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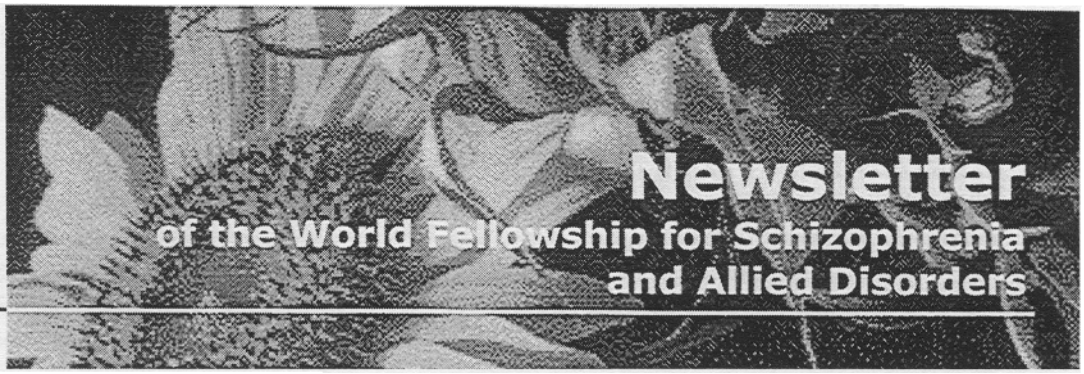

The First Quarter Newsletter is devoted to the Fourth Biennial Conference of WFSAD held in Jerusalem last May. We hope that these written versions of spoken presentations will extend your knowledge and understanding of schizophrenia and the family movement.

Conference 2000 *Issue*

Strengthening Families Through Empowerment

A ***Report*** *of* ***the***

Fourth Biennial Conference of the World Fellowship for Schizophrenia and Allied Disorders

A general overview containing a abstracts, summaries and full presentations of speakers at the Jerusalem conference, May 2000.

Our sincere thanks to the

Skoll Community Fund

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U;7F *SAD Conference and these proceedings.*

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STRENGTHENING FAMILIES THROUGH EMPOWERMENT - PAST, PRESENT AND FUTURE: A VIEW FROM DEVELOPING COUNTRIES

Keynote Speaker:

Professor R. Srinivasa Murthy

The place of family members in the care and treatment of persons with schizophrenia has taken a full circle. It was less than two centuries back that the ideal of moral treatment was to move patients away from families. In the past 30 years there has been a shift from considering family as the problem to family as the solution. This shift has occurred as a result of a large number of developments, namely (1) better understanding of the biological basis of the illness and symptoms; (ii) availability of specific treatments; (iii) recognition of the value of community life for the ill persons; (iv) emphasis on human rights; (v) advances in psychosocial therapies; (vi) better understanding of the differing course and outcome in different populations and communities. All these developments have resulted in a shift to consider families as partners in care. In the developing countries, persons with the illness of schizophrenia have always and even today lived with their families. As a result, families have been active partners in the care of the ill persons. The approaches of the mental health professionals in India and other developing countries has been as follows: 1) utilize the family as substitute for the non-available professionals, 2) provide education to them and through them change community attitudes; 3) enhance the skills of the family members to cope with the day to day living problems; 4) form self help groups to support each other, 5) strengthen the families to play the advocacy role for policy change and 6) provide emotional support to the carers. During the last 40 years, there is a gradual shift from a passive role to an active role for families. However, currently Strengthening of the Families is occurring more by chance than by design. This is in spite of the strong evidence to support family involvement as an essential part of all treatment programmes. The future holds out the promise of a better understanding of the causation of schizophrenia, improved treatment options and greater recognition of the rights of the persons with the illness of schizophrenia. These developments require that the relationships with the ill person, families and professionals have to be considered with greater partnership and sensitivity to the experiences of each of the three groups. In addition such an interaction has to be continuous, dynamic and rooted in the socio-cultural beliefs, practices of the communities. A positive outcome of such an integrated approach to care would be a better quality of life to the ill persons and their families, along with better professional satisfaction.

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BEST PRACTICE GUIDELINES FOR THE CARE OF PERSONS WITH SCHIZOPHENIA

Bernard McNair, Robert. B. Ramjan.

In 1997 the Schizophrenia Fellowship of NSW was approached by Professor Beverley Raphael (the Director General of Mental Health in NSW) to research and write Best Practice Guidelines for persons with Schizophrenia. This was a first for our organisation, as we had never gone through the tender processes for a project like this in the past.

The next 12 months of work were to be exciting, stimulating and at times frustrating. We prepared what we believed then, and still believe to be a landmark document. The over-all objective of our approach was to achieve better health and lifestyle outcomes for persons with Schizophrenia and their families, and by better informing the consumers and carers about the options available to them.

Firstly, some background regarding the Schizophrenia Fellowship. The Schizophrenia Fellowship of New South Wales Inc has been operating for the last 15 years to act as a non government agency of advocacy, supporting and encouraging the provision of services for persons with mental illness and their carers. We have approximately 5,000 members in NSW and in addition to our advocacy support and education processes, we operate two accredited Clubhouses one in Balgowlah, which is a Sydney Beach side suburb, and one in Tamworth in Rural NSW.

The Schizophrenia Fellowship of NSW Inc is part of the Schizophrenia Fellowships Council of Australia Inc which operates with similar objectives to the NSW fellowship on a National basis.

The best practice guidelines cover a person with schizophrenia from the first emergence of symptoms to death. It covers the areas of partnership, confidentiality and consumer empowerment as well as other areas such as:

- Assessment
- Medication
- ECT
- Dental care
- Leisure
- Diet
- Accommodation
- Homelessness; and
- Psychosocial Rehabilitation.

To achieve this we established five committees:

- Management Committee
- Consumer Committee
- Carer Committee
- Mental Health Worker Committee; and
- Research Committee.

A management committee was appointed to be responsible for the overall management of the project, and met on a monthly basis.

The Consumer Committee members were nominated by organisations such as the SFNSW, NSW Consumer Advisory Group, Mental Health Co-ordinating Council and the Australian Mental Health Consumer Network. Amongst the membership are people with non-English speaking

background, Aboriginal background, rural and metropolitan background. Further, this committee had amongst its representatives the President of the Australian Mental Health Consumer Network and three other persons who were working within the mental health services.

The Carer Committee members were nominated by organisations providing carer support such as SFNSW, ARAFMI and NOUS, the Greek speaking support group. Once again the membership reflects the diversity of our community with representation from NESB, Aboriginality, rural and metropolitan. This committee had amongst its members an ex-Attorney General, two university lecturers and a retired high school principal.

The Clinical and Research Committees had representation from the five main areas of mental health professionals. Invitations were sent to the following to nominate a person for each committee:

Australian College of Occupational Therapists;
Australian Association of Social Workers;
Australian New Zealand College of Mental Health Nurses;
Australian Psychological Association; and
Australian and New Zealand College of Psychiatrists.

I would like to acknowledge and most sincerely thank Janssen-Cilag for their support and funding of the general practitioner focus groups and printing of a special version of the guideline for this group. Their assistance has allowed us to broaden the scope of the project and make it much more relevant.

What was truly impressive about this process was its inclusive nature and the results that are already flowing from its inclusivity. Well over 100 people were involved through the committees, the focus groups and people just coming forward and volunteering to help. We were also impressed by the extra effort people were willing, and even demanding, to make.

Members of all committees assisted with the research, reading the mass of literature and writing papers for committee consideration. Members also volunteered their personal contacts outside the mental health field to assist the process.

We are very proud of the guidelines as we believe that they can and will form a blueprint for better service delivery in the future. I will now hand over to my colleague Rob Ramjan to describe some of the specific guidelines which have emerged.

1. Stakeholder
Involvement
Direction
Ownership

2. Stakeholders
Consumers
Carers
Professionals
Occupational Therapists
Social workers
Psychiatrists
Psychologists
Psychiatric nurses
Researchers

3. SFNSW Commitment

Cover the whole of life experience of a person with schizophrenia

4. Acknowledge impact of psychosocial factors on symptoms and course of illness

5. Evidence comes in many forms that are legitimate

6. Decide what needs to be included in the guidelines;
These committees met every four to six weeks. They met on consecutive days when it was required. Each committee met on the same day, meeting both separately and together. This allowed the perspective of each committee to be established, and then matters were openly discussed to reach consensus.

The role of these committees became all encompassing; and they were involved in every aspect of the project. The stated roles are:

- Decide what needs to be included in the guidelines;
- Review the text and specific guidelines;
- Come to a consensus, or non consensus for each guideline; and
- Rate the level of evidence to be assigned to each guideline.

It should be noted that each committee had equal input into this process.

We developed a process of reviewing the literature in a specified area, then preparing a paper for the committees which included summaries of the research literature and proposed guidelines. This paper was then fully and openly discussing and then amended or rewritten for further consideration. Quite rightly, the committees could be quite brutal and some papers required complete re writing.

We also engaged a consultant to undertake two rounds of focus groups.

Two rounds of four different focus groups were conducted. They were:

- Consumer Focus Group;
- Carer Focus Group;
- Mental Health Workers Focus group; and
- General Practitioners Focus Group.

The aims of the focus groups were:

- To broaden the base from which the guidelines were developed. It was important that the guidelines were strongly derived from the community in which they are to be used.
- To act as a "check point" to ensure that what was developed by the four committees is reflected in the wider community and to assess if any important areas were overlooked.

The first round of focus groups, which reviewed the structure and direction of the project was completed, and feedback from this round confirmed the directions that we were taking. The second round took place in November, 1998.

In the first round of focus groups we aimed to have 15 persons at each and came close to this figure with all groups except the general practitioner group. With regard to the carer and consumer groups, our target was the average person rather than the known person as was the case with the committees. We were keen to get a true grass roots response.

The mental health worker focus group was arrived at by inviting representatives from different area health services, with a spread of the various professions involved and an equal mix of hospital and community staff.

8. It is also impressive, and I believe instructive, how the atmosphere of collaboration and partnership has developed. As I mentioned at the start, what could potentially be full on confrontation has become optimisation for all parties.

9. Ownership brings rights and responsibilities.

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SELF HELP AND MUTUALITY: TOOLS THAT STRENGTHEN CARERS

Martha Piatigorsky, Diana Trumper

An active dialogue with the professionals and family carers attending the workshop coming from different cultures.
Five reasons that make self help groups a positive experience:

1. Sharing similar experiences join and help develop a social net
2. Self-help groups move members from the role of demanding help to the role of helpers.
3. Self-help groups stimulate specific ways of coping with difficulties based on results of experience.
4. Self-help groups unfold role examples.
5. Self-help groups foster meaningful structures which are created by its members and not imposed from the outside.

After more than 6 years sharing experiences with carers, we have the evidence that the negative symptoms of mental illness are one of the most difficult situations for the family to understand, accept with empathy and cope with.

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PSYCHOEDUCATION OR FAMILY EDUCATION: WHAT IS IT ALL ABOUT?

Dale L. Johnson

When people discover that a member of their family has developed a serious mental illness they typically are in shock. They are not prepared. They are puzzled and frightened by strange behaviors, worried about what will happen, appalled by this disruption in the course of what has seemed like normal development, and at a loss for what to do. The experience is virtually the same for families everywhere in the world. The burden of mental illness is great.

Almost always, the relative is taken to medical experts for help and usually the ill person is placed in a hospital. Examinations are carried out, sometimes members of the family are interviewed, medication is prescribed, and other treatments may be recommended. After a few days, or sometimes after a much longer time, the ill person is released to return home. Most often the family has been told nothing. There has been no instruction about medications, about coping with strange behavior, about dealing with a person who insists that she or he is not ill and that it is the family's fault. In short, the professional staff has ignored the family, until time to return home and then it is apparently assumed that the family will know what to do.

This situation has changed little; at least in the United States we have seen little change. Mental health professionals are more cautious about blaming families for causing the mental illness, but they have not yet learned how to help families. There are exceptions, of course, but their behavior should be the norm, not the exception.

What do families want? Many surveys have shown the same thing. They want information about the mental illness so they can cope better. They want to know specifics about medication, psychosocial treatments, housing options, and social supports. They want to know how to obtain the best treatment possible and they want to know what they can do to help and not interfere with treatment.

When my son became ill with schizophrenia 28 years ago, there were few options. Even though I am a clinical psychologist with many years of experience in working with people with serious mental illness and my wife is a medical sociologist, we were in the dark. We did not know how to care for a person who had a mental illness twenty-four hours a day.

Now the situation is different, and vastly improved. There are several ways of helping families. Some of these have demonstrated effectiveness with carefully conducted clinical trials. Others have not passed the tests of scientific examination, but offer benefits that are obvious to families. I have compiled a list of these, and I have reviewed them for what each can offer families. The list and the judgments are my own, although I have searched the research literature for confirming evidence.

In reviewing evidence for the effectiveness of ways of helping families I have taken into consideration several kinds of information. These include reports by family members of what they found useful, or not useful. I have also looked at reports by mental health professionals who have described their programs and offered their opinion about effectiveness. Most important, however, are the controlled trials when research participants are randomly assigned to the program in question or to a control group. These controlled trials are the

most convincing ways of learning whether an intervention is effective or not.

Ways of Working with Families

This review will consider several types of assistance to families. They are as follows: family therapy, family consultation, nurse visiting, family education-brief, family psycho-education-longer, and family organizations.

Family Therapy

Family therapy is the oldest professional intervention for families having been developed in the 1960s by Ackerman (1966) and others. In a short time, several versions of family therapy were created, many of which were designed for use with families of people with schizophrenia. There were many uncontrolled studies of effectiveness, and the usual anecdotal accounts, but few controlled studies and these were so flawed that Ken Terkelsen (1983), a family therapist, after reviewing the literature, stated there was no evidence for effectiveness. Perhaps even more important is that families of people with schizophrenia tended not to like family therapy. A key element of family therapy was that it was reasoned that the family must have been a pathological system to have produced a child with a serious mental illness. Therefore, the family as a system was the patient. Relatives did not like this because they knew it was not they but the ill relative who was the patient and who needed treatment. The other principal objection is that family therapy does not provide information. It is not an educational program. As adaptations to include more education are made to family therapy, results appear to have improved (DeGiacomo, Pierri, Rugiu, Buonsante, Vadruccio, & Zavoianni, 1997).

Family Consultation

Family consultation is a particularly attractive choice for a mental health professional in independent practice and who is seeing people with serious mental illness. The basics of this approach were first laid out by Kayla Bernheim (1982) and then refined by Lyman Wynne (1994). Both emphasized that the professional works with the family in a collaborative way. The family's strengths are recognized and the professional is an expert in the area who can bring ideas and information to the family for them to use. Like other consultant relationships it is continued as long as it is going well and discontinued if it is not helpful.

There has not been much research with this form of family assistance. Zastowny and associates (1992) compared a version of Bernheim's counseling with behavioral family management. At a 16-month follow-up assessment, the family counseling patients had a 47% relapse rate compared with 53% for the behavioral family management group. As the sample size was small the differences were not statistically significant.

Nurse Home Visiting

Another study that followed neither Bernheim nor Wynne, but showed some similarities to these methods was carried out by Pai and Kaipur (1982) in rural India. Nurses visited families at home on a regular basis, checked on medications, answered questions from the patient or family, and made suggestions about coping. Families reported less burden than families whose ill relative was kept in a hospital. Patients in the nurse visiting condition were found to be improved clinically and to have better social functioning. This method of having nurses make visits to the homes of people with schizophrenia was done by Pasamanick and associates (1967), with good results, but the decline in use of home visiting nurses in the United States has ended the practice. Community psychiatric nurses are widely used in Northern Ireland.

Family Education-Brief

It appears that the most popular way of helping families in the United States has been what I call family education. In this I have followed Lam (1991), although he did not give a clear rationale for the distinction he drew between family education and family psycho-education. I will say that the latter requires a longer period of time, includes the patient with others in the family, and involves more actual practice in addition to the presentation of information. Both family education and family psycho-education provide information about the illnesses and how families can cope better.

The various family education programs seem to have similar objectives and to present similar material whether they are presented on a single day or in a series of evening meetings. Most family education programs are presented by mental health professionals. My own experience is typical. I suggested to a hospital administrator in Houston that it would be helpful to families to take part in an educational program. She agreed and hired me to organize and present such a program. Sessions were on Saturdays from 9:00 a.m. to 3:00 p.m. I followed the Survival Skills Workshop method described by Anderson, Reiss and Hogarty (1986). Over a period of several years I conducted about 20 such programs with perhaps 400 people involved. There was no formal evaluation, but family members reported finding the sessions helpful.

There have been many evaluations of family education programs (e.g., Abramowitz & Coursey, 1989; MacCarthy, Kuipers, Hurry & Harper, 1989; Posner, Wilson, Kral, Lander & McIlwraith, 1992; Smith & Birchwood, 1987) The results are fairly consistent. Families in the shorter family education programs do learn about serious mental illness, they show a change in attitudes toward the ill family member and they sometimes show improved views about themselves, such as having a greater sense of self-efficacy.

A more recent variation of family education is the NAMI Family to Family program. The unique feature of this program is that it is presented by trained family members who have been especially trained to conduct the sessions. The topics included are shown in Table 1.

Table 1

Family to Family Schedule

Class 1. Introduction. Basic philosophy and goals of family education. Family needs and emotional responses to mental illness.

Class 2. Schizophrenia. Diagnosis and characteristics of thought disorder; questions and answers about getting through the critical periods in mental illness.

Class 3. Bipolar disorder and depression: Characteristic features of mood disorders; schizoaffective disorders; sharing our stories.

Class 4. Causes of schizophrenia: Basics about brain biology, brain research and theory; Genetic research; Environmental theories; Family blaming; Vulnerability in post psychotic periods; Short-term and long-term prognosis.

Class 5. Problem-solving workshop; Defining the problem; Solving the problem; Setting limits.

Class 6. Medication review and side effects. Psychopharmacology of schizophrenia and affective disorders; Compliance and treatment issues.
Class 7. Inside mental illness: Gaining empathy and understanding; Problems in developing a sense of self; Loss of positive identity.
Class 8. Communication skills workshop.
Class 9. Self-Care: Learning about family burden; Sharing in relative groups; Handling negative feelings of anger, guilt, grief; How to balance our lives.
Class 10. Rehabilitation: Issues in psychiatric rehabilitation; principles of rehabilitation and case history; Rehabilitation locus (new models of family support).
Class 11. Advocacy. The power of stigma; Let's gripe about the stigma; Let's gripe about the system; How advocacy works; Let's change the system (practice in advocacy strategies).
Class 12. Review, sharing and evaluation; Certification ceremony; Party.

How effective is the Family-to-Family program? There has only been one study (Dixon, personal communication)and it did not have a control group. In that research it was apparent that families learned about serious mental illness, they felt empowered to deal with the mental health system, and they felt better able to cope with problems presented by the ill family member. Again, without a control group it is impossible to know whether these changes were caused by the program or simply occurred over time. There is another outcome: the membership of NAMI has increased substantial since the Family-to-Family program was begun and many NAMI members at the local as well as national levels attribute the cause to participation in the Family-to-Family program. If this is true, and if the effect generalizes to other nations, then this type of family education may have great importance for struggling family organizations.

Despite this apparent success for the Family-to-Family program, it may be that its sponsor, NAMI, is doing families a serious disservice if they do not go on to urge adoption of the longer, more intensive programs. However, NAMI leaders seem to lack of interest in these programs and have been unwilling to see that there is a real difference in outcomes for patients between shorter and longer family programs. The World Fellowship for Schizophrenia and Allied Disorders has reviewed these differences and has chosen to promote adoption of more effective programs.

