, replacing Nicholas Lines as Rethink's delegate. His experience in business made Philip an invaluable resource for our strategic planning, while the knowledge he gained as Chairman of the National Schizophrenia Fellowship (now Rethink) helped lead WFSAD towards maturity. Philip had just finished working on a review of our goals and bylaws in 1997 when he advised the board that he was stepping down from his position as president-elect. Despite his illness, he kept up his interest in WFSAD and early last year was well enough to take on one last role for us. Taking part in the WHO meeting on the mental health General Action Plan, Philip was able to bring back the news that WFSAD would soon be officially recognized by WHO. It was a fitting end to his relationship with WFSAD, though, of course, we would rather that he had been able to remain with us and become our president. Philip, you will be sadly missed by the WFSAD board, past and present.



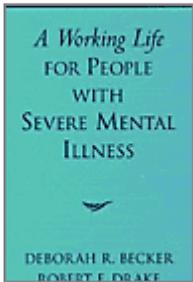
BOOK REVIEWS

A Working Life for People with Severe Mental Illness

By Deborah R. Becker and Robert E. Drake

Published by Oxford University Press

ISBN 0-19-513121-5



"The message that people need to hear is that clients want to work, that work is therapeutic, and that everyone in the community mental health agency needs to participate fully for a supported employment program to succeed. Work is a way that many people with severe mental illness are able to develop normal adult roles within the community, reversing the patient role that is so debilitating."

This passage from Part Two of Becker and Drake's book about making employment a significant part of treatment for someone who is severely mentally ill, summarizes the main tenets of their model. People need and want to work and assisting people towards the independence that employment offers is a worthwhile and entirely possible endeavour.

Becker and Drake have been studying the U.S. employment field since the early 1980s and have developed an effective system to support those who want to work in finding and keeping a job. The book is a comprehensive description of their program: "Individual Placement and Support (IPS)". Part One describes conceptual and empirical support for the model. Part Two gives practical guidelines for implementing supported employment and describes in detail the competencies needed by the employment specialist and supervisor. Part Two is the most comprehensive and longest section of the book. Part Three describes issues experienced by clients with dual diagnosis or those who were highly trained prior to illness.

Throughout the book, passages in italics outline the basics of the model while the general text fleshes out the details. Numerous anecdotes and case studies are used to illustrate the model and bring it to life. The appendices provide forms, letters and a fidelity profile to assist those setting up the program.

There are frequent references related to the danger consumers face of losing their government benefits if they take up work as well as some suggestions for overcoming these difficulties.

The purpose of the book is clearly to excite mental health workers

in the U.S and elsewhere about this model of care and then to implement it rather than continuing with standard models that are now available. It is as much a "how to" manual as an informative text. A philosophy that believes in the value of work for the recovering patient and the use of employment specialists who work with the treatment team to make employment tailored to the client a reality is key to the model.

From the detailed descriptions of employment specialists and the examples given, this job is multi-faceted, requiring someone with exceptional skills and who is flexible about hours of work. Strong interpersonal skills and "likeability" are a must since she or he must work not only with the team, but with all kinds of potential employers and all kinds of clients with different and often challenging employment needs.

This is a very stimulating read for those interested in the model and provides all the basics for beginning the work.



This children's storybook is told from the perspective of eight-year-old Alex. Alex, whose father has depression, faces a variety of emotions when trying to deal with his father's illness. With the help of family, friends and professionals, Alex learns about depression, treatment

and his own feelings.

Written for children aged five to nine, *Can I Catch it Like a Cold?* can be used by family members, educators or mental health professionals to address the impact of a loved one's depression on a child's life.

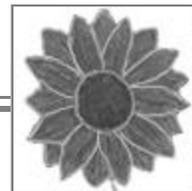
Can I Catch It like a Cold? - A Story to Help Children Understand a Parent's Depression

Story by Gretchen Kelbaugh and the Centre for Addiction and Mental Health

Illustrated by Coral Nault

ISBN 0-88868-416-9

For more information on the Centre for Addiction and Mental Health resources materials or to place an order for this book, please email marketing@camh.net.



Dialectical Behaviour Therapy and Borderline Personality Disorder and Substance Abuse Workshop

March 12-13, 2004
Kelowna, British Columbia, Canada

For more information contact:
Borderline Personality Disorder Association
Tel: +1 205 862 4175 or +1 205 717 3562



World Psychiatric Association International Congress Treatment in Psychiatry: An Update

November 10-13, 2004
Florence Congress Centre - Florence, Italy

For more information contact:
Organizing Secretariat, Newtowns S.p.A.
Tel: +39 055 33611
Email: info@wpa2004florence.org
Web: www.wpa2004florence.org



World Association for Social Psychiatry (WASP): 1st Regional Congress of Social Psychiatry in Africa

March 22-26, 2004
Caesars Convention Centre, Johannesburg, South Africa

For more information contact:
Sonja du Plessis
Londocor Public Relations and Event Management
Tel: +27 11 768 4355
Email: Sonja@londocor.co.za
Web: www.sawasp.co.za



World Psychiatric Association Regional Congress: Advances in Psychiatry (in collaboration with the Hellenic Psychiatric Association)

March 12-15, 2005
Athens, Greece

For more information contact:
Organizing Secretariat: Era Ltd.
Tel: +30 210 3634944
Email: info@era.gr
Web: www.era.gr/wpa2005athens.htm



8th European Clubhouse Conference 2004

September 15-18, 2004

For more information contact:
International Center for Clubhouse Development
Fontanhuset/Malmo
Tel: +46 40 120013
Email: fontanhuset@zeta.telenordia.se
Web: www.iccd.org



XIII World Congress of Psychiatry: 5000 Years of Science and Care

September 10-15, 2005
Cairo International Convention & Exhibition Center, Egypt

Further information can be found at:
Web: www.wpa-cairo2005.com



XXIII Congresso APAL 2004

November 17-20, 2004
Punta del Este - Uruguay

For more information contact:
Email: apal2004@montevideo.com.uy

**See page three for information on
WFSAD's 6th Biennial Conference - The
Power of the Family Movement: Sharing
the Knowledge**





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