Family Psychoeducation

It may be that the main difference between what Lam (1991) has called family psychoeducation and the family education programs is length of time families spend with the program. Nevertheless, there are other important differences. The patient is included as a full participant with other members of the family in these sessions. This is not the case for family education programs. These programs tend to involve problem-solving, not just as an exercise in a single work-shop, but as an on-going part of family life.

There are many versions of family psychoeducation. Goldstein (1978) was first, quickly followed by Leff (1985), Falloon (1987), Hogarty (1991) and Tarrier (1989). McFarlane developed a form that makes use of multiple families (1990, 1995). There have been 39 controlled studies of family psychoeducation. They are one of the most researched forms of psychosocial intervention for schizophrenia.

For purposes of brevity, this review will focus on only one form of family psychoeducation; that of Falloon.

Rationale for Family Psychoeducation

According to Falloon, families have the following problems in dealing with schizophrenia: 1) lack of understanding of the complex nature of schizophrenia and its social impairments, 2) lack of skills to cope effectively with acute and chronic symptoms of schizophrenia, 3) difficulties in expressing feelings, negative and positive, toward the patient, 4) difficulties in reducing tension in the family through effective problem-solving, and 5) a tendency to feel stigmatized and to limit social contacts outside the family circle.

Method

The major elements of Falloon's family psychoeducation program (Falloon, Boyd & McGill, 1984) are shown in Table 2. A program of this type may continue from a few months to several years. The length of time is based on family interests.

Table 2
Principles of Family Psychoeducation (Falloon)

1. Family work integrated into an interdisciplinary team.
2. Engagement--listen to the family; capability of doing home visits when needed.
3. Expectancies of interventions; on-going assessment.
4. Assessment of family strengths, problems; individualize goals.
5. Attention to social and clinical needs of patient and the family.
6. Optimum management of patient's medication.
7. Initial intensive education program for patient and family followed by continuing education targeted at family needs.
8. Promote clear communication and active listening.
9. Train family in problem-solving techniques.
10. Regulation of affective interactions.
11. Address feelings of loss through reduced capability secondary to the illness.

Family Psychoeducation Results

Table 3 shows the results on relapse for the early family psychoeducation programs. Patients in program and control groups received medication, and most patients were adherent. Of the 39 controlled studies of family education the mean effect sizes for relapses for the program groups is .83 and for the control groups it is .20 (Falloon, personal communication. The .83 effect size is regarded by statisticians as being in the high range. In addition, results reported by Falloon and associates (Falloon, McGill,m Boyd & Pederson, 1987; Falloon & Pederson, 1985) showed positive effects that went beyond those for relapse rates. Patients were better adjusted socially and relatives reported being less burdened.

Table 3
Family Psychoeducation Relapse Rate Results

		Follow-Up Period (Months)					
		9-12		24		Longer	
						Group (%	
Relapse)							
Investigator	Year	P	C	P	C	P	C
Goldstein	1981	0	16				
Leff	1982	8	50	20	78		
Falloon	1985	6	44	17	83		
Hogarty	1986	0	41	25	66		
Tarrier	1988	12	53	33	60	67	88
Xiong	1994	12	33	13	44		
McFarlane	1995	8	21	18	32	50	78
Combined Mean		7	38	21	61		

P = Program; C = Control

As may be seen in Table 2, family psychoeducation programs have a powerful effect on relapse rates. Significant group differences have been shown to persist for two years, and one program (Tarrier, Barroughclough, Porceddu & Fitzpatrick, 1994) has demonstrated significant differences at five and eight years follow-ups. It should be noted that the control group for McFarlane's research was a single-family form of the program. It was compared with a multiple-family form, but both received essentially the same program.

Family Organizations

Family organizations such as Zenkaren, the oldest, or NAMI, the largest, or any of the many other family organizations found in most parts of the world provide many benefits to families. Most provide mutual support, education and advocacy. Mutual support sessions help people cope with the strangeness and sadness associated with serious mental illness. Usually, these sessions are facilitated by other family members, but sometimes the group leader is a mental health professional. Nearly all family organizations have regular meetings, often with a person invited to speak on some topic of interest; e.g. the newer atypical anti-psychotic medications, or coping with depression. These speakers typically are expert in some way and bring useful information to the members. Some groups have annual conventions like the one we are at now, and more information is conveyed. Perhaps most important, however, is the person-to-person communication that takes place and in which information of vital personal value is transmitted. I learned of a good residential facility in the community that my son could live in from another NAMI member, not from a mental health professional. He has been there 18 years and has not had a relapse in all that time, whereas before, he had many relapses.

Advocacy is an important, perhaps the most important, part of family organizations. Members work as a group to influence policy and decision-makers at the local, state and national level. In the United States NAMI members can claim advocacy successes at each of these levels, and will agree that there is much more to be done.

Best Practices

The Schizophrenia Patient Outcomes Research Team or PORT reviewed family interventions and recommended that they last at least 9 months (Dixon & Lehman, 1995). However, the first of the family interventions, that of Goldstein and associates (1978) lasted only six weeks and produced positive results. As there was no follow-up it cannot be compared with the longer programs. In addition, the intervention reported by Xiong (1994) was only 4 months long and the results for relapse and symptom reduction were positive. It may be that it was effective because Chinese families have and expect to have primary care for a mentally illfamily member and they applied what they learned with more consistency and intensity.

Which methods are best? There is some evidence that the behavioral family management programs produce best results. However, there are many exceptions. In the large NIMH study conducted at 5 sites, there were no differences in relapse rates between behavioral family management (Falloon-type) and a system-oriented intervention (Hogarty-type). At two years, the results for both were strong (Schooler et al., 1997). The programs were equally long with families receiving the same amount of attention, both included education about mental illness and support from the professional staff.

Reviews of evidence-based treatment by Mari and Streiner (1994) and Baucom, Shoham, Mueser, Daiuto, & Stickle (1998) did not resolve the question of whether one form of family psychoeducation was better than other forms.

Are family programs better than direct interventions with patients? When family programs are compared with standard services consisting of medication and case management, family interventions are usually superior. However, if the patient-intervention is one that provides carefully designed behavioral training on medication usage, the meaning of the illness, problem-solving and coping training, as was the case in a Dutch study (Linszen et al., 1997) results are about the same as for family psychoeducation. However, the Linszen individual program may have been extraordinarily good. Individual treatment was not better in Falloon's study where the control group received supportive psychotherapy, or Hogarty's study where one of the control groups received social skills training.

For Which Families?

For which families and patients are family psychoeducation most useful? This is a difficult question to answer. It is clear that the psychoeducation programs have proven useful for families over a wide range of our planet, but to say that they would be useful for people of all ethnic groups is irresponsible. The range of cultural groups has not been tested. I could not say, for example, whether these programs could be used effectively with people of some of the ethnic groups of my home state of New Mexico. Would they be accepted by Navajo, Taos, Zuni or Apache families? I don't know. I think so, but it is a matter to be tested.

The programs have been effective with patients who were first admissions to treatment, and with others who have been in the mental health system for years. They have worked for women and men, for families high in expressed emotion, that is the tendency to be critical, hostile or over-involved, and families that are low in these behaviors. They have worked for schizophrenia and bipolar disorder, and there is some evidence of their effective use with depression, eating disorders, and substance abuse.

It should be kept in mind that the family consultation model offers great flexibility and so may be better in locations where the mental health system is too small to provide the

team required for family psychoeducation. This may apply in rural areas, or where the mental health system is not highly professionalized.

Can the programs be effective if highly trained professionals are not available for their operation? The answer is no and yes. To provide family psychoeducation a trained staff is needed. Training of staff for the special attitudes or ideologies of this approach, and in the special techniques that are used, is essential and should have high priority. Falloon in England, McFarlane in New York and Michigan, and the several Chinese studies show that staff can be trained to operate in usual work settings and provide quality services.

Is family psychoeducation enough? Hogarty's addition of his Personal Therapy (Hogarty, et al., 1997) to family psychoeducation was superior to the family intervention alone. The same was true for Buchremer's (1997) study in which adding cognitive therapy to the family intervention resulted in a better outcome. Furthermore, the best short-term outcome obtained in research studies was Hogarty's family psychoeducation plus social skills training group.

Comparative Costs

What does each method cost? Obviously, membership in a family organization is the least expensive, but there are some costs, such as membership fees and convention costs, but these tend to be minimal.

Family education sessions conducted over a period of 6 to 12 hours by mental health professionals are quite inexpensive. Nevertheless, the family sessions I conducted at St. Joseph Hospital in Houston were stopped when managed care administrators took over control of the hospital. They said the sessions did not generate revenue for the hospital.

The Family-to-Family program is relatively inexpensive, but there are start-up costs, including payments to trainers-of-trainers. Most of these costs have been covered by state mental health programs or private foundations.

Extensive family psychoeducation has been demonstrated to be cost effective, primarily because it leads to a decrease in use of expensive hospital facilities. It should, therefore, be attractive to administrators, but in the United States it is not attractive because insurance companies are unwilling or reluctant to pay for participation in such programs, and they will certainly not pay for long-lasting programs. The obsession with corporate profit even at the expense of human welfare is once again apparent.

There are other barriers to implementation of the programs. Chief among these for professionals is the continuing influence of psychodynamic theories. I cannot emphasize enough how insidious and destructive this is for families. As an example, I was told by one psychiatrist that I could not insist on seeing my son in a state hospital because I and my wife had caused his illness. This refusal came directly from a psychodynamic orientation. There are other barriers to be overcome if programs are to be implemented. A partial list appears in Table 4.

Table 4
Barriers to Effective Treatment and Rehabilitation

1. Stigma
2. Complexity of the illnesses
3. Inappropriate application of theory
   Psychodynamic
   Family systems
4. Belief that mental illnesses are caused by brain dysfunction and that psychosocial methods do not apply.
5. Belief that brain dysfunction can only be treated with medication.
6. Belief that mental illness is a myth.
7. Belief that medication is bad for all.
8. Belief that people with mental illnesses cannot be helped.
9. Health care systems that place profits ahead of effective care for patients.

Some Generalizations About Family Programs

- The various family methods are not the same and do not have the same outcomes, costs are not the same, and amount of family time required is not the same. What does each do? It is possible to make a few generalizations.
- If information is provided there tend to be positive outcomes for relatives.
- More sessions are better than few sessions.
- Include the patient in sessions if the goal is to reduce relapse.
- Maintain medication at an optimal level.
- Programs that individualize are better than those that do not
- An environment that is clear, simple and free of excess emotions is unlikely to cause relapse (Lam, 1991).
- Family psychoeducation is not always better than appropriate individual therapy.

Choices To Be Made

Family members, family organization administrators, and mental health professionals have choices to make in selecting ways of helping families. These choices can be made on the basis of what their goals for families are and what resources are available. If they want to help relatives of people with serious mental illness, to relieve their burden and help them cope better, but have only limited resources then family education or family consultation may be the reasonable choice. If, however, the goal is symptom alleviation and relapse reduction, in addition to support for relatives, and if necessary resources can be found, then family psychoeducation or possibly nurse home visiting should be the choice. If the goal is recovery and resources are available, the question is still open. It may be that family psychoeducation carried out for a long time will suffice, or it may be that even more powerful interventions, yet to be developed, are necessary.

Conclusion

As the father of a son who has struggled with schizophrenia for nearly thirty years, and recalling the terrible first ten years, I can say that I wish any of the family programs I have described had been available to our family. We would have reached out for information, training, advice, consultation, and education. A one-day session would have been welcome, and I think we would have benefited, but a two or three-year program would have been better. The state of science for family interventions is such that we know they are effective. It is time to see that every family has the opportunity to take part in these programs. Not all families will be able to take part, some will not want to, and for them alternatives should be available, but all should have the opportunity to participate if this is this is what they want.

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OPTIMAL USE OF ANTIPSYCHOTIC MEDICATIONS

Dr. Abe Dorevitch

Antipsychotic drugs have greatly reduced the devastating symptoms of schizophrenia. Unfortunately, not all patients respond. The older or conventional antipsychotic drugs often produce troublesome neurological side effects. The newer antipsychotics appear to be less problematic while at the same time offer hope for treatment-resistant patients. This presentation highlights major aspects regarding more optimal use of antipsychotic drugs.

Some notes on the presentation:

What one can expect from taking anti-psychotic medications over time

- Sedation
- Delusions and hallucinations and bizarre behaviour usually controlled
- Judgement and insight of ill person may not be improved
- Side effects.

What influences side effects

- Dose
- Route of administration
- Length of time medication is given – not all side effects appear right away
- Age of patient
- Other medicine patient its taking
- Elimination of medication (organs – liver, etc.)

Older medications tend to have more neurological side effects (Parkinsonism – tremor). The vast majority are reversible. Akathesia-psycho motog agitation is not deterioration in the condition but a side effect. This doesn't always manifest itself in movement – sometimes there is an inner restlessness. Tardive diskinesia – involuntary movement in mouth or jaw. Patient with insight usually doesn't want to be seen if he has this. There has been no cure – periodic assessment must be made by giving the minimum effective dose.
Key to successful treatment – keep regimen simple – minimum number of drugs usually to be taken at night. Patients who have trouble taking medication can be given longer duration medications (by injection), but the newer medications are not yet available in this form.
New Atypical medications: 1990: Clozapine (Clozaril, Leponex) has a lower incidence of neurological side effects. Works on other chemicals in the brain not only dopamine. Appears to have a more beneficial effect on negative and positive symptoms.
Every effective drug has side effects such as sedation, dry mouth, decrease in blood pressure, dizziness, excess saliva. Most serious is its detrimental effect on white blood cells. Other newer medications may have side effect of weight gain. To truly know a drug one must wait 5-10-20 years

Dr. Abe Dorevitch, Senior Clinical Lecturer in Clinical Pharmacy, Faculty of Medicine, Hadassah Hebrew University, Jerusalem.

TREATMENT OF PSYCHOTIC ILLNESSES,CURRENT CHALLENGES

Prof. Michael Davidson M.D.

Obviously the most major challenge is to elucidate the pathophysiology and etiology leading to psychotic manifestations. Based on the presumed heterogeneity of psychotic manifestations it is not expected that we are close to a scientific "breakthrough" in this area. It is more likely that during the next decade we will elucidate risk factors, prodromal factors and contributory factors, (genetic and environmental) which under certain constellations lead to manifestation of psychosis. Some of these factors such as peri-natal complications, lower intelligence, poor social adjustment

are already known but their contribution is not sufficient to explain alone the manifestation of psychosis. The second challenge is to determine from among the available interventions, pharmacological and non-pharmacological which are the most appropriate for whom. The availability of the novel neuroleptics have made a major impact in our abilities to improve treatment and it is a major challenge to educate physicians in their use and to remove any barriers from making them available to all patients who can benefit from them. Finally since very early treatment might improve the long term outcome of psychotic illnesses it is also essential to determine how early is early enough and when it is too early. It is essential to balance the attempt to accomplish secondary prevention in targeted individuals at risk of becoming ill against the risk of unnecessarily exposing individual to the stigma of illness and to the potential adverse effects.

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WHY RUSSIAN PSYCHIATRY NEEDS CONSUMERS' ORGANIZATIONS

Prof. Vassily Yastrebov

The up to date economic situation in the country demands that we look for the additional forms of medical-social support to the mentally ill. Organizing public, non-professional movements in psychiatry can become one of the effective forms. It is important to answer the question: "Why?"

Before an attempt to answer this question the general situation in Russian Psychiatry should be characterized briefly. Domestic psychiatric service disposes of the powerful material-technical and manpower resources: there are 16 596 psychiatrists, 164 outpatient clinics, 278 psychiatric hospitals with 183 474 beds in them. And a substantial relative weight of in-patient forms of care, more expensive and less effective from the point of view of opportunities of social adaptation of patients, also attracts special attention.

Meanwhile, as our special research has demonstrated, approximately one third of the population of the country is in need of different forms of psychiatric care, the main forms of which should be rendered outside the borders of in-patient hospitals.

One of the most serious problems of Russian psychiatry of the latest decade is the problem of its financing. In the beginning of the latest decade the volume of financing was substantially lower in comparison with the developed countries, and by the end of this decade this difference had already constituted several orders: for instance, expenditure for Public Health per capita in 1998 was: in US - $ 2,700 and in Russia - $ 9 only. A sharp decrease of assortment of drugs, quality if care, payments to personnel were the consequences of this financial provision. So, Russian psychiatrists came across the whole range of problems demanding a complex solution. A common program on improvement of care was necessary, and this program was adopted on the federal level, but it will need time for its realization.

In this critical situation we had to pay attention to the development of public forms of support and defense of the mentally ill and their family members: a public movement of psychiatric care in which the consumer is an important part. Thus there were several reasons which lead to forming psychiatric care consumers' movements in Russia:

1) a sharp decrease in the volume of care, which had been formerly rendered by state institutions; - necessitating the development of additional, alternative forms of care, which should render the types of care being ignored by the state institutions;
2) democratic changes in the end of eighties: adoption of psychiatric law; presence of positive experience abroad; - understanding of importance of this activity; consumers' desire to be valuable members of society; supporting of this activity by the foreign volunteers.

During this period the relatives' anxiety about the further destiny of their mentally ill patients has substantially increased. According to our investigation, the greatest concern of the relatives for the future of their patients were: isolation of the families of mentally ill; unsatisfactory results of treatment of mental diseases and living conditions in mental hospitals; insufficient volume of social support to the mentally ill; unsatisfactory state of modern rehabilitation system; insufficient attention of the specialists and society towards the needs of the mentally ill; a general anxiety about the future of their mentally ill. This anxiety becomes more and more severe because of the serious economic situation in Russia.

These circumstances made relatives take an active part in public work, especially taking into consideration the fact that society itself was not interested in the problems of mentally ill. Today such organizations successfully work in 20 regions of our country. There are more than 20 such organizations in Moscow alone. As it is known an antipsychiatric campaign has resulted in a negative public opinion concerning the mentally ill. In connection with this one of the most serious problems which should be solved by the consumers of psychiatric care themselves is the problem of stigmatization of the mentally ill, low tolerance of the population to them.

It should be noted that professional public associations also participate in the solution of these and many other social problems. They work on the whole range of programs, aimed at solution of actual social and legal problems of care consumers. For example, the non-governmental association "Public Initiative in Psychiatry" has the following programs: - Educational program for relatives; Legal and social support of the elderly; - Self-group Support program; - Psychiatric education of social workers; - Newsletter "Katharine" for the consumers. (*Please, visit web- page: www.pubinitpsy.da.ru)*

Thus, today in the conditions of social-economic crisis public movement of psychiatric care consumers becomes an extremely important form of support; assistance of professionals and the whole society plays an important role in the further development of this movement.

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NOT HERE TO HOLD

Jill Sadowsky

I'm a wife, mother, grandmother and English teacher and do what I can to give support to parents whose children are suffering from mental illness no matter to which organization they belong. I have been there. And I know how impossibly difficult life becomes when mental illness strikes.

A man was found lifeless on a sidewalk – a psychotic psychiatric patient who'd leapt to his death. People shrugged sadly but this is what his mourning father said in his eulogy**:**

"I'm proud of you, my son. You battled your demons for sixteen years. I hope that you have found the peace of mind you've been searching for.

"Rest, my son." The date was 18th January 1996.

That father is my husband. We shared the responsibility for caring for our son, David. In many ways my husband coped better than I did. I call on all fathers to follow his example. My sense of humor had dried up but he used humor to defuse potentially explosive situations. Of these there were plenty as David turned to violence as an outlet for his frustration. Our different approaches led to conflict. We argued and fought, fought and argued. But his love and commitment were unconditional. We survived crisis after crisis. In spite of all we've been through, we have just celebrated our 40th wedding anniversary. My husband is a rarity.

I think of all the people who attended David's funeral. They knew how to handle death but not paranoid schizophrenia. They could come to share our grief at David's death, but most could not give us support and love while he was alive. David was almost thirty-four years old then, kind, generous and sensitive with an indomitable spirit and sense of humor. If only the neurotransmitters in his brain hadn't gone berserk and doomed him to the agonies of incurable madness. Yes, schizophrenia made him crazy.

At least we had eighteen good years with David. He came to us full of promise, gurgled and flailed his strong arms and legs, grew into a happy child, a sportsman then a surfer. His schooldays were carefree and he received his school-leaving certificate. Our family was a happy one, until David's attempted suicide in the army.

I imagine how beautiful the world would be if we could use the expression 'mental wellness' instead of mental illness. I hate to hear someone described as a 'schizophrenic.' It is as if the person has disappeared and only the disease remains. We don't talk of a cancer but of a person suffering from cancer. Why not a person suffering from schizophrenia? This would not allow us to forget the human being, however sorely afflicted he might be.

I want to sign my name to the book I have written about my experiences with schizophrenia but my daughters asked me to write under a fictitious name. They can't handle exposing such personal details to the public. After the Hebrew edition was published by Czerikower, I received hundreds of telephone calls – some people said I could have been writing their story. Many of them wonder why they don't get the respect they deserve from professionals. Others were pleased to hear about the existence of ENOSH, the Israeli Society for Mental Health. ENOSH does not have a sponsor. All the other organizations here have sponsors. I wonder why. Yes, this is an appeal. We need someone to sponsor us.

I still receive calls and letters thanking me for helping, thanking me for giving them my time and for listening. I will always listen. I repeat. I have been to hell and back and know what it's like.

I have changed the name of my book in English from the Hebrew name "Weep for Them" to "Not Here To Hold". My motives for writing this book were quite complex. In the beginning it was simply my way of searching for a deeper insight into what I was experiencing. Then my horizons expanded. I wanted to share my experience with other parents travelling the same road and to convey the message that they are not alone. With love and courage, one can survive adversity, even paranoid schizophrenia. I also wanted to explain the illness to a wider public and to breach the barricades that people have built so that they can hide from what is seen as different and threatening. And finally, I wanted to reach the professionals, to appeal to them to listen more carefully to the voices of those they are trying – genuinely and devotedly – to help. Parents need to know that they are not alone.

Hope brings us to Jerusalem today. When David was ill I had trouble finding a professional who would really listen to me. Today, those same psychiatrists and psychologists may even be sitting next to the many consumers in this hall. If so, there is hope.

I read a newspaper report about a young man suffering from Down's syndrome who was chosen to be one of the thirteen people to light a candle at Israel's Independence Day Celebrations. A great honor. It is indeed heartwarming that someone with a handicap was chosen and corroborates the fact that change is in the air.

I was feeling quite despondent about the issue of stigma, when out of the blue, Mr. Amos Danieli from the Ministry of Health called to ask whether I minded if he ordered 5,000 copies of the Hebrew version of my book to distribute to psychiatric professionals. I smiled and quipped: "What would you say if I asked you that question?" Later, he enlarged the order to 6,200. At last I feel as though I am beginning to make a small difference. Change in the air?

Whenever I am asked to speak at a psychiatric hospital I end by saying: 'If I have managed to change the attitude of one single person attending this meeting, I will feel as though I have done something useful.'

David's doctors agreed with us that his illness was probably triggered off in the army. He'd entered the military with a 97 profile - the highest one can score. He was chosen to do an officer's course that meant he would have to spend at least an extra year in the armed forces, which he did not want to do. He told us that he was prepared to do his duty and serve the compulsory three years but that was all. He was forced to do the course and failed due to his reluctance. His commanding officer never forgave him and humiliated him at every turn. David was among the many recruits who broke down in the army. The medical officers should have picked it up and sent him to hospital. This happened to David a long time ago and I do hope that there has been a change in attitude since then.

We know many hospitals here intimately. When David was in hospital, I know that some people pointed a finger at me saying: "She's the one with the crazy son. Maybe the family is crazy." But do they ever say "Her daughters are healthy and successful because they come from a healthy family?" I wonder. After David committed suicide a finger was pointed at us again and we know that we will always be talked about.

Now they say; 'She's the one whose son committed suicide.' Our family has had to cope with all that too.

At one stage, David lived alone and some people asked why we'd allowed him to live by himself. My husband only agreed to let David live alone after two of his doctors had told us that it might be better for him. Some people felt that we could have prevented David from taking his life if he'd been living with us – but, nobody can be watched 24 hours a day.

For sixteen years we tried everything. Unfortunately David's paranoia didn't allow him to let us in, to protect him, to accept our help, believe we wanted only the best for him. And his paranoia didn't allow him to believe that a rehab center, if not his home, might help. So I ask you – what were our options? What options can you offer others who are suffering right now? After all, even in psychiatric hospitals and guarded jails, people kill themselves.

In the beginning we had no idea that schizophrenia could become chronic. We had no realistic expectations as we'd had no previous experience with mental illness. When we were called to attend a meeting with other parents at the hospital during David's first time there, we were still in shock. It was too soon. At that stage, I needed somebody to put an arm around my shoulders, to show some understanding, to behave to me the way they would to the mother of a cancer patient for example. No one ever did.

I wonder whether professionals are aware of how little families know about mental illness. We need detailed explanations. Don't take it for granted that we know anything! We don't. We read about cancer and diabetes, AIDS and pneumonia. We see posters on these subjects as well as those reminding us to have regular mammograms and bone density check ups. We are reminded to inject our kids against the new strain of jaundice, told to take care of our teeth as we only have one set – but schizophrenia? **…** We neither see nor read about it anywhere unless a mentally ill person becomes violent! Maybe general practitioners and psychiatrists could hang posters listing the warning signs of the onset of schizophrenia in their clinics. This is done in campaigns to stop smoking, drugs, and alcohol abuse.

Parents should not allow newspaper articles or commercials on television to be offensive to psychiatric patients. On a visit to America I once heard a weatherman describe the weather as schizophrenic. Most suspected murderers are described as psychotic, crazy, demented. Comedians do routines about 'hearing voices.' Trust me, to the tortured soul hearing those voices, there is nothing funny about it.

I would like to help dispel some of the myths surrounding schizophrenia by discussing it openly. Public education programs are an important part of anti-stigma activities by advocacy organizations. I would like to be part of a campaign here in Israel to help remove this terrible stigma. How about incorporating information on handicapped and mentally ill people (on how to behave naturally to them) in our school curriculum?

Our families suffer enough without that additional pressure. How about a "mental health awareness week," like the one the media is running right now to get people to fasten their seat belts on the back seats? Another idea is to publish a booklet for school children, distribute leaflets on the subjects and show a movie – even to children in kindergarten. Maybe then I'll be more able to help my daughters overcome their, shall we say … reticence?

Does a caregiver know what it's like to live with a mentally ill person day after day after day? Home was no longer a place I wanted to spend time in. Do you know that the mother of a mentally ill patient is also a cleaner, cook, baker, laundress and psychologist without any benefit of training – handling bizarre behavior she didn't know existed beforehand? It was my worst nightmare coming true for me – a holocaust. Each day I expected to find that my hair had turned white

I needed realistic expectations, to know how to set limits - how to help our aggressive son regain control. I needed help and guidance when David had thoughts of suicide. I needed to know how to encourage him build social contacts, how to organize our daughters' and our social lives. I needed to learn how to handle stress, how to deflect difficult situations. Most of all, I needed to be approached with respect. Some mothers appeared to me to be superhuman. When I met some professionals, I asked: "Do you have children?" Because, but for the grace of God, this patient could be anybody's child.

I know that a psychiatrist has to respect his patients' privacy but where chronic paranoid schizophrenia is concerned, isn't it possible to bend the rules just a teeny bit? Surely even psychiatrists break traffic regulations or tell a white lie … sometimes? How can a psychiatrist react to what a paranoid schizophrenia patient says without hearing the parents' version? Do you have any idea what they say about you?

Parents' voices need to be heard. We need to bond together to form one strong organization. ENOSH support groups helped my husband and I a great deal. First, we attended one in Hebrew then - a friend and I started one in English on a voluntary basis under the auspices of ENOSH. When we invited some siblings to visit our support group to tell us about their experiences of living with a mentally ill brother or sister, I was sorry that every professional I'd ever met, was not present. These teenagers spoke about life with a mentally ill sibling and we cried with them. They also told us NOT to pressure them to seek help. "When we feel the need for help, we'll get it. Leave us alone. We have seen how professionals have helped our brother/sister."

How come in the year 2000 lecturers and some professionals too, still tell their students that parents cause schizophrenia? Dr. E. Fuller Torrey, a well-known expert on the subject of schizophrenia says we can't do that, no matter how hard we try. How come there are still psychiatrists and psychologists out there who still blame parents for causing schizophrenia in our children?

It's important for doctors to understand how badly families are affected. Schizophrenia permeates every facet of our every day

lives. We love our children even when they are mentally ill and suffer their torment.

Forgive the repetition but, when a consumer like me, a mother and English teacher, is asked to speak at a professional gathering of this kind, well, there is change in the air.

The concept of empowerment is a way of revering the fundamental value of every person. My son, David was not an object to be acted on. I wanted to see professionals share their knowledge with us and with him. I wanted them to move and be moved by his suffering.

David once said: "Doctors are so busy doing things to me that they forget to be with me. " Then he said: " I don't take medication because I'm sick. I'm sick because I take medication and I feel like a pincushion. On clozapine I had to have constant blood tests to check whether the medication that was supposed to help me, would kill me. I've taken so many pills that I feel I have chemicals flowing through my veins and arteries instead of blood."

During periods of extreme frustration, David's words came back to haunt me. He often said something that I was to dread in the years to come; "I'll dance on your graves." David was a psychiatric survivor until the day he broke.

We live in a society that is as yet unwilling to fully acknowledge that persons with mental illness are full citizens with all the attendant benefits. The law cannot grant that which society is unwilling to provide. Homeless mentally ill people are in many ways like human graffiti – a public display of all that's wrong with our society.

Our son, David wanted to get better.

He fought to get better.

He wanted work.

He wanted to have a girlfriend, someone to love and most of all – he wanted his peace of mind restored to him.

My request to all psychiatrists is - Please, don't ever tell a patient of yours that he/she is suffering from a severe mental illness and that there is nothing you can do for him/her.

There most definitely is. You can care for him, you can instruct him, and you can listen to him, really listen to him**.**

He is having an even harder time than you will ever know. Give him hope. Nobody can live without hope.

This is a poem written by David wrote during one of his many hospitalizations.

"Autumn is drawing near

Soon the leaves will fall

Autumn, I am waiting

because the summer is lost.

There is no sea, no sun.

Here I am waiting for the leaves

to fall from the trees

to symbolize winter's arrival.

Spring, summer, autumn, winter

I'm stuck in the same place.

My doctors refuse to help me

But leave me stuck in the same place."

"Death waits at the door

Waits around the corner

And I know it is near

Yet … far away.

I don't want to die

But THEY don't let me live.

What shall I do?

What shall I do?

That is the question.

There is no answer.

Shall I become a plant

Like a tree in the field?

I don't want that.

What shall I do? What shall I do?"

Jill Sadowsky is a wife and mother whose book "Not Here to Hold" has sold several thousand copies in the Hebrew version. She is at present living in Israel and working on the English edition.

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HELPING FAMILIES TO COPE WITH SCHIZOPHRENIA

Prof. Julian Leff

Professor Leff gave his talk extemporaneously and we therefore do not have any text to refer to. Following is the abstract he provided prior to the conference.

The evidence for the efficacy of family interventions for schizophrenia will be reviewed and the components of successful interventions explained. One or two brief vignettes of families caring for a person suffering from schizophrenia will be presented by participants. These will be used to illustrate the process of identifying families' strengths. The nature of the relationships and power structure in the presented families will be identified. Strategies for positive re-framing of criticism will be explored. The ground rules for improving communication will be presented and ways of putting them into practice. The influence of the seating arrangements will be illustrated through role play. The value of co-therapy will be emphasized and methods of working together investigated. The importance of helping family members come to terms with loss and move on to develop realistic expectations will be explained. The workshop will consist of a mixture of didactic presentations and role play by participants. The techniques of ensuring the safety of role play will be shown.

Professor Julian Leff, MRC Social and Community Psychiatry Unit, London, UK. Email: spjujpl@iop.kcl.ac.uk

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WORKING WITH FAMILIES AND FAMILY ORGANIZATIONS: THE NEED TO WEAR TWO HATS *Dr. Radha Shankar*

Working with families of people with major mental illness and working with family organizations in India is a challenging experience for mental health professionals. The remarkable diversity of caregivers in this vast country, the acute shortage of trained personnel and various socio-cultural factors which mediate family professional interactions in clinical settings suggest that professionals need to be both flexible and practical, but importantly acknowledge the primacy of families as the primary providers of care. Working with family organizations requires professionals to take on non-traditional roles which are primarily facilitatory, supportive and non hierarchical. This presentation discusses the role of psychiatrists in these distinctive settings.

Following is the slide presentation:

PRINCIPLES OF FAMILY WORK (WFSAD)
PRINCIPLE N0 15:TO PROVIDE FOLLOW UP CONTACTS FOR FUTURE ACCESS TO SUPPORT IF WORK WITH FAMILY CEASES

IN THE INDIAN CONTEXT,
" WORK WITH FAMILIES "IS ONGOING

WHAT ARE THE ISSUES INVOLVED ?

GOALS OF THE WFSAD STRATEGY
GOAL NO.1 : TO ACHIEVE CONSENSUS ON WHAT CONSTITUTES FAMILY WORK?

IS THERE A NEED TO EXAMINE THIS STATEMENT IN THE INDIAN CONTEXT?

WHY DO WE HAVE ONGOING INTERACTION WITH FAMILIES?

- LIMITED MENTAL HEALTH INFRASTRUCTURE
- NEGLIGIBLE NUMBER OF AFTERCARE OR REHABILITATION FACILITIES
- EXTREME SHORTAGE OF PROFESSIONALS (3,500 PSYCHIATRISTS AND 3000 ALLIED PROFESSIONALS)

- NO DISABILITY BENEFITS
- NO Y0 YO OR PENDULUM SWINGS: FAMILIES HAVE ALWAYS BEEN INVOLVED
- NO CONFIDENTIALITY LAWS WHICH PREVENT FAMILY INVOLVEMENT
- FAMILIES HAVE REMAINED PRIMARY CAREGIVERS

WHAT IS THE NATURE OF FAMILY PROFESSIONAL INTERACTION?

A CRITICAL APPRAISAL

- MOST LARGE TREATMENT CENTRES OFFER ONLY MINIMUM INPUTS
- STUDIES HAVE DOCUMENTED INCREASING BURDEN OF CARE
- LACK OF ALTERNATIVES SUGGEST THAT FAMILIES MUST REMAIN PRIMARY CAREGIVERS

POSITIVE DEVELOPMENTS

- A FEW TEACHING HOSPITALS OFFER LIMITED INTENSIVE INPUTS.
- GROWING RECOGNITION OF THE NEED TO DEVELOP APPROPRIATE PARADIGMS FOR FAMILY WORK
- THE TASK IS CHALLENGING
  SEVERAL ISSUES NEED TO BE CLARIFIED

1. **IS THERE A "TYPICAL INDIAN FAMILY"?**

- DIVERSITY IN EDUCATION, SOCIAL CLASS AND RELIGIOUS AFFILIATIONS
- DIVERSITY IN SETTINGS WHERE PROFESSIONAL FAMILY INTERFACE TAKES PLACE
- DIVERSITY IN STAGES OF THE ILLNESS WHEREIN HELP IS SOUGHT

1. **WHAT THEN CONSTITUTES "THE FAMILY"?**

- 80 % OF FAMILIES IN URBAN AREAS ARE NUCLEAR
- KINSHIP OBLIGATIONS ARE CHANGING
- STIGMA STUDIES SUGGESTED THAT "FAMILIES" THEMSELVES STIGMATIZE

2. **CAN FAMILIES PROVIDE ENDURING, UNQUALIFIED SUPPORT**?

1990: REPORT BY DR LEFF
ONLY 6 OUT OF 78 PATIENTS MOVED AWAY FROM FAMILIES

VERSUS

ICMR COMMUNITY SURVEY REVEALED THAT 28%OF PATIENTS WERE UNTREATED AND SEVERELY DISABLED

1996 : TEN YEAR FOLLOW UP

ONE OUT OF 76 PATIENT LEFT THE FAMILY HOME.

VERSUS

THE "BANYAN " REPORT: 212 MENTALLY ILL WOMEN PICKED UP FROM THE STREETS: 25% WERE ABANDONED BY THEIR FAMILY

1998: CROSS CULTURAL COMPARISONS SUGGEST THAT PATIENTS IN INDIA LIVE WITH FAMILY. MORE ARE EMPLOYED AND MARRIED.

4 DO ALL FAMILIES HAVE SIMILAR BELIEFS AND NEEDS?

- NOT ALL FAMILIES SUBSCRIBE TO A MEDICAL MODEL OF CAUSATION
- DIFFERENCES IN FAMILY EXPECTATIONS FROM THEIR ILL RELATIVE
- DIFFERENCES IN FAMILY EXPECTATIONS FROM MENTAL HEALTH SERVICES
- CURE VERSUS CARE PRIORITY

PROFESSIONALS HAVE TO UNDERSTAND THE DIVERSITY BUT WORK TOWARDS EQUITY

KEY ELEMENTS OF FAMILY WORK MUST INCLUDE

1. RESPECT FOR THE CONTRIBUTION OF ALL FAMILIES

2. NEEDS BASED INFORMATION TO BE GIVEN TO ALL FAMILIES

3. PROACTIVE SUPPORT FOR HIGH RISK AND VULNERABLE FAMILIES

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TEN YEARS OF "PSYCHOSIS SEMINARS" IN GERMANY

Ursula Brand

I want to talk about the opportunity for professionals, patients, family members and friends to discuss and exchange their knowledge and personal experiences.

History of the movement

It might be said that a realisation led to a concept and this gave birth to the movement!

It was the realisation ***(mostly by the patients)*** that psychiatry can only continue to develop if it takes into account the subjective experiences of all those involved in the process of a psychosis. One precondition is to overcome the existing barrier to communication between the people suffering from psychosis, who may feel they have no voice**,** and their relatives, friends and psychiatric staff. Conflicts of interest should be acknowledged and never denied.
"To argue you also need a common language."
(in Germany patients call themselves: psychiatry experienced; in short I will call them PEPs (Psychiatry experienced patients).
A patient who has recovered or is well enough, for example, to be able to lead a discussion I will refer to as a professional PEP.
Psychosis seminars should be conducted with mutual respect leading to authority free discourse during the sessions.

In 1989 a teaching event at the Psychiatric Hospital, Eppendorf University in Hamburg set the ball rolling. There was a meeting of the three groups: PEPs, relatives and professionals. The world congress for social psychiatry 1994 in Hamburg was clearly influenced by the previous seminars. At this congress the PEP, Dorothea Buck, the initiator of the first seminar in Hamburg, impressively (***I was there)*** described her "self-healing process".

There are now more than 100 of these forums in Germany and the neighbouring countries Austria and Switzerland.

Purpose of the seminar:
The aims of the seminars are described in detail in the book "An aid to psychosis seminars - aids for dialogues" whereas both the bibliography and the examples I have chosen are incomplete. Some examples I've used are of prime importance and occur routinely when a tripartite dialogue takes place. Others used can be described as the "long-term goals of an emancipation movement" and some are more concerned with the inter -relationships between the three groups, while others have more emphasis on the content of discussion which is negotiated.
I was surprised by the expression "negotiation" Some are concerned with psychiatry in practice, others as a science, some are obvious, some even controversial.

Seminar conditions.

1) Advertise the event e.g. in the local press, university lecture timetable and adult education centre, etc. ***In my opinion this is then no longer an "intimate dialogue" but a public discourse and who is up to that?*** It is necessary to invite all three groups as this is the best way to ensure the tripartite character of the event.

2) Normal seminar rooms, rooms in adult education centres, libraries or churches should be used. ***We always use a very nice room in a day centre for senior citizens.***

3) Some psychosis seminars start with a discussion of topics to test participants attitudes e.g. What is meant by a psychosis? What do you need in a psychosis?

4) The length of time a group runs is varied, it can meet weekly or monthly, between 8-20 times. ***For our last seminar we planned 8 meetings.*** A meeting usually lasts 2 hours with a break which is very important for informal discussions between the participants, and should be adhered to.

5) Voluntary means that selective participation on a certain topic is possible. Prospective seminar participants should also be able to attend a "trial meeting". ***Such freedom has always been possible in our seminars, it becomes more difficult when the participant has to pay a fee for the whole course.***

6) It should be possible to take part anonymously (whether you are a PEP, a family member or a professional). Each participant should be left to make his/her own contribution.

7) If the groups are too small this can lead to a direct obligation towards intimacy. Too large a group can cause participants to be too reserved. ***In Hamburg there have been seminars with up to 100 participants, in Konstanz, my little home town, we are a lot more intimate without obligation with a maximum of 30 participants.***

Structure

1. The tension of a seminar comes from the participation of the three groups. It is assumed PEP's are often more convinced by the consternation of carers who are strangers to them and vice versa. in that caregivers are in a better position to listen to PEPs who are strangers to them***.***
   I am very much uncertain as to whether this observation is appropriate.
   Professionals can perceive objectively, within the seminar format, an aspect of psychosis which they might otherwise miss.

2. Trainees and students are usually curious and willing to ask questions objectively. They have not internalised the attitude of many professionals. **The reference to *trainees and students makes me wonder, if I get the idea, whether the 3 groups have suddenly expanded to 4?***

3. PEP's and relatives make a large contribution to training during the seminar. Nowhere else will trainees learn so authentically about the subjective experiences of PEPs and the relevance of all efforts to help.

   In 1994 the "psychosis seminar" in Hamburg received the "Fischer-Apelt-Prize" of the University for outstanding training discussion***s.*** Because some seminars turned into training events.

4. ***The assumption of an increase in the number of groups is not unfounded, as lay helpers and other interested persons are described by Bock and co-authors as a possible 4th group.***
   It has been suggested that seminars be open to the public, but with care. This has been regarded as an opportunity to positively influence the image the public has of psychiatric illness and could counteract the stigma associated with mental health problems.

How do they envisage this working ? Is the public to see and hear only less ill people, or as I call them professional PEPs, and how they can heal themselves and view their psychosis as a positive experience and do not consider it to be a disease. We want mentally ill patients to be treated with the same respect as somatically ill patients!

However, this is unlikely to happen if the public are only aware of professional PEPs and not patients like my daughter who are plagued by fear, and unable to attend meetings, and express their views, because they are too ill and housebound.

Moderation.

1. Most seminars have a single moderator, however there have also been moderator groups whereby representatives were included from each of the three groups.

2. The topics should be formulated by the moderator such that the three groups feel that their views are being considered. Emphasis should be placed on direct questions and comments. The groups should all be equally involved. ***From my experience one of the most difficult tasks is when one group tries to classify the other.*** The moderator should then identify the conflict.
   It is the entire seminar's task to solve the conflict.
   This is, in my opinion, no longer possible if there are more than 30 participants.
3. A major problem will arise when one participant is monopolising the discussion. This can often be better solved in a group discussion rather than in the seminar proper. An authoritarian moderator is definitely not desired in this situation.

Contents

1. **There are two main topics**.
   a) How can a psychosis be understood comprehensively and not simply medically?
   b) What do people need in a psychosis and what do families and professionals need, to be able to have an open and sincere meeting and discussion?
   For me this question involves many prejudices, as if we didn't meet sincerely beforehand.

2. Topics are often determined at the start but also frequently at the end of the meeting. Some seminars stick with one topic until it is finished, others circulate according to an agreed plan.

3. Topics apply to all three groups, for example - on the topic *fear*, it is not only the PEPs who are being addressed. On the topic *guilt* it is not only the relatives.
   It is a shame that the topic of "guilt" is still on the agenda. With respect to the topic "power" not only the psychiatrist but also the families are being addressed.

4. **Attention must be paid to the subjective experience of PEP's and families. The psychiatric staff too should contribute with their knowledge and feelings. Contributions should be made calmly without force.**

5. ***Personally I have great problems with this aspect.*** If it is said that a psychosis is exclusively a symptom of a disease, it is thus disengaged from general life experience and the split, allegedly caused by the disease, is made or widened.
   These seminars provide a space for holistically approaching the psychosis patients and asking them

about the meaning of their psychosis in a relaxed manner. A psychosis may appear as the last resort for peculiarities, a conduit for a feeling of fear, or a way out of an irreconcilable conflict.

6. There should be room for different opinions, including those on the sensitive topic of neuroleptic drugs. The idea is to get to know different viewpoints and to develop a mutual language, i.e. a discursive culture that is able to deal with conflicts between different attitudes.

Personal comments of family members:
A Father: "If only my son were here". Most relatives represent an army of the speechless who are never able to visit a seminar.
A Mother: The PEP's present often appear so normal, so clever and articulate that it's difficult to imagine they have been patients.
A Mother: after an information evening on psychosis seminars in which Mrs. Buck represented the professional sufferers (it is 40 years since her last psychosis): "She sat behind a pile of books, singing the praises of psychosis:
how reviving, how inspiring it was, so much so that you were almost ashamed if you hadn't had it. It was good that the PEP's actively recounted and discussed.
It must be possible to get PEP's a forum in clinics and out-patient institutions where they can talk about their psychotic experience in an uninhibited way!"

I have always been only a co-moderator in our small seminars. I always felt myself responsible towards those non-professional PEP's, as during 2 seminars some had deteriorated. If a PEP dominates, the others become small, the relatives also become quiet and sad, that their son or daughter is so completely different, that their children are ill and not in such a good mood as the others, the professional PEP's.
Now don't think we have no feeling for the year 2000 and the importance of the internet. At a meeting of the different groups on "Self-help, advice and therapy in the internet" we decided to start with a virtual psychosis seminar. It began very animatedly, we used an e-mail address and I was surprised. Most of the participants are users. First the language was aggressive directed, mostly, against professionals. We are about 120 on the mailing list. It is amazing how open the discussion turned out. How we try to help each other. The main subject is how to handle fear, how to deal with closeness and distance. To seek help but to be afraid of the helper. The feeling no one understands me. The anger to be labelled by a diagnosis. As you realise, we discussed without a moderator, without special topics. In the near future we will have different topics with an expert as moderator who will give an introduction to the topic of discussion.
The members on the list are very active. Per day I get about 8 emails. I am sure, many people will want to take advantage of the opportunity to contact others who have experience of psychotic episodes. The internet provides a medium where people do not have to wait for a special date of a seminar, they can have access to immediate discussion, when they feel like it. The internet enables people who find it difficult to speak in front of others to voice their opinions. It allows them to react when and how they feel, or to participate just by reading and listening. The address is: internet@psychiatrie.de
(Literature which has been used: Psychosoziale Arbeitshilfen 10 „Es ist normal verschieden zu sein" Psychose-Seminare - Hilfen zum Dialog- T. Bock, D. Buck, I. Esterer, Psychiatrie-Verlag 1997)

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10 COMMON BIASES ABOUT MENTAL ILLNESS -

MOHW, KFAMH, SNPH – Presented by Professor Susie Kim

1. Mentally ill people are dangerous trouble-makers.
- People receiving treatments are composed and are not dangerous.

2. Mentally ill people need to be kept isolated.
- Once the acute phase is over, rehabilitative care in an out - patient setting is preferred.

3. Mental illness is incurable.
- Improvements are seen through pharmacological treatment (therapy with medicine) alone, and various therapeutic rehabilitation skills and interventions have been developed.

4. Mental illness is hereditary.
- There is only a genetic tendency, that is the same as the likelihood of high blood pressure, diabetes, or heart disease in families.

5. Mental illness afflicts certain types of people.
- Three out of ten people in their lifetime are likely affected by mental illness.

6. Mentally ill people act strangely.
- Strange behaviors are seen temporarily only when symptoms are severe.

7. Mentally ill people have a hard time in relationships with others.
- Although mentally ill people are often alone because they lack friends, they actually desire getting to know others.

8. Mentally ill people can not maintain a job.
- Mental illness does not mean losing the ability to work. Lack of opportunities to work is rather the problem

9. Mentally ill people can not drive or participate in sports.
- Taking caution and limiting such activities are required only when illness is severe.

10. Mentally ill people are inferior.
- Mental illness does not lessen a person's intelligence or abilities.

TEN CARING BEHAVIORS FOR THE MENTALLY ILL

Presented by Professor Susie Kim

1. Noticing them
2. Making them comfortable
3. Comforting them
4. Actively listening to them
5. Sharing with them
6. Complimenting them
7. Understanding them by putting yourself in their place
8. Being a companion to them
9. Encouraging them
10. Instilling hope in them

TEN RULES FOR PRESERVING MENTAL HEALTH

Presented by Prof. Susie Kim

1. Have a positive outlook
2. Live with a thankful heart
3. Greet others with sincerity
4. Eat and enjoy three meals a day
5. Put yourself in other person`s shoes
6. Compliment anyone
7. Get to your appointments with time to spare
8. Put a smile on your face, even if it takes effort
9. Live honestly according to principles
10. Be willing to undertake losses in life

Professor Susie Kim, RN, DNSC, FAAN, Director, Research Institute of Nursing Science, Ewha Womans University, Seoul, Korea. Email: susiekim@mm.ewha.ac.kr

BETWEEN THE SHIPYARD AND THE HORIZON: ARS GRATIA ARTIS

Craig Mills

I will be speaking today about a collaborative project between clients and staff of the MWAMHS Ships Program. The basic aim of the project was to produce and release a compilation audio CD of original music and spoken word pieces written by the participants. The discussion will give some indication of whether that aim was achieved and how. The greater aim of the project however was to facilitate the works of these people and to allow them access to resources to pursue their interests independent of mental health services. So this project was undertaken essentially **with** the clients and not **for** the clients. To put this project into context I will give you a brief overview of the nature of the services provided to assist people who suffer from mental health problems. And how a project of this nature dovetails into the model of community psychiatric rehabilitation.

Preamble:

SHIPS a Community Rehabilitation Program

Orange is nestled in the Central Tablelands of New South Wales, Australia. Roughly three and a half hours by car from Sydney, Orange is the major medical referral centre for the region. A predominantly rural city of 36000 people, Orange is serviced by a medical surgical Base Hospital, Bloomfield Hospital, a psychiatric inpatient and admissions facility and affiliated Community Health and Mental Health Services.

In 1985 the Satellite Housing with Integrated Programmed Support or SHIPS Program was developed in response to a need that existed at Bloomfield Hospital for a community based rehabilitation program for people suffering from serious and enduring mental illness.

"*Central to the theme of SHIPS is the notion of fostering a quality of life that is both rewarding and directed towards independence within the least restrictive environment."* (SHIPS 1998. Sn 2.1) SHIPS staff also recognise that rehabilitation is a process that is done *with* clients rather than *to* them.

SHIPS is a residential rehabilitation program which offers supported accommodation using the core/cluster house model. Endeavour House is the core house and administration area, a nine bed unit which offers respite care as well as being the primary assessment area for clients undertaking the Better Living Program. SHIPS considers that development and maintenance of basic living skills is essential to independent community living. In addition to the central unit are 4 satellite houses located around the Orange area. These provide less structured living environments for clients of the program who require less support. This system allows for a more realistic lifestyle with minimal staff intervention and is a precursor to independent accommodation. SHIPS runs a continued treatment program for clients who live in their own homes. This may range from medication support, to ongoing assistance with living skills and other mental health issues.

Kallara and Tallowood Hostel are integral support units for SHIPS and provide more intensive, longer term care for clients that may require this as a result of chronic disability related to their illness. In addition, Kallara, on a 25 acre property out of Orange, runs a semi commercial horticultural nursery as well as other prevocational activities.

The SHIPS Activity Centre operates during the week and offers a range of programs that comprise both social and educational components. The Centre caters for clients of the SHIPS program and takes referrals from Bloomfield Hospital, the Adult Community Mental Health Team and self referrals. Emphasis is placed on developing social skills and increasing access, involvement and participation in community life. To this end, the Centre offers a range of occupational and prevocational activities and engages in larger projects from time to time to further develop and enhance the skills and talents of its members.

Art for Arts Sake

In the role of a care provider I have found it useful to attempt to find some common ground when forming a therapeutic alliance with a person. It became apparent to me that many clients (or consumers) of our services are extremely talented individuals in the areas of the arts. They might be musicians, writers, painters, photographers or poets. For any number of reasons however, it appears that the ability of these individuals to access and utilise mainstream resources to pursue their interest was compromised.

Around 6 years ago one of the community workers applied for and received a grant from the Arts Council of NSW to run a workshop for clients who wanted to learn music. This project entailed employing an arts worker to work with clients in a performance based framework teaching them basic music theory and some instrumental skills. The project culminated in

a performance of a few works for invited guests and the media. Whilst successful, the sad thing about this was that there was no follow on and the thing stopped there.

As a musician myself and a worker at the Activity Centre, I was able to see that there were pockets of talent and enthusiasm amongst the members, some of whom had participated in the previous project. Every so often someone would bring his or her guitar along and sing a few songs, or just practice, and these occasions generated quite a deal of interest from those other people who were there to listen.

The germ of an idea formed in my mind at the time, of seeing if these people would be interested in recording their work and having a demonstration tape that they could give to friends or family or just to have for themselves. There was scattered mild interest in the suggestion, perhaps a little cynicism, another big idea that probably wouldn¹t be seen through. But enough interest to think a little more carefully about it.

A lengthy process of consultation started, canvassing people that I knew within SHIPS, seeing what they would like to do and how they would like to see it done. The idea gathered momentum as the imagination of the clients took hold. I ran the idea past a friend of mine, Rocky Rochelli, a musician, teacher, sound engineer and mental health nurse. He sat patiently as I tried to explain myself and said finally, "Well why don¹t we make a CD and have everybody on it?" He went on to explain that the technology of digital recording and sound production had taken leaps and bounds and was in the reach of almost anyone who owned a computer and a few other bits and pieces. The trick was knowing how to use it. Rocky told me he would love to do it at his studio, and he had nearly everything that we needed, the bits and pieces we didn't have could be begged borrowed or stolen from various contacts we both had.

A submission to the Arts Council of NSW yielded a Country Arts Support Grant, somewhere in the vicinity of $600 which enabled us to contract Rocky as the Arts Worker for the project. To make the project easier to manage we had broken down the process into 3 stages. Each stage had an end result so that if for any reason the project folded we could say that the time had been productively spent. By the end of the first stage we would have made rough demo tapes of the rehearsal sessions. The end of the second stage would have been the DAT master tape of the recording sessions. The end of the final stage was of course the finished product.

Finally we had engaged 13 people to write and rehearse 3 or 4 pieces each. This was a tall order and daunting for those people who had never done anything like this before. Orange Technical and Further Education (TAFE) College has a well equipped Arts and Media Department which runs a Contemporary Music Course. It became possible to enroll the participants in this course via a flexible delivery program to work through specific modules which would assist them in preparing their pieces.

These modules included: Rock Performance Craft, Effective Rehearsal Techniques, Basic Songwriting Skills, Digital Multi Track Recording, and Recording a Demo. As a teacher, Rocky was able to deliver these modules to the participants using his studio as the classroom.

The project developed from there as the pieces came to light. We had a broad range of styles and influences ranging from techno, through jazz and classical to heavy rock and spoken word works. The members formed themselves into a cohesive group and soon assumed artistic control of the rehearsal sessions. This process involved constructive critique and suggestions to improve or enhance a piece. We were able to access session players for the pieces but it soon became unnecessary as the resources were within the group to add what was needed to a song. In this way the artists made the project even more of their own. These rehearsal sessions were fairly loose in structure but were continually dynamic and creative and really formed the framework for the recording process.
Recording is a grueling but rewarding process. The concentration and patience required of the performers was extreme, however throughout the entire process each performer was the mediator and judge of his own work. Often we would be pushed beyond what we thought was acceptable, into making each work the finest of which the artist was capable. It is a fine line between catching the raw essence of a piece on the first take and then improving it on subsequent takes, but Rocky¹s professionalism and the encouragement from other group members gave each player the confidence to do better.

There were many moments that defined the project for me but one of the highlights was after a particularly long session that finished in the wee small hours. Sitting around nearly brain dead and munching on cold pizza and beers, Don who was playing bass on some of the tracks, picked up Robs guitar, cranked up the Marshall amp and was soon into a full on rendition of Led Zeppelin¹s Kashmir. Rocky jumped on the drums and the rest of us joined in and jammed for ages. We all knew Don could play a bit but this was something else. While this was a reasonably average occurrence, it represented something of an awakening for Don. Don was a guy who loved his music but suffered from a particularly severe episode of schizophrenia as a young man which had changed his life drastically and left him chronically disabled. Being involved in this project had re-ignited his enthusiasm and had seemed to achieve what no amount of medication or therapy had been able to do, that is help him regain his self esteem and confidence.

It is fair to say that involvement in this project touched each of the participants in a similar way. The final product contains works both as diverse and as interesting as the participants themselves. Each piece is polished and professional and represents the result of many long hours of work, not only in the recording but the post production. This entailed sitting down with each artist or groups of artists and letting them decide when the piece was finished. We were able to offer technical support and suggestions but in each case the final say came from the individual.

The opportunities to display our wares and let the artists strut their stuff were fairly frequent. The project had generated a lot of interest amongst the friends and families of the participants as well as the mental health community in general. Another

Activity Centre project which I was running at the time was a weekly 3 hour Community Radio Program which focused on mental health issues. Each week some of the musicians would bring some instruments along and play live on air material from the CD as well as their other pieces. These people pioneered live music on Community Radio which had never been attempted before.

Another opportunity came when the organising committee of Mental Health Week invited us to perform at a public concert in the park held to promote public awareness for Mental Health. A sunny Saturday in October saw us take the stage and perform works from the CD for over an hour to a large, warm and enthusiastic audience.

Throughout the recording process we had interest from the print media and local radio. The national broadcaster had sent some documentary film makers along to film some footage for a program they were compiling on alternative music in the region. We were invited to submit some pieces to Triple J, a national radio station, who were running an Unearthed competition in which new artists from around the country were given the opportunity of air play and recording contracts in professional studios.

Stage 2 was finished, and this alone had more than exceeded our expectations. If things had stopped there the project would have been considered an outstanding success. What remained now was to put the whole thing together into a package to let people know what we had done and to show them how good we were.

We were finally ready to start to finish. David Toombs painted the cover and Mick Humphries and myself spent many long hours assembling the layout. We did all the graphic design for the sleeve and sent the whole thing away for reproduction. It was like waiting for a child to be born. 500 copies of the CD were returned to us, ready to be assembled into their boxes with the booklets. Two days with many willing hands at the Activity Centre saw the end result. Very very satisfying.

Having done all the hard work all that remained was to christen the project in much the same way as a ship is launched. We prevailed on the Orange Council to let us use their art gallery for an afternoon in June and invited a special guest, actor and comedian, Mr Glynn Nicholas to officially launch the CD ***Between the Shipyard and the Horizon.*** This was a great bash with about 100 guests and the media in attendance all with the opportunity to own their own copy of the CD.

Conclusion:

For too long mental health work has focused on the illness and not the wellness of the individual. Here was our opportunity to show how, by working together, satisfactory outcomes may be obtained. The bean counters and managers find it difficult to quantify outcomes in mental health, if it can't be measured then it doesn't exist. Well this exists, and God forbid they may find themselves having to talk to the people who matter to find out what is really going on.

The basic aim of ***Between the Shipyard and the Horizon*** was to encourage, develop and record the works of people who had not felt confident that their work or talent was worthy of display. By assuming artistic control of this project, the artists have taken the opportunity to enter the mainstream and be as good as they possibly can. The end result is a professional, polished, broadcast quality compilation CD that is as good as if not better than anything you might hear anywhere.

The fact is demonstrated on the CD that suffering from an illness should in no way impede and individual from writing and performing quality work. The success of this project is due entirely to the enthusiasm and dedication of the artists and the thing speaks for itself.

The greater aim was also achieved insofar as allowing the performers to develop independence from the umbrella of mental health services. This is evidenced by the fact that for most of the people the project has not ended with the launch of the CD. They have taken the bit between their teeth and are pursuing independent interests.

Without doubt the artists would love to be here today to meet you and tell you their stories. Allow me to introduce them to you now:

Kerry Toombs is a fine wordsmith and her music and voice have the ability to transport the listener from the peace of a rainstorm in the bush where she lived with her husband, to the hurley burley of the streets of New York. The two songs she contributed to the CD give us diverse snapshots into different periods of Kerry¹s life. Kerry has set up a Writers Recital Group and performs spoken word pieces and songs regularly at a local cafe.

Dave Murphy¹s contributions showcase his ability as a player as well as a composer. He has developed a unique playing style and is equally at home playing contemporary as well as classical pieces. Dave is currently composing a classical string quartet opus and performs solo at a cocktail lounge.

Tony Kalayzich is very much a feel player and has a delightful touch which he is able to convey to his audience. Tony as well is an accomplished classical player. He has contributed 2 sensitive and evocative songs to the CD which show us a little of his inner self. Tony continues to play and regularly performs at songwriting contests and attends workshops.

Sue Hall has one of those strong, rich bluesy voices which she trained as a busker in the tunnels under Central Railway Station in Sydney. Sue has a fabulous ear for harmony and her input during rehearsal sessions provided texture and verve with the result of lifting a piece above the ordinary. Sue can still be heard belting out tunes from the Activity Centre and remains in touch with most of the artists.

John Rabey personifies the adjectives intense, principled, powerful, raw, energetic and passionate. He is a long streak of hairy lightning whose songs are driving relentless and angry. John now has formed his own band, plays in pubs and records original music in his home studio. He has completed the TAFE Contemporary music Course and is ready to release his own CD with his band.

Don McPherson is a guy who loves his music, and loves playing. Don lost interest and motivation during the course of a severe and protracted illness. Invited to play bass with some of the other artists, Don worked the rust out of his fingers and blew the cobwebs off his old guitar. He put together a catchy solo piece for the CD which surprised us with its lyrical simplicity. Don still plays from time to time with some of the other artists.

Kruno Baricevic, the Rock God, his music is as unpronouncable as his name. He loves to play jarring, atonal melodies which somehow go together to make a cohesive something. Kruno¹s soundscape behind Peter¹s prose is haunting and mysterious and one of my favourite pieces on the album. He loves the vicious feel of electric guitar and is transformed by his playing. Kruno lives with Don at Tallowood and frequently play together for their own pleasure and they do various gigs with the church groups.

Paul Spence gives us a private glimpse into his life with his short poems, baring his soul with concise brevity. These works are sparse and poignant and give the feel of having been etched onto glass with a diamond. Paul is a tattooed giant who peers out on the world through perpetual sunglasses and, though occasionally noisy, gives little away. He has left the area however remains in touch and will occasionally recite poetry to me down the phone.

Roslyn Errey was like our musical Jimminy Cricket. She is classically trained and would continually challenge us with big words and concepts like transpositions and modulations. She tackled a difficult piece, re inventing a Charlie Parker jazz tune. She remains supremely clever and continues to play the violin and takes classical piano lessons.

Mick Humphries (aka ASH) contributed a couple of laid back grooves, seductive and hypnotic brimming with loops, sequences and cool samples. He has an ear for perfection and often would pull these pieces down to the smallest component of the sound wave and build it up again. Mick is also a useful drummer and played his hand pretty well when up against Young Rob¹s complex stuff and John¹s full on thrash. Mick has set up his own graphic and web design business, last heard of carrying a suitcase and peddling his wares around Israel.

Peter Formella describes his spoken word piece as the words an 18 year old wanted to say when they should have been said. Better late than never he reckons. Peter lives a chaotic life to say the least but is able to view it with humour and insight. He remains a very prolific author and regularly participates in the Writer¹s Group events.

Dave DeRooy is a talented lyricist and musician. He has the ability to match his words with well crafted arrangements. Dave has a powerful and rich voice from the classic rock era and an ear for production and effect. His confidence took a battering when he became ill but now he has invested in some updated equipment and is in contact with people with whom he used to play, having the view of starting a band again.

Rob Stephen or Young Rob as he is fondly known is a prolific writer and a mature and powerful guitarist. He has an innate feel for good music and his pieces are densely textured and challenging. His voice has that blown out gravelly quality which perfectly complements his work. Young Rob continues to grapple with his illness and is chronicling his life in the form of a rock opera.

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COMMUNITY MENTAL HEALTH SERVICE FOR THE THIRD MILLENEUM

Ma. Rosanna E. de Guzman, M.D.

The development of a community-based educational program for the training of primary health workers and the establishment of a community mental health service (CMHS) in the Rural Health Unit (RHU)

Introduction

The growing trend of improvement in psychiatric treatment and care have paved the way for the gradual decongestion of chronic patients from mental institutions towards the availability of psychiatric services in the general hospitals. This is the projected goal of the National Mental Health Program of the Department of Health (Philippines) with the proposed plan of developing acute psychiatric units in the regional general hospitals all over the country. Progress seems very slow and it meets resistance considering the negative attitudes towards mental illness among the medical and paramedical professions, the lack of mental health policies, the lack of well-trained professional staff, and the low priority being given to mental health services.

Given the above scenario, there is a need to look for adequate alternative services to the state mental hospital system and to rethinking the real nature of psychiatric care. The move in the 1970's in Britain and the U.S. for undertaking the care of the mentally ill in the community was seen as an alternative to the state hospital system through the establishment of *community mental health centers*. This was a tremendous advance in psychiatric care for its aims were:

1) To provide a ready access to mental health services and offer psychosocial care for all persons within a given population who needed such services, and;
2) To offer a model in which to build in the evolutionary process of constructing an effective national health system.

Since then, the CMHC have steadily grown in size and numbers, vitality and range of tasks they are assuming in the community. This phenomenon worked well for the U.S., Italy and Britain because they had the resources to build structures that were to house their chronic mentally ill patients and to provide social assistance for rehabilitation and reintegration. The concept was welcomed with enthusiasm only to fade away in a few years. The failure of the program was seen in logistic problems, and the lack of enhancement of community capability, thus, resulting in the phenomenon of the homeless chronic mentally ill that continued to remain isolated from the community. It is for this reason too that the establishment of

community mental health centers did not take off in the third world countries considering the previously mentioned obstacles.

Background situationer

In 1989, the Section of Social and Community Psychiatry of the Department of Psychiatry and Behavioral Medicine of the University of the Philippines- Philippine General Hospital responded to the pressing need of supporting the families and the community in the care of the mentally ill members. This was in response to the ballooning number of homeless chronic mentally ill patients in the community and unreported cases of untreated patients in the community. The development and implementation of a community based program called the ***Family Care Program (FCP)*** by Tronco, A. in 1989 for the chronic mentally ill. It was conceptualized to support the families and the community in the care of the mentally ill member with the assistance of the local government unit. Families with a chronic mentally ill member ran the program with the support of the primary health workers from the Rural Health Unit (RHU). The RHU forms part of the local government unit and it provides for primary and secondary general health services to a geographically defined area.

The focus of the intervention were the families with a chronic mentally ill family member. The objectives of the FCP included explaining the nature, the course, prognosis and treatment of chronic mental illness, identifying the priority problems and coping skills utilized by the families in the care of their chronic mentally ill member, and motivating families towards the development of multiple self-help groups. The FCP was so well received by the families that they formed a family association called "Lingap Kapatid" which means fraternal love, a brotherly concern for one another.

The success of the FCP can be attributed to the generous support of the primary health workers of the RHU from the municipal health officer, the public nurse, the midwives and the barangay volunteer health workers of the community. These workers have facilitated communication and rapport between those who provided services and the patients and their families. After a year of implementation of the FCP, it created a "ripple effect" because they were being requested to extend their services beyond the families of the FCP to other families of the neighboring communities. A need arose then to develop a community-based education on mental health for primary health workers with the goal of establishing a community mental health service (CMHS) at the level of the RHU. This will make accessible mental health services and enable the primary health workers to accept and to meet the growing responsibility for mental health care for the community. The concept of a CMHS evolved as the answer to the needs of the community whose services go beyond the scope of the FCP, but is within the area of responsibility of the RHU. With the establishment of a **CMHS** in the RHU, it then became the most important ally of the FCP.

Significance of the project

Long term benefits will redound to preparing the families and communities at the level of the RHU to help care for the chronic mentally ill. This move will encourage the patient's reintegration and rehabilitation into the community and will improve the quality of life for the patients and their families. The other expected benefit is for the RHU to provide mental health services (e.g. treatment of other psychiatric disorders like anxiety, depression, and care for the elderly, and substance abuse) as part of the general health service they render to the community. Lastly, to promote the destigmatization of mental illness in the community.

Project objective

To develop:

- a **community-based education on mental health** for primary health workers
- and to establish a **community mental health service** in the Rural Health Unit

Objectives

The specific objectives of this project were the following:

1) To determine the primary health workers' knowledge, attitudes and skills towards mental health and illness.
2) To develop a community based educational program for primary health workers.
3) To evolve a system of mental health services in the RHU with the establishment of a community mental health service.
4) To provide for continuity of care.

Methodology

The project site was in Calumpit, Bulacan because it was one of the areas identified by the provincial health officer to have a high prevalence of psychiatric morbidity. Calumpit is one of the 21 municipalities of the province of Bulacan, which is 1-½ hours away from Manila. It is composed of twenty-nine (29) barangays with a population of 70,000 people. Its economic resources are primarily agricultural. The project was implemented in the Rural Health Unit (RHU) of Calumpit covering 5 barangays.

The implementation of the project involved four phases:

1) Research Phase
2) Training Phase
3) Establishment of the CMHS
4) Phase of continuity of care

Ratio of health personnel:

1 MD per rural health unit : 35,000 population

1 public health nurse per rural health unit

15 rural health midwives

1 midwife: 5,000 population

GANT chart for the development and implementation of a community mental health service in the RHU

The Research Phase was initiated to determine the primary health workers' knowledge and attitude towards the mentally ill. A Focus Group Discussion was initially done to be able to obtain in-depth information about the priority problems of the primary health workers in working with families for the care of their mentally ill patient, and identify their roles in providing health services. This was followed by:

1) An interview questionnaire, Community Attitudes towards the Mentally Ill Inventory
2) Two self-report questionnaires: The Self-Descriptive Health Workers Belief Scale and the Empathy Scale.

Results of the Focus Group Discussion:

The results of the FGD revealed the inadequacy of the primary health workers regarding their knowledge on mental health issues and their lack of confidence in handling mental health problems in the community. The barangay health workers have unanimously expressed the need for a mental health service.

Socio-demographic profile of Primary Health Workers

- 64 female workers
- Age group: 20 – 79 years, (mean ave. 46 years)
- Civil status: 90% married, 10% single
- Occupation: 1 doctor, 1 nurse, 9 midwives, 53 barangay volunteer health workers (housewives, teacher, dressmaker, market vendor)
- Highest educational attainment: 40% high school, 30% elementary, 30% college
- Years of service as a primary health worker
  - ➢ 5 years – 80%
  - < 5 years – 20 %

Community Attitudes Towards the Mentally Ill (CAMI) Inventory

The Community Attitudes Toward Mental Illness Inventory (CAMI) was developed by Geoffrey Wolff et all in 1996 to test the hypotheses that negative attitudes to mentally ill people may be fuelled by lack of knowledge. There are two parts. Part I - Interview questions which consist of the following items:

- Demographic data
- Knowledge of mental illness
- Reactions towards the mentally ill
- Knowledge of psychiatric hospital care
- Attitude to psychiatric hospitals
- Knowledge of the shift to care in the community
- Attitude to community care policy
- Opinion about the need for education).

Part II is a self-report inventory of fear of and behavioral intentions towards the mentally ill. This was given as a pre-test to the primary health workers who were the participants of the training-workshop on mental health. The results support that the community's attitudes towards the mentally ill will have a major influence on the acceptance of the mentally ill and their social integration.

Results of the CAMI Inventory revealed the following:

1) The inadequacy of the primary worker's knowledge on mental health issues was found to be associated with a poor understanding and low level of comfort towards mental illness.
2) There is also a lack of confidence in dealing with mental health problems in the community because of absent or poor skills in patient care.

Health Worker's Belief Scale

The Belief Scale determines the primary health worker's belief of the relationship between mind/body physical and psychosocial issues. It consists of item statements each of which is answerable by a check on a 5-point scale from strongly agree to strongly disagree. Assigning numerical equivalence to the 5-point scale and adding in all scores in all the items scores the instrument. This instrument was given a pre-test and post-test to assess the effect of training on concepts of mental health and psychosocial issues. Higher scores also mean improved beliefs on psychosocial care and its importance to a person's health and well being.

Health Workers' Empathy Scale

The Empathy Scale measures an individual personality attribute – the capacity to feel/put oneself in another's' situation. It consists of 18-item statements each of, which is answerable by a check on a 5-point scale from strongly agree to strongly disagree. Assigning numerical equivalents to the 5-point scale, and adding on the scores in all items scores the instrument. Comparison of pre-test and post-test scores is advisable to determine the extent with which the primary health workers respond to their patients in dealing with psychosocial problems. A high score means a high empathy level for the primary health workers.

Results of the Health Workers' Belief and Attitude Scale:

Health Worker's Belief Scale – 43%

Health Workers' Empathy Scale – 66%

These results demonstrated that the primary health workers' attitude toward the mentally ill will have a major influence on the acceptance of the mentally ill and their reintegration into the community. Thus, any intervention aimed at changing attitudes should take into account the negative attitudes of the primary health workers because these were associated with a lack of knowledge and understanding of mental illness. Education may possibly improve the community's attitudes towards mental illness and help patients' reintegration and rehabilitation in the community for which the training phase was conceptualized.

The Training Phase paved the way for the creation of a community-based educational program for primary health workers on mental health. It is an educational program on mental health which is carried out in the community setting

and which considers the community as an important environment in which learning takes place.

Objectives of the Community Based Education Program on Mental Health

General Objective

To equip the primary health workers with the necessary knowledge, attitudes and skills to become a mental health service provider which will prepare them for the proper identification, evaluation and management of the mentally ill.

Specific Objectives:
At the end of the training period, the participants of the training and seminar workshop are expected:

a. To acquire a holistic framework in helping them understand their patients through the biopsychosocial model of health and illness.

b. To acquire skills and the necessary knowledge in doing a clinical history, in taking a mental status examination and in identifying psychiatric signs and symptoms.

c. To develop a comprehensive plan of action regarding initial interventions and management for the family and the community.

d. To do a needs assessment of their community, identify problems on mental health and find out available support systems and resources for referrals.

Participants in the Training and Seminar Workshop on mental health for Primary Health Workers:

- MHO
- 1 public health nurse
- 9 midwives
- 64 barangay volunteer health workers

The learning activities were organized into an instructional plan were the following modules were presented:

Module 1: The Biopsychosocial Model of Health and Illness
Psychiatric Interviewing

Module 2: Detection of Mental Disorders: Depression, Anxiety and Psychosis

Module:3 Psychosocial Intervention and Management

INSTRUCTIONAL DESIGN - modules with learning objectives

Learning strategies

The activities were designed to increase awareness, clarify values and attitudes, and promote creativity and initiative in problem solving. The goal of the educational program was for the primary health workers to identify mental health problems among individuals consulting them, and to acquire some degree of competence in handling these problems. Thus, it developed in them sensitivity to the psychosocial aspects in health and illness.

The Phase of establishment of a CMHS will not create a new framework nor a new center, unlike the community mental health centers because there is already an existing structure, which is the Rural Health Unit . The RHU, is the microcosm unit of the Department of Health at the level of the community and it takes care of disseminating and implementing the health programs of the national government at the primary care level. This is the reason why the CMHS was conceptualized within the RHU as a system of services organized to accept and to meet the responsibility of mental health care of the community. The CMHS is to provide a ready access to mental health services and offer psychosocial care for all persons within the community who need such services.

Objectives of the CMHS:

1. Primary and secondary prevention of mental illness in the community
2. Access to referral systems
3. Continuity of care during illness and rehabilitation of the mentally ill in the community

CMHS:

A. Organizational for service programming

The organizational structure of the **CMHS**, although determined by specific local conditions, is a major factor in the delivery of services. Centralized responsibility is essential to assure continuity of care within a comprehensive range of accessible and available services. The RHU - 1 of Calumpit, Bulacan has a definitive organizational structure as has been delineated by the local government code, with the roles, responsibilities and competencies of each member of the RHU staff.

B. Manpower utilization

Manpower utilization is enhanced by the use of auxiliary mental health workers or the **barangay health workers (BHW)**. The BHWs are a growing number of lesser-educated health workers who are receiving on-the-job training. Since the RHU caters to the low-income areas, the idea of using the local residents as mental health aides have enhanced the responsiveness of the **CMHS** to local health needs. There are more patients being brought in for first consult at the RHU. For such workers are able to establish relationships quickly with the patient and their families who are often hesitant to deal with professionals, most especially a psychiatrist, considering the stigma of mental illness in a family member. The MWs and BHWs are making home visits and engaging in many tasks that were usually limited to professional staff, e.g. dissemination of health information and the access of referrals systems. As non-professional personnel, the BHWs are very helpful, but they must be carefully chosen and properly supervised. With this in mind, the **CMHS** will necessarily provide for the appropriate training and professional back-up and supervision of the BHWs. This can be achieved through a community based educational program

on mental health and regular consultations with the psychiatrist and MHO.

C. Community participation

Experience has shown that the best service program is one in which the community is involved. If the service program is to be relevant to the needs of the community, there must be open channels of communication. This communication can be achieved in a variety of ways, including interaction with other social institutions that serve the population, such as health resources (e.g. district hospital, provincial hospitals), citizen groups (e.g. medical associations, private medical practitioners), and other formal and informal organizations. The organizational set-up allows for representation from all levels. A very concrete program that the **CMHS** can pave the way for, is establishment of the **Family Care Program (FCP)** in each of the identified areas of the community. The **FCP** will provide the avenue for community participation by involving the families of the chronic mentally ill patients.

D. Development of interagency network of service- to provide continuity of care for patients-affiliations with the nearby state hospital.

The **CMHS** maybe said to have reached a mature phase when it can establish networking and coordination with other mental health resources to provide for continuity of care for patients. This networking is facilitated by the staff of the **CMHS** who take responsibility for certain aspects of hospital care for the residents in their catchment area. This is still at its initial phase, and therefore, may need planning and coordination among the different networks. Affiliations of the **CMHS** will also provide a means for exchange of information about the community's changing needs, for joint planning and problem solving.

The basic working principle in establishing the CMHS is that it has to be responsive to the needs of the people they are too serve. If the mental health service program is to be relevant to the needs of the people, there must be open channels of communication between the health service providers and the local officials. This is essential to assure the phase of continuity of care. Continuity of care demands commitment and advocacy if the CMHS is to stay and to continue its functions. Being a pilot project, necessarily the CMHS encountered many difficulties during its initiation. Continuous nurturing and support had to be provided by the consultant psychiatrists in coordination with the municipal health officer until such a time that the primary health workers feel confident in providing mental health services. For the primary health workers to be able to maintain a high standard of quality of treatment, it is the responsibility of the RHU to provide for continuing training and supervision.

Continuing Medical Education on Mental Health

Evaluation of services

Evaluation of services is necessary if the CMHS is to continue to provide mental health services. This will have to done two years after the program's implementation. The variables to be used for the evaluation of the CMHS are the following:

1. Volume of throughput (no. of patients, referrals)
2. Clinical and socio-demographic characteristics of patients
3. Modes of treatment and management employed
4. New morbidity emerging from care
5. Mortality
6. Effects of the CHMS on families and on the RHU staff
7. Utilization of personnel; levels of training
8. Measures of satisfaction in patients, relatives and staff
9. Financial and non-financial costs.

The information on all the parameters of the CMHS evaluation is essentially descriptive, describing the pattern of consumption of the CMHS. Further follow-up studies will have to be designed to determine the effectiveness of the CMHS as a community alternative to institutional care.

Recommendations

If the RHU and the barangay community health centers are to be the future focus of mental health delivery, this project recommends the following:

1. Propose to the National Program of Mental Health – the policy-making body of the Department of Health a mental health program that will address health promotion and disease prevention, as well as cure and rehabilitation at the primary care level for chronic mentally ill patients. This will be facilitated with the availability of psychiatric services at the regional or district hospital or rural health units, instead of concentrating them in mental institutions. Psychiatry residents in training and privately practicing psychiatrists can furnish additional resources in the form of direct patient care or assistance as consultants and advisors in the community. They can network with possible non-government organizations (NGOs) and government organizations (GOs) in the provision of mental health services.

As well as benefiting patients, it is hoped that the CMHS will provide an opportunity for physicians who are not psychiatrists to see that mentally ill patients are not untreatable, and not as dangerous as sometimes believed. Families too, will be closer to their chronic mentally ill member and thereby learn more about their illness and management through the organization of Family care Programs for the chronic mentally ill for the empowerment of mental health. This is one way to promote the destigmatization of mental illness and the deinstitutionalization of the chronic mentally ill not only among families, communities but as well as the health profession.

It is planned that the service will eventually extend to encompass drug abuse, victims of violence, depression in the medically ill, as well as care of high-risk individuals (the care for the elderly, behavioral problems in children, disaster victims and women facing specific gender-related issues).

3. In the promotion and delivery of mental health services, close coordination with community leaders and local government officials is necessary through mental health advocacy program to help mobilize community resources, as do initiatives in the planning, implementation and delivery of services. The goal is to provide mental health services close to where patients live.

3. It is hoped that the Philippine Psychiatric Association will accord a high priority to community alternatives to institutional care by funding social and community psychiatry projects.

4. In line with the community oriented medical education of the UP College of Medicine, this can provide a very good venue not only for exposure but interaction of medical students with families in the care of their chronic mentally ill member. This will help them understand that psychiatric patient care should extend beyond mental hospitals, health centers and even patients' homes, providing a comprehensive health care delivery system for everyone.

Conclusion

This project was such an ambitious task. For it implied a radical orientation of services away from the acute hospital care and chronic institutionalization to a community service model whose aim is to achieve long-term stability and a decent quality of life for the mentally ill in the community. The provision of easily accessible treatment of all types for all patients in need is of incalculable value. So also is the concept of continuity of care during illness and rehabilitation of the chronic mentally ill in the community. At this point, the project does not have evaluation studies to show significant improvements in clinical outcome, though outcome trends do support them with lesser rate of relapse among patients, family satisfaction of care, added number of new patient referrals, etc.

The success of this project gives hope for the next millenium with mental health services becoming more integrated and coordinated in the general health services. Yet, a lot of groundwork has to be done, if the RHU will take the responsibility and leadership of making these services available and effective. Because of the RHU's strategic position at the community level, it is in the best position to provide for a continuum of coordinated health and mental health service.

If Community Psychiatry is to offer a new paradigm shift, then the establishment of a CMHS becomes a very good training ground for psychiatry residents to meet this challenge. We all started our medical training with the traditional viewpoint of psychiatry. With this community service, we now have learned to go beyond the confines and comforts of clinical practice preparing ourselves to face the challenges for the next millenium with the devolution of mental health services to the community.

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MISREPRESENTATION OF MENTAL ILLNESS BY THE FILM INDUSTRY

Margaret Helfgott

SYNOPSIS

In 1996 the film Shine became an international box office hit, claiming to tell the true story of my brother, David Helfgott, a child prodigy pianist whose remarkable career was dashed by mental illness in adolescence. Family members were appalled when the film industry, contrary to all objective facts, chose to portray David Helfgott's deceased father as a cruel and violent man. The gross implication was that the father's "savage" mismanagement of his son led to the development of debilitating mental illness.

This presented dramatic cinema and boosted sales. However, from the outset a vigorous press campaign conducted by those who had personally known my own father, Peter Helfgott, defended his character fiercely as a loving and kindly man. Moreover, modern psychiatric thought rejects the notion that organic mental illness can be produced by "bad parenting." Overall, Shine exemplifies the powerful film industry designing a box office hit distorting the facts of a family to suit its own purposes, and stigmatising mental illness as caused by "bad parenting".

The purpose of this presentation will be to present and analyse scenes from the film on video, and compare them to what happened in reality. This will be achieved by the use of real life personalities' actual words and documentation. The result will illustrate the disservice which the film perpetrated on the Helfgott family in particular and mental illness in general.

This film was made about my family, and in particular my brother David. It was promoted as a true story – using our real names - in publicity throughout the world, but in fact is full of distortions. Although I personally asked repeatedly for an advance copy of the script, my request was consistently refused.

SUMMARY:

The film "Shine" is an outrage of distortion - both with regard to personal family privacy, and the issue of mental illness. It causes distress to family members by inferring that mental illness is caused by bad parenting, and by extension suggests that families stricken with mental illness are in some way guilty and responsible. All this was conveyed in a film seen literally world-wide and using real names. After the initial shock, my policy was to adopt a vigorous campaign refuting the distortions – in newspaper articles and media appearances, culminating in a book refuting the film. The success of these efforts may be reflected in the fact that the film Shine is rarely mentioned without the family opposition to its distortions being emphasized at the same time. If I have a moral to leave you from my experience, it is that distortion and inaccuracy regarding mental illness must be fought vigorously.

Margaret Helfgott became an activist as a result of the false portrayal of members of her family in the film "Shine". She previously lived in Australia and is now resident in Israel. Email: allamag@netvision.net.il.

PSYCHOEDUCATION: VILNIUS HEALTH SEMINARS

Danute Kasubiene

Lithuania is a Baltic state, which regained its independence 10years ago. The population of Lithuania amounts to 3,7 million people. Lithuania's neighbour countries are Latvia, Belarus and Poland. The number of the mentally ill in the country increased from 145 thousand in 1990 to 153 thousand in 1997.The number of disabilities caused by mental illnesses increased from 19 thousand in 1990 to 23,5 thousand in 1997. In total, in 1999, there are 11 217 persons with disabilities and those ill with schizophrenia.

The Lithuanian Welfare Society for Persons with Mental Illnesses was registered at the Ministry of Justice on March 27, 1997.Soon a treaty of co-operation was signed with the Polish coalition for mental health and at the end of 1997 a joint Warsaw – Vilnius health seminar was organised. In order to improve life quality of mentally ill persons and their families, camps of psychosocial rehabilitation are organised every summer at the Baltic Sea. The Council of Invalids affairs and the Ministry of education support the camps.

In 1997, 3 branches of the Society in Kaunas, Vilnius and Vilkaviškis represented the mentally ill. The branches took part in Warsaw – Vilnius health seminars actively, which had aimed to share the experience of working as a team, when providing psychosocial services in the community. The first seminar took place in Vilnius in November 1997. The second took place in December 1997 in Warsaw. The Council of invalids' affairs, Open Society House-Lithuania and the municipalities of the cities sponsored seminars.

The advantage of the seminars is that we exchanged delegations of 40-50 people, who represented NGOs, social workers, doctors-psychiatrists, municipality officers, and journalists. The disadvantage was that we could not expand the services for the mentally ill in the community because it was against the views of the social workers. Obviously, social workers took care of the mentally ill, provided the mentally ill addressed them. But without Day centres in the community it was difficult to organise occupation for the mentally ill, because these people are normally taken care by the health system. When we began to organise centres of mental health, problems of co-operation between institutions arose inevitably. We invited representatives from municipality, social care centres, medical institutions to the meetings of the council of the Society. We also took part in Warsaw health seminars in Poland actively. In December 1998 the third Warsaw – Vilnius health seminar took place in Vilnius. It dealt with the rights of patients, psychosocial services and art therapy. The advantage of the seminar was that practising specialists as well as the child psychiatrist of the Health care Mr. D. Pūras, the head of Vilnius support centre A. Čepėnaitė and other specialists spoke there. It is clear that there are people, who find the problems of the mentally ill and their families relevant, as well as their rehabilitation and integration.

The disadvantage was that there was no co-operation between corresponding institutions. That is why, with the support of a PHARE program, idea was approved so as to organise seminars for the representatives of the institutions concerned (about 50 people). The seminars were to deal with the co-operation between NGOs and municipalities, in providing services for the mentally ill in the community.

In January 1999, a two day seminar took place where a member of Parliament, now minister of Health care, Mr. Alekna as well as leading specialists psychiatrists and psychotherapists, social workers and representatives from various NGOs lectured briefly. The participants of the seminar also discussed the following meetings, which would deal with the problems of mental health. Due to the facts that there were 7 branches of the Society operating in towns and districts, it was decided to organise 8 round tables, in order to involve a wider range of the society in the discussion called "Mental health – our task". That is why 2 round tables took place in that very month – in the psychiatric hospital in Švėkšna (district of Šilutė) and in Vilnius municipality. The participants of the discussions supported co-ordination among municipalities, health institutions and NGOs when providing assistance for persons with mental illnesses, in accomplishment of the Social services Act in the boarding houses, and they shared the experience of the centres of mental health.

The representatives of the Polish coalition for mental health took part in meetings held in Vilnius and Klaipėda. Before the discussions, people from other areas had a chance to learn about various institutions – the psychiatric hospital, retired people house, centres of mental health. The Society prepared various materials related to the problem of the mentally ill and relative laws, which was distributed. Around 50-120 people took part in the meeting. Interest to the problems of mental health was expressed by the officers from municipalities, ministries and districts, as well as doctors –psychiatrists, psychologists, social workers, people from various NGOs which mostly represent the mentally ill and, obviously, our users. For instance, the head of the social affairs in Šiauliai district took part in the meetings 4 times, the vice-mayor of Telšiai – 5 times in various places of the country.

Obviously, 60% of all participants took part one time only. The heads of the districts expressed in their speeches that they understand the mentally ill and the situation of their families in society. I think that round tables, called "Mental health – our task" contributed to the process of fighting stigma in Lithuania. We discussed the round tables in the conference of psychiatrists in June. The experience of the round tables was assessed positively by our counterparts in Poland too, because they strengthened and motivated all those interested in the problems of mental health. The heads of the mental care centres discussed the advantages and subtleties, expressed problems share their experience of how the reform of mental health will take place in different localities.

The discussions were conducted more professionally when Vilnius social support centre and the Day centre "Šviesa" took part in their organisation. During the discussions, participants submitted their suggestions on issues, relevant to them, and filled in 280 questionnaires about the views of society to the mentally ill. It is interesting to point out that 61% of teachers, who took part in the questionnaire, expressed discrimination towards the mentally ill. There are 0,5 m.. pupils in Lithuania,

and only a small proportion of them will be educated in the spirit of tolerance and democracy.

When the round tables were over, we looked for the assistance of professional organisations in order to be able to organise Vilnius health seminars according to the suggestions we were given. The minister of Health care, Mr. R. Alekna, agreed to be the patron of our seminars. In autumn 1999, 2 Warsaw – Vilnius health seminars took place, as well as 3 Vilnius health seminars.

The international seminars are supported by the Open Society fund–Lithuania (programme East – East), and the Council for Invalids affairs supported the first 3 Vilnius health seminars. Pharmaceutical companies Eli Lilly and Jansen-Cilag supported 3 Vilnius health seminars, which took place in 2000. During the Warsaw – Vilnius health seminars we learn about the organisations and Day centres in Poland, and share their experience. When in Lithuania, our counterparts eagerly share their positive experience both with the specialists and the NGO. The advantage of this is that this experience is based on progressive teamwork, and there is basically no communication problem with language. The disadvantage is that the Lithuanian doctors-psychiatrists from psychiatric hospitals do not feel at home in the seminars, and conservative attitude to the reforms of mental health prevails.

Six Vilnius health seminars, which have taken place, have proved to be relevant for professionals, NGO and users. The qualification of professionals is also rising, and certificates are issued. We especially appreciate the support of the director of the National mental health centre, Dr. O. Dovidonienė, and the head of the Psychiatry clinics of Vilnius University, Prof. A. Dembinskas, when organising the seminars.

The first Vilnius health seminar had task to learn more about the amendments of the medical, social and professional rehabilitation of the disabled Act.The second one was concerned with the commemoration of the world day of mental health. National programme of the mental health prophylactics was presented to the participants.
The third seminar was to commemorate the year of the elderly. The speakers presented medical services provided for the Alzheimer patient sand the problems of rehabilitation and care. The forth seminar dealt with the medical rehabilitation of the mentally ill, because the order of compensation for medicine has been changed. The fifth one dealt with the psychological and social rehabilitation, and speakers shared the experience of their clubs and various therapies. The sixth seminar commemorated the year of the youth. During discussions, psychological support, problems and the growth of suicidal rate amongst the youth was covered.

In total, there were 334 participants in the seminars. Representatives from mental health centres and psychiatric hospitals accounted for one third of participants. Professionals working in social care centres and in day centres for the mentally retarded persons formed more than one third of the participants. The representatives of the NGO accounted only for some 10% of the participants. This autumn 3 Vilnius health seminars are planned, and their topics are as follows: the expansion of the psychosocial services in the community, mental health and mass media, diseases of dependency**.**

At the present moment the Society has 11 branches and the representatives of the branches take part in all seminars. We appreciate chance to listen to specialists, discuss with them and so to become partners in the process of the integration of the mentally ill into society. We are proud that in this way we fight stigma. We think that this year funds will be given to 16 mental care centres, so that rooms of occupation will be equipped and this will expand the community services to the mentally ill.

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SCHIZOPHRENIA FOUNDATION OF SOUTH AFRICA: THE WAY FORWARD FOR THE "RAINBOW NATION"

Brenda Brett

The everyday realities that confront the individual living with schizophrenia in post-apartheid South Africa can only be appreciated against the backdrop of our country's recent political transition and the modern context of South African society.

The impacts of the transition to democracy on the public healthcare system have resulted largely from the redefining of provincial areas and authorities, changing the previous era's bureaucratic structures (where four provinces had existed nine now exist). As a function of this restructuring the health care services of the former provinces and the TBVC (Transkei, Bophathutswana, Venda and Ciskei) states were amalgamated into a new healthcare services structure.

Additionally as part of this restructuring the focus of the public healthcare system has changed to one of primary care, for the individual living with a psychiatric illness, who had previously relied on psychiatric nursing staff for support and understanding, the new system brings with it uncertainty and confusion. Ever-changing nursing staff provide for little by way of accessible, consistent psychiatric care.

Within this political and infrastructural milieu the social facts on the ground additionally provide obstacles in providing appropriate care for the IWS:
Non-acceptance- lack of knowledge causes a low acceptance level of an illness that is poorly understood.
Lack of Support- in all rural and suburban areas for individuals and their families.
Poverty- lack of employment opportunities places immense financial strain on families, currently an estimated 30% of the South African population is unemployed and disclosure of a psychiatric history exacerbates this figure- the constitutional rights of citizens not withstanding.
*Poor Housing***-** overcrowding and lack of essential services.
*Traditional Healers***-** co-operation between western medicine and traditional healing methods should be encouraged in moderation, working to establish a base of trust and understanding.

All of these specific factors occur within a highly complex multicultural society: South Africa has 11 official languages,

35% of the population is under 14 years old, and additionally the demographics of the school system and residential areas has been changing in the last years. The resultant social reality is one of uncertainty, dislocation and upheaval.

In a country where the state healthcare system is unable to provide an adequate level of mental healthcare, the role of the NGO's is easily defined. However, our function is complicated by various factors, one of which being an explosion of interest groups in post-Apartheid South Africa which are all public level concerns adding to the cacophony of voices among which we *must* be heard. The SFSA thus seeks co-operation between all players in the mental healthcare field: staff of psychiatric community clinics spanning a vast rural population; the Mental health Information Center in Cape Town; the Depression and Anxiety Support Group in Johannesburg, as well as the South African Federation for Mental Health.

To have effect (as advocacy and service organizations) in the mental health field we need to network both nationally and internationally in view of funding opportunities and programs and initiatives undertaken by similar organizations worldwide.

The Goals of the SFSA are thus:

- To provide **information** and **education** by media and groups, both to the general public and to healthcare workers.
- To facilitate **betterment** in terms of employment, housing (assisted living projects), skills training and rehabilitation, which is sorely lacking as an initiative of the state healthcare system.
- To function as an **advocacy organization** at the level of government, the pharmaceutical companies, medical aid schemes and the Internet.
- To provide **counseling services-** both telephonic and walk-in facilities.
- To seek **contact** with the **international community** in terms of **ideas**, programs and projects, lobbying, support and encouragement and visits.

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FAMILY FELLOWSHIP FOR PSYCHOSOCIAL REHABILITATION SERVICES - A FEASIBLE MODEL FOR DEVELOPING COUNTRIES

Dr. M. Ranganathan

Considering the paucity of Government sponsored rehabilitation facilities for mentally ill persons in developing countries in general and India in particular an attempt was made to enlist the support and cooperation of the families of the mentally ill to plan and organise a residential rehabilitation centre at Bangalore, South India. The genesis of such idea, transformation of the idea into action, planning the activities, policy formulation, administering day to day activities, family participation, patient involvement, utilisation of community resources, involvement of professionals, making the programme cost effective, problems encountered in the past 6 years of establishments, strategies adopted to overcome the problems and allied issues related to Family Fellowship for Psychosocial Rehabilitation are highlighted, specially in the context of 75 families and their experiences. This project indicates that families can be empowered/strengthened only through their collective efforts and initiative aiming at understanding their felt needs, prioritizing these needs and achieving the goal of the rehabilitation by striking the balance between the needs and resources available within themselves and in the community. Based on such ongoing family centred and community based rural rehabilitation services, suggestions are offered for replicating this model in other parts of the developing countries.

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EXPERIENCES IN EMPOWERING FAMILIES: LESSONS FROM AMEND, INDIA

Nirmala Srinivasan

INTRODUCTION

The Association for Mentally Disabled or AMEND is a self help family support group in Bangalore,India. It is presently eight years old and has serviced nearly 500 families including consumers suffering from psychiatric disabilities ever since its inception. Looking back, as a member of the founding family, it is undoubtedly a rich personal experience for me and my son, a consumer. But over and above personal benefits, the process of empowering families as an "insider" i.e. one affected family empowering another , offers some practical insights to confront the challenges of empowerment. Above all, it provides a model which may help those involved in family movements to understand the fact that the process of empowerment has multi facets to it that are not evident at the surface. Similarly, the families are not uniformly impacted by empowerment inputs ; there are variations between families just as there are variations between individual members of the same family. The levels or units of empowerment can be the entire family or just one member who may be the consumer. In a family support group initiated by affected caregivers as in the case of AMEND, it is difficult to control the degree and dimensions of empowerment since the entire process was set off from the "heart" rather than "head".

EMPOWERMENT IN AMEND

As a family when we started AMEND, in spite of the four years of experience with my son's illness, we had no clue as to how to handle the new developments in our life. Like it happens with most families even in India, the affected family usually isolates itself from the rest in every way. So AMEND was started mainly to give us a place to socialize with other families like mine. I believe that the initiative itself was a radical step in becoming "bold" or self empowered though I was not aware of this in the context of mental illness. However with passage of time , I realize that it does not happen just like

that. It is so because the process of empowering families is a complex set of action moves inhering discreet strategies and stages of growth. **These may be described as Emotional Empowerment, Informational Empowerment, Cultural Empowerment, Social Empowerment and Political Empowerment.**

EMOTIONAL EMPOWERMENT

Our expectation as a founding family was to seek and offer solace and exchange some tales of "guilt" that used to make us all cry. Most of us were equally ignorant and woefully helpless to face the day to day problems of coping with a mentally ill person. We must remember that in India the primary caregiver is the family . Community support is not only few but beyond the reach of many. So attending to the needs of the consumer is a daily routine *like reading the morning newspaper*. We discovered that many of us felt the need for a support group but most of us were still on the "denial" trip. Even the few enlightened persons were cynical and bitter; told the rest of us to stop bashing our heads against a wall that refuses to break. We were not aware of anything other than medication *but just to be sure , many of us used to carry the prescriptions to monthly meetings and exchange notes*. Soon it was evident that as affected family members we were not ready to *accept* the bitter truth.

Looking back, I now realize that the first step we took forward to empower ourselves was the **emotional acceptance** that our family member is suffering from an illness. It is the emotional strength that reinforces us from *within* and act as a buffer to go through our lives. This was and still continues to be an uphill task but AMEND has definitely helped many of us to not just cope with the problems but play a proactive role in seeking solutions to our problems; this happens formally during our monthly ventilation meetings and informally among members and consumers almost on a daily basis over telephonic conversations. In fact , the hallmark of our emotional empowerment is the recent wedding that took place as an arranged marriage between two AMEND consumers. Be it a consumer, caregiver or a professional , it is essential to remember that Emotional Empowerment is a stepping stone to others.

INFORMATIONAL EMPOWERMENT

The next milestone in empowerment is helping families to have a scientific understanding of mental illness, medication and other treatment methods, side effects of medicines, non-compliance and its consequences etc. As I had already mentioned, familiarity with medicines was not an issue. However, we realized that there was hardly any information on the side effects of medicines, the variety of medicines available, the choice of a drug , shock therapy etc. . The absence of reliable informational inputs among the families and consumers about mental illness set the pace for growth of AMEND. It was decided to meet once a month and also to invite professionals from various fields of mental health to empower with information so as to promote better understanding followed by problem solving skills. This line of action has been a very effective form of empowerment in meeting the immediate needs of families and consumers. The birth of AMEND DATA BANK was a welcome addition to lectures and seminars. WFSAD newsletters are a rich source of information besides many other books and journals and magazines donated by professionals.

Knowledge based empowerment is not enough unless one acquires the skills to implement the same. For example, patients may discontinue medicines due to drowsiness, one of the many side effects . Surprisingly in a quite few cases, it had the approval of family members because they felt that there was good improvement and that any further medication might be harmful or coming in the way of the individual's career and life plans as decided by the families. The inevitable relapses could have been easily done away with if only the families had proper information and communication skills to enforce medication. The widening gap between information and communication was overcome finally as late as 1998 when we designed our Family Education and Training program combining knowledge, techniques, attitude changes and skills inputs, known as TASK training model in short form.

CULTURAL EMPOWERMENT

The history of AMEND is more or less the history of family movement in India. However what is not well known is the fact that it is also a great testimony to the growing camaraderie between families and professionals. The traditional culture imposes a strict hierarchy between the professionals and families identifying the former with the role of "providers" and the latter as "recipients". The communication pattern was mostly one way and the families out of awe and reverence would not venture to share anything other than what the doctors asked for. Differences on a case-to-case basis could not be ruled out but the upshot of our observation was that the families' care giving role, as partners could not be effectively discharged due to cultural factors.

By virtue of my participation in international forums promoted by WFSAD, WAPR and WPA , conscious measures were introduced in AMEND to make families realize their role as partners in care. The positive response to our initiative from professional institutions such as NIMHANS (National Institute of Mental Health and Neuro Sciences)Bangalore, IPS KB (Indian Psychiatry Society, Karnataka Branch) helped in convincing many of us in our commitment to partnership on par with professionals. With the help of WFSAD office bearers Dr.Margaret Leggatt and Mr. Jim Crowe in September 1999, AMEND took the initiative to launch KARNATAKA ASSOCIATION FOR PSYCHIATRIC DISABILITY or KAPD as an advocacy forum of family groups and professionals to ensure and promote the rights of persons with psychiatric disabilities.

For lack of space , I am unable to go into *niti gritis* of the underlying dynamics of cultural empowerment . Nevertheless, the major characteristic of AMEND families as observed by many professionals is the attempt to open up and seek clarifications, something which is culturally alien to India.

Currently there is an increasing emphasis on empowering AMEND consumers. Active consumer participation started as late as 1996. Since then, the voice of the consumers are regularly heard in our monthly meetings *even* in the presence of

their family members. This is a cultural "leap" for a country like India with strong emphasis on seniority and wisdom associated with age. AMEND **pioneered consumer training program in India through its indigenously designed package called "Living Skills Training and Education".**

SOCIAL EMPOWERMENT

Stigma is universal to mental illness irrespective of the countries or cultures involved. The families are deeply affected by the social consequences of stigma that at times it even violates patient's access to information, treatment and medication. Above all, the unbearable emotional and social burden like facing inquisitive neighbors and their volley of questions puts a heavy premium on the well-being of the family in general and consumer/s in particular. These were personally **experienced** by me and other AMEND members too. In fact even when AMEND was started by me, my family and I were not keen to disclose our identity and hence the announcement the inauguration was given against a box number in the local newspaper! Hence to be socially empowered is to confront stigma and overcome it. Once again, we use multiple intervention strategies especially 'PERSONAL STORIES' as a tool to empower our members against the bulwark of social stigma.

Social empowerment poses the greatest challenge because of its close links with emotional empowerment. In other words, even if a family member accepts that her relative is suffering from mental illness, to acknowledge it in public and seek help is a radical step. The two need not go hand in hand. This is what I realize when families, (barring a handful) even highly educated or "westernized" ones for that matter ,are comfortable within the four walls of AMEND but do not wish to disclose their membership in AMEND nor face media publicity. As one mother puts it "why risk more? I have another son to be married. No one will come forward to marry him".

Social empowerment is an uphill and unpleasant task. To be really effective, it needs to have a two pronged attack –one for the affected caregivers and consumers and another for the community at large. Community education is an indispensable input to liberation of the mind from old perceptions, myths and theories. While we have not gone in a systematic manner into it, in Amend community education is done through participation in public rallies, protest marches besides lectures to corporate clients and schools.

POLITICAL EMPOWERMENT

Chronologically speaking from the perspective of AMEND, political empowerment is the last weapon in the empowerment armoury. I believe it is last because AMEND embarked on the political agenda of advocacy only as a response to the PERSONS WITH DISABILITY ACT legislated by the government of India in 1996. However prior to this, the spadework for launching advocacy efforts was in full swing ever since our participation in the protest rally organized by Family Fellowship Network of Bangalore, India. Networking with other disability groups and activists provided further fillip to our nascent advocacy efforts. The burgeoning awareness of consumer rights has led to greater involvement of AMEND in promoting better understanding of mental illness among the officials in the local government. The positive outcomes for families is to appreciate the disabling nature of the illness for developing appropriate enabling and support systems at home and in the community as well.

CONCLUSION

The word empowerment is so widely used to the point of abuse. It is misleading to believe that it implies a neat simple strategy of talking to families. From the experience of AMEND described above, it is clear that it is only the beginning of a multi attack in removing ignorance and helping families eventually to help themselves.

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WORKING THROUGH THE HEART: A TRANSPERSONAL APPROACH TO FAMILY SUPPORT AND EDUCATION

Sheila Shulman Le Gacy

Supportive Family Training (SFT) is a structured approach to family support that focuses on selfcare, education and advocacy. SFT actively works with the suffering endured by families whose relatives have schizophrenia, bipolar disorder, or serious depression. The transpersonal perspective of the intervention is designed to free the energy of individuals who suffer by connecting them to the pain that we all share. The training extends family education more deeply into the emotional and spiritual realm than conventional family interventions. The primary goals of SFT are to improve family coping, teach families to appreciate the importance of self-care, reduce their burden, and enhance their quality of life. Families are taught ways to care for their own needs at the same time that they learn to become more effective advocates for their ill relatives. The 12-week curriculum (and 600 page syllabus) includes practical techniques which can be easily integrated into a variety of family interventions. Based on the article of the same title published in the *Psychiatric Rehabilitation Journal* (Fall, 1998), this presentation will introduce professionals and family members to the methodology of this highly successful approach to working with families.

One of the first lessons family members must learn is to separate the pain they feel for their relatives with mental illness from the pain they are feeling for themselves. Some family members, especially parents, are so acutely tuned into their relative's pain that they haven't dared enter into their own. Once they are able to get in touch with their own pain, however—to enter this pain and work through it—they gain the strength that enables them to accept their relatives with mental illness as they are, not as they wish they could be. It is only at this point that family members can begin to truly address their own needs.

The techniques that I teach in Supportive Family Training are grounded in a transpersonal framework. I use the term transpersonal to mean "beyond the self" or "larger than self."

The goal of the transpersonal approach is to free the energy of individuals who suffer by connecting them to the pain of the world. It may seem a paradox that connecting individual pain to the world's pain decreases suffering, but it can and it often does. Normalizing pain makes it more bearable.

People are hungry for connection and meaning in their lives, and sometimes painful experiences, like the wrenching loss and grief experienced by the families of individuals afflicted with serious neurobiological brain disorders, provide opportunities for making that connection.

> *Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When it is experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares these meanings. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension, it is deeply spiritual.*
> (Eric Cassel, MD. 1982, pp 639-644)

I work with families on several levels. Working with emotions, for example, is given equal status with discussing the causes and treatments of the schizophrenias and affective disorders. I also draw on a wide variety of techniques from adult education, peer counseling, stress reduction, meditation, yoga, bereavement work, and advocacy training. In short, families are taught methods to care for their own needs at the same time that they learn to become more effective advocates for their ill relatives. And though I concentrate on working with caregivers, my long-term goal is to ease the burden for all members of the family, most particularly the person with the illness. My essential message to caregivers is that by attending to their own needs, they better serve the needs of their loved ones and the family as a whole. Any rational systems approach would support the view that once their own well-being increases, families will become more successful at dealing with their relatives.

There are two effective ways of reaching people: through their minds and through their hearts, and combining both approaches is more powerful than using one of them alone. Conventional educational techniques are needed but do not go far enough. Families need both head knowledge and heart knowledge. In my experience individual family members make real breakthroughs when they are able to confront their pain around the illness of their loved ones on a deeper level than that encountered in conventional educational programs. The most important and the most difficult work for families is facing the pain and grief of what will not be. When they get in touch with this reality, and stop pushing it away, they become stronger.

Defending against the pain: I believe that much of the high e.e. behavior manifest by some families, especially critical comments, comes not from just an ignorance of the nature of their relative's disorder, but also from defending against their own painful feelings, especially feelings of grief. Grief can be expressed in many different ways. Sometimes it may be expressed as anger, or as criticism.

Researchers have found higher levels of acute and ongoing grief in families with a mentally ill child than in families whose child has died. Parents of people with mental illness go through he same general phases of grief that parents travel through when they lose a child to death. The difference is that the parents of an individual with mental illness are at risk of "disenfranchised grief" because their loss is not openly acknowledged, publicly mourned, or socially supported.

Grief Work: It is not easy for family members to fully admit to their anger and grief over a loved one's illness and to acknowledge what it has done to their lives. To bring grief issues out into the open, I frequently uses examples from my own experience, using a transpersonal perspective—the sense of shared suffering—as my guide. Grief is intense, but it does not have to go on forever. Lindemann's (1945) work demonstrates that, once persuaded to yield to the grief process, an individual can change in a relatively short time. Supportive Family Training incorporates all the steps that Lindemann considered necessary to the grieving process. The truth, as McGregor (1994) wisely concludes, is that serious mental illness can represent a tragedy to a family, but it does not have to be an unending tragedy. Times of loss offer everyone the opportunity to deepen emotionally, to grow in maturity, to experience spiritual healing, and to connect with one another as human beings.

Working through guilt: I spend a significant amount of class time discussing and working with guilt, which I think of as a very "sticky" emotion: it tends to hang on and take energy away from the family. Many relatives have to be reminded that they have a right to their own happiness. One can choose to do the best one can for one's ill relative, but there has to be a balance. Caregivers who do not care for themselves are not, in the long run, going to be helpful to everyone else. I encourage families to let go of blaming themselves. What's done is done. The past is over. They are not responsible for their family members being ill, but they are responsible for the way they respond to their illness.

The heart of the work is the heart in the work: The classes that I teach are ultimately about personal empowerment. They are not only about pain and loss and suffering although working with these issues is critical. I place more value on families retaining the principles of self-care that I highlight throughout the course than in retaining specific information on brain disorders. It is dramatic to see the change in people from first class to last. Friendships happen in every group and social isolation significantly decreases. The act of moving out of their lonely pain and connecting to one another results in a real change in consciousness for many of the participants: they discover another way of looking at the world. Through suffering one learns to share the suffering of others, and through the gift of compassion, the experience of chronic illness leads to the recognition that somehow, things work out in an examined life that is judged to be worth living.

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ENOSH – DEVOTION TO THE MENTALLY ILL

Chana Abruzki, Chanita Rodney

ENOSH, the Israel Mental Health Association is a public volunteer organisation, dedicated at one and the same time to the promotion of better mental health and to the development of a better quality of life for the mentally ill and their families. The road to reintegration of the mentally ill into the regular community is not a straight one, with very windy, tricky curves, sometimes coming to a dead end, causing us to look for other avenues to carry on to the final destination. Enosh's aim is to discover and develop every possible avenue, leading to the road of rehabilitation and re-integration. In the past twenty years, Enosh established 52 branches all over the country. Support from the government ministries of health, welfare, housing and the National Insurance Institute, have helped the dedicated army of hundreds of volunteer families and other caring citizens to pave the way. In a few branches of Enosh we have been able, with luck and hard work, to find a very generous patron from abroad enabling the mentally ill to live with dignity in the quality of life they so deserve. The latest example of this achievement is the Harry Stern Family – Enosh Center in Kfar Saba, Israel, which provides accommodation for about 20 individuals together with a rehabilitation program, all in a new building opened recently. *Chana Abruzk developed a housing complex for the mentally ill in Kfar Sava. Chanita Rodney was the co-chairman of this conference and Chairman of ENOSH. Email (C. Rodney): rodneyc@netvision.net*

PATIENT EDUCATION: HOW TO COPE WITH FAMILY PRESSURES

Haya Ascher-Svanum

This presentation introduced a comprehensive and interdisciplinary illness management program for adult patients with schizophrenia, aimed at education about the nature and daily management of their illness. The process and contents of the program will be reviews, and focus will be placed on a specific content module of the program: "Familial Stress", or: How to cope with pressures and demands from family members. In this module, the first step is to identify patients' perceptions of the behaviors and attitudes displayed by family members. Patients often feel dislikes, misunderstood, criticized, bossed around, and trivialized. The patients then describe the manner in which they typically react to perceived demands, and are offered alternative, practical and more adaptive modes of reaction. Such strategies are seen as helpful for the patient and the family members, as they place clear expectations and greater responsibility on the patient, without waiting for family members of change first.

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AASHA – THE STORY OF INDIA'S FIRST FAMILY GROUP

KK Srinivasan

Aasha, India's first family organization recently completed ten years of eventful existence. In a country where the family is central to the care and rehabilitation of people with schizophrenia, a family group such as AASHA has had its share of successes and disappointments. We have encountered many problems and attempted to find solutions. This presentation will trace the history of AASHA from its inception to its current status and highlight the above issues.

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COMMUNITY MENTAL HEALTH THE REGION OF PATAGONIA, TERRITORY: 212, 000 SQ. KM; POPULATION: 600, 000

Hugo Cohen

With the arrival of the democracy in 1985 we started our work of providing decent answers to the people who for one reason or another were marginalized and as such were hospitalized in psychiatric institutions. This long process, still in progress nowadays, has had several great achievements.

Among the principal ones:

- the closure of the only psychiatric hospital of the province and the creation of twenty mental health centres at a local level with their bases being the general hospitals.
- the creation of 'Law 2440 of Social & Health Promotion of the Mentally Ill People', the first mental health law in Argentina.

Following the principles of community mental health we are attempting to bring out the best in these people (as much as their health allows), strengthen and promote the talents and abilities of all individuals. Unconventional work methods are being incorporated in the work of the local mental health centres.

Along with psychiatrists, psychologists and mentally ill there are natives, teachers, priests, recovering alcoholics, artisans, etc., accounting for more than 40% of the total paid personnel. The task of helping others meant there would be a serious reorientation of the services. In reality people in crisis are interned in the common halls of the general hospitals. Also, domestic care is being promoted.

As far as the socio-community aspect is concerned, the work of the health centres has had one significant development and that is the creation of seven social and cooperative clubhouses with the objective of being places for effective rehabilitation, avoiding the protected practices or the practices of ergotherpay. The rehabilitation includes the person within his/her usual social circle getting satisfaction from the recognition others show for the product of his/her work. The consumers and their families get support by these health centres by getting visits at home.

Therapy and self-help groups have been formed, similar to the seven mental health centres we previously mentioned. For a short quantitative summary of their work we can list the following:

- the average reduction of the period of hospitalization has gone from six months to eleven days;
- the significant increase in the regions covered by these support groups greatly facilitates accessibility;
- the previously 14 000 annual consultations are now approximately 175 000;

- number of people hospitalized (internalized) due to a crisis has gone up to 1250 from previously 195.

Only in the last five years 5000 people have been hospitalized without the need for being locked up, neither needing the use of electric shock (prohibited by Law 2440). Episodes of violence occur rarely, since the community has gradually built the mentally ill people's original ability of resistance by supporting them and making living with those who are different easier.

Dr. Hugo Cohen's paper was read by Martha Piatigorsky
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BEGINNINGS IN ESTONIA

Galina Podverjoznaja

Families in Estonia are still standing at a distance from the psychiatric rehabilitation system feeling guilty, defensive, lonely and often not willing to cooperate, afraid to be too critically reviewed by us and labeled as pathogenic. Our social authorities are verbally positive to support but are lacking the resources, willingness or competence to give real help. If helping they often assist with housing, social economical support and home assistance. Often, the existential problems of our patients find no answers. They get in contact with regressive religious movements, which sometimes lead to social network and significance, but all too often to psychotic relapse.

The patients' families are helpless and lack our support. They often have to face impossible choices and conflicts of loyalty when family members are relapsing. We need professionalism to inform patients and their relatives about the facts of schizophrenia, its prognosis and possible treatments, in order to reduce anxiety through knowledge. We need to create a basis for mutual trust. The right treatment has to be given at the right time during the different phases of the disease process. Patients with different types of schizophrenia differ greatly concerning symptoms, course of disease, prognosis and treatment. Patients on the way from schizophrenic psychosis to health become often more neurotic and have completely different therapeutically needs than during the acute psychotic phase. Professionalism is needed to facilitate the understanding of supervision, psychotherapy and family therapy. It's difficult to manage patients with schizophrenia without involving relatives even if it is only to interview a family member in order to provide corroborative history.

In the psycho-educational family program the family support consists of different parts during the time of treatment rehabilitation.
The program includes:

- Support in crisis
- Information and advice
- Psycho-educational family therapy
- Support groups

When a person develops schizophrenia, everyone in his family becomes affected. Family members see someone they care about develop strange ideas and behaviour and unusual rituals or belief systems.
The patients themselves do not seek help from professionals on their own. Therefore families probably have gone through a long period of stress before they are able to get in contact with psychiatrists. In our meetings we must focus on getting knowledge about the family with attention paid to individual needs and hopes of each family member, as well as to the method the family has used to be able to live with the illness and how they respond to the crisis. The patient is always invited to the family sessions. Instead family members should be helped to feel that they would enter into a cooperative relationship with the treatment team to help the patients. We can decrease anxiety and give specific information about the treatment process. It is very important to give family members the message that we do not believe that families cause this illness.
Our education of families is laid out as a study session. We invite family members by a letter and by the newspapers where we describe the program, the purpose and time for the sessions. Sometimes I make contact with the family by telephone.
It is very important to know that consumers are individuals with unique experiences that respond well when they are listened to and understood and they can manage their illness better, if they are educated about it. We educate our consumers. The aim of this education is to give to the clients the opportunity to come out from everyday routines and to participate together at the workshops and communicate with other clients. The major goal of our training program to users is promotion and maintenance of people with severe or long term mental disorder and severe or medium retention of mental development implying their integration into social life as independent as possible through their psychosocial rehabilitation. At first what we told to clients are guidelines toward wellness.

- Learn to recognize the signs of an oncoming bipolar cycle
- Knowledge about the medication
- No human being is perfect; we all need help.

All these topics for seminars we were looking for together with organization for consumers of mental health services "Davy" with NGO "Independent Life" and with NGO "Union of Supporters for Estonian People with Psychiatric Disorders".
Working together with families I know that the goals for treatment and care are understood and agreed by the treatment team, which includes the family. Relatives have a great deal of experience in caring for their relative and professional careers can learn much for them.
We have done educational programs for volunteers who will work with patients with schizophrenia. The aim was to provide further training for people who had some experiences.
We know that it is hard work but we are sure that we found a lot of enthusiasm to work with young schizophrenia sufferers who already have a long psychiatric history. The counseling care helps both families and client to deal with unpleasant experiences caused by the "mystery of madness". It helps to solve everyday difficulties using the creativity of the families. We consider it fundamentally important for clients to take active roles in their treatment by participating in our program.

Mental illness is not only a medical question but it has been a human problem for hundreds of years, which has had different solution, both good and bad. I believe that our projects attempts will make people understand that people with schizophrenia are not dangerous among us.
Our family camps, what we do always together - clients, family members and professionals- show that together we have power which helps us in our hard days.

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INFLUENCING POLICE TRAINING IN MENTAL HEALTH - AN INSIDE STORY

National Schizophrenia Fellowship (NSF) Training Project for Prison Officers in the UK

Fred Carney

The Director General of the Prison Service, Martin Narey, has invited NSF to conduct a series of courses on mental health awareness for Prison Officers throughout England and Wales. This initiative is welcomed and supported by Sir David Ramsbotham, HM Inspector of Prisons. NSF is commissioned to give input to the core curriculum training for new prison officers at HMP Training Colleges in Wakefield and Newbold Revel near Rugby, on a pilot basis.

Lord Justice Woolf who spoke at our AGM a few years ago remarked how good it would be if prison officers were to receive the sort of training which NSF was providing for social workers, at that time. NSF has tried to many times to influence the training of prison officers. We have negotiated meetings with the Healthcare Directorate of the Prison Service; conducted workshops at conferences for prison governors; conducted NSF exhibition stands at other prison conferences and last January conducted our first training day within a prison involving the governor and nearly fifty of his officers and other staff.

CARE OF MENTALLY ILL PEOPLE IN PRISON AND ON RELEASE

NSF POLICY

1 NSF endorses the World Health Organization statement that deprivation of freedom is bad for mental health and that prison can cause significant mental harm. Nevertheless mental well-being can and should be promoted in prison.

2 All prisoners assessed on reception or subsequently as having a mental health problem should have a health care of a standard equivalent to the National Health Service, including access to second opinions.

3 In general, offenders known to have, or identified as having a mental illness should not go to prison, either on remand for a psychiatric report, or when sentenced, but be diverted from the criminal justice system into the care of health and social services at the earliest opportunity.

4 Where they have committed a serious crime they should receive care in a secure setting, such as a special hospital or secure unit, with a level of security appropriate for their needs.

PRESENT POSITION

1 Despite the development of diversion schemes, many offenders known to have mental health problems still go to prison rather than being cared for by health & social services. *(1)*

2 There is a high incidence of mental disorder among prisoners. 66% of those on remand have a psychiatric diagnosis, and 40% of sentenced prisoners.*(2)*

3 10% of men on remand, 70% of sentenced men and 14% of female prisoners were recently found to be suffering from psychosis, and around 5000 people with psychosis are detained in prison at any one time.*(3)*

4 About 75% of in-patients in prison healthcare centres have mental health problems *(4)*

5 There are 135 prisons and 135 models of healthcare" *(5)*

ACTION NEEDED IN PRISONS

1. Better training of healthcare staff , who often lack appropriate psychiatric qualifications *(6)*

2. Training for disciplinary, workshop, education and other staff to raise awareness of mental illness, help with recognition of the symptoms and their management, and understanding of the needs of those who suffer in this way. *(7)*

3. The role of Mental Health Resource Officers for each wing or unit should be created. A written practical guide for each wing should be provided. The Prison Service should commission accredited training for trainers by a Voluntary Organization acting in partnership with a university. This would include the development of training materials. *(8)*

4. Special attention to identification of mental health problems at reception screening and to prevention of suicide *(9)*

5. Arrangements for speedy transfer to high and medium secure psychiatric services where these are needed *(9)*

6. Use of the care programme approach when planning and delivering services and for individual prisoners *(9)*

7. Special efforts to provide appropriate treatment and care for mentally disordered prisoners who have not been offered or who have refused mental health services in the community *(9)*

8. Careful preparation for aftercare and follow-up services after prisoners' release in co-operation with community mental health teams.

Notes:

(1) 1997 Social Services Inspectorate Report – Services for mentally disordered offenders in the community
(2) 1998 Health Education Authority factsheet

(3) *1998 Survey by Office for National Statistics. These figures vary considerably higher than those reported in other studies*
(4) *BMJ April 2000, Survey by Dr John Reed and Nurse Maggie Lyne*
(5) *Dr Sheila Adam, speaking at Prison Healthcare Conference, June 1999*
(6) *NHS Executive and Prison Healthcare Working Group Report*
(7) *World Health Organization – Mental Health Promotion in Prisons*
(8) *Training Needs of Prison Officers in relation to Mental and Personality Disorders: assessment of interviews in four prisons by Jo Paton, Institute of Psychiatry*
(9) *Principles of the New Prison Mental Health Strategy, McCann, Mental Health Care, Oct 99*
(10) *Survey by Dr John Reed and Nurse Maggie Lyne 1998 reported in BMJ April 2000.*

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EMPOWERING COMMUNITY WORKERS TO BETTER CARE FOR THE MENTALLY ILL

John C. Mbuthia

Kenya like many other developing countries is disadvantaged as far as mental health is concerned. Mental health professionals are very few. Mental patients are associated with violence and not many people want to train in this field. Mental disorders are still associated with witchcraft or a curse. It is therefore important to train community health workers. These are opinion leaders in community and at village level who could be trained to assist in the care and management of the mentally ill. They could also assist to dispel the fear and misinformation about mental illness.

The removal of ignorance among the family members of these patients will encourage them to participate in caring for the mentally ill. We have encouraged every member of our group which has reached to over 80 to participate in these activities. We would also like to publish a news letter both in English and local languages in order to pass information related to mental illness. Lack of drugs, poor communication in form of transport has made it difficult to discharge this important proposals. Mental health delivery services in Kenya is a long way from what it should be. Many husbands have walked away from their wives and vice versa because they have become mentally ill. Some students have been sent away from school and some people have lost their employment for the same reasons and lack of intervention. A female patient turned to the streets by relations may fall prey to street boys and watchmen and pave way for possibility of acquiring HIV/AIDS. This makes it all the more important to educate the community to take care of their mentally ill people though we know that the availability of psychotropic drugs is a real problem.

Psychiatrists in our country are very few and the nurses (psychiatric) who have been the backbone of psychiatric services have moved to other countries in search of greener pastures. That makes it more important to empower community and family participation in caring for the mentally ill.

The task ahead of the Schizophrenia Foundation in our branch is really hard but not impossible to achieve. But we need assistance and participation of every person who has the welfare of mentally sick at heart.

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PROGRESS IN THE SLOVAK REPUBLIC: OPORA

Jana Lojanová

In Slovakia, organizations of families in Bratislava, in Michalovce, in Košice and Banská Bystrica began their work in 1996-97. In 1999, the Slovak National Association of Relatives and Friends of People with Mental Illness, OPORA was established to coordinate the activities of these organizations. OPORA's main goals are to develop solutions to the problems of mental health care and to advance the position of people with mental illness in society. Our main areas of concentration are human rights of people with mental illness, addressing their needs and demands, and providing some basic necessities, e.g. housing and employment. OPORA would like to cooperate with our partners to eliminate discrimination against people with mental illness and their families, to promote their integration in society, and to achieve their equality with other people.

Relatives of people with mental illness recognized and understood that they can be useful in the following ways:

1. To openly discuss the situation of families, to eliminate feelings of shame and embarrassment

2. To request institutions to perform their duties appropriately

3. To participate and cooperate in the solving of problems.

Our short term goals are:

- To widen the network of associations of relatives;
- To educate the members of our organizations;
- To strengthen our identity and commitment to improve the lives of people with mental illness

Currently, OPORA, with our partner, Integra is involved in opening a "House of Mental Health" in the town of Michalovce, the first of its kind in the Slovak Republic. The house will include supported accommodation and a rehabilitation center.

In Slovakia, we have a strong tool in the tetralogue, a dialogue of four partners: users of mental health services, professionals, relatives and the public. OPORA actively participates in the tetralogue.

Our association wants to be strong, knowledgeable and aware enough to recognize and break down the barriers faced by people with mental illness. It is important for OPORA that society recognizes and takes our work seriously.

If the Geneva Initiative of Psychiatry and Open Society endorse our projects, we can reach our goals.

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FAMILY CLUB, MOSCOW

Nellie Levina

I represent Family Club, a regional Society of Parents and Friends of Mental Patients in the city of Moscow. At the present time the role of a family in the creation of favourable environment, better quality of life and relapse prevention of mentally ill relatives finds wider recognition and understanding. At the same time family itself is in need of assistance and support. The cultural peculiarity of Russia is that young mental patients live with their families. So parents appear to be the main caregivers. The problem of family burden is very painful in Russia in the absence of necessary support from the state and community resources. This conference is focused, in particular, on different types of support to families facing the problems with their mentally ill relatives.

We set up our public association Family Club as one of the ways to give practical realization of this support. We tried to use relevant experience of similar organizations in other countries and we gained modest experience during the course of our work.

Our efforts were focused on self-help through the exchange of knowledge, practical experience and moral support. We started from small groups of 2-3 persons at the neighborhood level to give psychological advice to families under extreme situations. Then, we arranged visits to a swimming pool for groups of mentally ill children accompanied by one of the parents and we attracted coaches from the Faculty of Rehabilitation Physical Training of the Russian State Academy of Physical Culture to help us in this activity.

Furthermore, we applied to the board of directors of theatres and concert halls for a possibility that we could attend performances and concerts on a free of charge basis and many of them positively responded to our request.

We arranged free bus excursions to visit memorial places in the vicinity of Moscow including a boat trip down the Moscva River. This experience turned out to be very useful for both children and their parents who had a good chance of getting acquainted and communicating with each other. Unfortunately, under the current conditions of limited financial resources it is not always possible to realize all our plans. However, our relatives and friends try to help us as much as possible.

To provide the necessary advice to our parents we organized a seminar called "Psychological Self-support and Communication Skills which was arranged on a permanent basis with the involvement of psychologists from the Psychological Centre Circle to take place at the Public Center Peace Progress, Human Rights named after Andrei Sakharov. The whole cycle of seminar lectures, which attracted a great deal of attention from parents, was repeated three times.
In the course of our survey investigating the possibilities and conditions of various families we devoted special attention to one-parent families which in first place we are in need of psychological support.

To provide our parents with the necessary books and journals we organized our own library to include papers and information materials sent to us by various international organizations of parents and friends of mentally ill people such as WFSAD and Geneva Initiative of Psychiatry.

We think it very important to promote contacts with professionals such as psychiatrists, psychologists and social workers. We are closely collaborating with the Russian Society of Psychiatrists, which supports our initiative and renders us its free advisory assistance. Thus, the Head of one of the Moscow Outpatients Mental Health Clinics provided us with premises for our activities.

Among our parents there are people of great creative potential including teachers of higher educational institutions, researchers in various fields, etc. We try to use their potential to involve them in our work as much as possible and they are ready to help us. So some of them run classes for our children in various interest groups. The main direction of our activity is Families for Social Rehabilitation of Mentally Ill and in this respect we hope to get necessary financial support of charitable funds to carry out a project including the following major programmes:

- Educational rehabilitation
- Psychological education for people with mental health problems
- Psychological training for family caregivers
- Information
- Advisory assistance including on duty service of organization members and consultations of professionals provided on a regular basis

Educational rehabilitation programme will include:

- Leisure time educational classes for various interest groups (foreign languages, music, painting hypnotherapy, swimming, sports, computer classes, traditional handicrafts)
- Leisure time and subject meetings
- Excursions, visits to theatres, museums, etc.
- Library and cinematheque activities

The Psychological Training Programme for people with mental health problems and family caregivers will be arranged in the form of group educational classes.
The Information Programme is to provide with information about relevant services which could give their assistance to mentally ill people and their families including information about job opportunities, legislation in social sphere. The most important information will be published in the Internet and press.

Advisory assistance and on duty service of organization members and one-time consultations of professionals is to be provided on a regular basis. Necessary individual advice will be given to families with mental health problems on specific issues and if necessary assistance will be given in establishing contacts with relevant services. Sensitive groups will be operating on a constant basis.

All of the above referred to our Moscow organization Family Club. However, the Russian Federation includes 89 subjects and all of them come across similar problems. The

Plenary Meeting of the Russian Society of Psychiatrists supported our initiative to establish All-Russia public organization of relatives and friends of mentally ill people and we started our practical steps to set up the regional divisions in various subjects of the Federation. In this case it is possible to use both our own experience and experience accumulated in various regions, for example the cities of Kaluga, Kirov, St. Petersburg, Kaliningrad, etc. We sent the necessary foundation documents a draft Charter to the regions and started our activities in each region. Information on our initiative was published in the journal of the Russian Society of Psychiatry.

We hope to finalize our work for the establishment of all Russian public organization of relatives of mentally ill people during the current year.

In conclusion I would like to stress once again that we are a voluntary organization and we need each other because it is our common grief that has brought us together and made us consolidate our efforts to support and help our mentally ill relatives.

Nellie Levina, Family Club, Moscow, Russia. Email: eu@qub.com

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ADVOCACY AND EDUCATION – TWO ZENKAREN PROGRAMS

Kazuyo Nakai

ADVOCACY (ANTI-STIGMA MOVEMENT)

Stop the Disqualifying Clauses (D.C.) against mentally Ill Persons

The Disqualifying Clauses are various regulations which sweepingly exclude mentally ill persons from certain occupations and prohibit them from certain actions. An example of these exclusions is that mentally ill persons are prohibited from taking an examination to obtain a license to drive. Mentally ill people may not take up occupations such as cook, hairdresser, interpreter and so on. The most ridiculous example is that transportation companies must refuse a mentally ill person from boarding a bus if he/she is not accompanied with his/her attendant.

Ten years ago mentally ill persons were prohibited from entering city hall, museums, libraries or public swimming pool. At that time there were more than three hundred Disqualifying Clauses (D.C.) in Japan but now after thirty years' fighting by family groups to abolish them, the number of D.C. has gradually decreased.

Still, at present there are seventy-two D.C. against persons with disabilities and fifty-five of them are targeted on people with mental illness. These D.C. are nothing but discrimination against mentally ill persons and as a result, increase stigma against them.

Zenkaren is now on the high road to abolish all of these D.C.

EDUCATION

From Family Education To Doctor Education

Inspired and supported by WFSAD these ten years, Zenkaren has been successful in family education and we found professionals are not always professional.

More concretely, doctors sometimes are not so much interested in new (atypical) medicine as families; do not know what Expressed Emotion is or how to cope with patients. This is the first reason why doctor education is needed. The second reason is that we need to stop critical comments by doctors in high EE. We have just learned how important it is to keep a calm and positive atmosphere (as espoused by EE theories) to reduce the relapse rate of patients. We go to hospital to be treated. Still, in reality many patients and families get worse and feel pressured after visiting hospital because of critical comments of doctors in high EE. We can not endure this situation any more. Zenkaren is now aiming at the new century when doctors do not choose patients but patients choose doctors.

Families are working together and finding a new better road.

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This first quarter newsletter of the World Fellowship for Schizophrenia and Allied Disorders is a special issue devoted to the proceedings of our Biennial Conference: "Strengthening Families Through Empowerment" which took place in Jerusalem in May, 2000.

The editor for this issue: Diane Froggatt

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