



The World Fellowship for Schizophrenia and Allied Disorders

THE CONSIDERABLE CONTRIBUTION OF FAMILIES IN THE REHABILITATION AND CARE OF THEIR MENTALLY ILL LOVED ONES

Address to the World Federation for Mental Health Congress, Tokyo, 1993 by Diane Froggatt

This is a historic moment for families and the relationship of family organizations to the World Federation for Mental Health Congress. Tokyo is the first location where the role of the families of the seriously mentally ill has been recognized as important enough to have its own Theme. And could there be a more suitable beginning for such a partnership? A country where there has been a family organization: Zenkaren, for almost twenty-five years -- one of the oldest of the family self-help support organizations in the world.

A little historical perspective is in order here. It was the decade of the 70s in which the family movement really got going. The most representative story comes from England where John Pringle, whose son had schizophrenia, wrote for the Times of London, a moving article about the plight of his family and his son. He was inundated with empathetic responses. Within months the National Schizophrenia Fellowship was born. The names of our revered founders all around the world are etched in the memories of families, who speak of them with pride, love and gratitude. Those men and women have indirectly released hundreds of thousands of families from the isolation, despair and the stigma that comes from being alone with serious mental illness.

Over the years each organization as it was born, nurtured, and grew, developed its own special identity and was molded by the love within it, for make no mistake, the family movement is created of love -- love for people struck down with schizophrenia or depression -- love for others whose situations mirror your own -- love for all disadvantaged people. It is this love and the commitment to pass on its benefits to others, which makes us unique. We are not a bureaucracy, we are flesh and blood. We can never abandon the movement while people still suffer major mental illnesses and families and their loved ones are out there struggling with them. And this is what makes us strong. We are life members.

Those who do not understand the family movement have sometimes called us "weeping willies" -- inward looking and sorry for ourselves. Having spoken to families who have just heard the diagnosis I can attest to this description. The personal agony can be overwhelming. But when you look at the accomplishments of families and their patients you realize that while the weeping never stops, the strength, solidarity and determination of the family movement in its mission to make life better for patients, goes far beyond tears.

There are more than fifteen family self-help/support organizations, which have taken on a national role in their countries. (Slide) The majority of these fellowships and associations have membership in the World Schizophrenia Fellowship which acts as a conduit for information around the globe. (Information about the WSF is available at the session.) These organizations are lobbyists for serious mental illness in their respective countries (slide #): urging reforms, drawing up proposals, gathering statistics, influencing public and government opinion, raising research funds, and generally dragging schizophrenia reluctantly out of the closet. Because governments are not notorious for innovation, it is the families who have pushed for new types of comprehensive care for their relatives. It is a rare government that provides more than basic care for its country's mentally ill. Politicians do not win votes by opening residential care facilities in peoples' neighbourhoods. The only people who can be

found to truly care about the mentally ill are their families. In many instances look behind the office door of a drop-in centre or a residential care complex and you will see a parent/ spouse/ sibling or family organization directing the operation. (Slide: NZ House) Quite often it is after families have taken considerable risks and begun such a venture that funding and government agencies become interested.

By far the major role of families as a movement, as a national group, as a local group or singly, is to fight for decent care for their relatives and to provide the information and education that are so sadly missing from doctor's waiting rooms. (slides: books, public awareness display, fight schizophrenia banner). And because each family knows it is part of a local, national, and global network it gathers strength from that knowledge. All around the globe the mental health systems can be called to task for not dealing honestly, compassionately or fairly with the mentally ill. Families, with their family organizations backing them up, may confidently question these systems: in their political representative's office, during court hearings, at the doctor's office. The mere words: "I am a member of Zenkaren/ or the New Zealand Schizophrenia Fellowship or other group); " . . . they have advised me that ... this care is inappropriate/ this housing is inadequate/ . . . gives them strength to speak and seems to open doors, or at least introduces an atmosphere of professionalism.

But if everything on the family movement horizon were positive I would not be here. There is an incredible amount of work to be done. The most recent and shocking television scenes from just outside Sarajevo, where mentally ill and retarded patients were abandoned in locked wards, is a chilling reminder that people with serious mental illnesses are truly at the bottom of the pile; the most rejected; the least respected; the most reviled (Slide # Quote June Beeby, SSO Canada). They have no authority, now power, no clout. Emergency departments often turn a schizophrenia patient seeking help away without the least fear of consequences. Psychiatric patients are regularly discharged to the street without any means of support and who is to care or censure this action? How different would be the case if cardiac or cancer patients were treated in such a cavalier fashion. In some places a hospital can deprive a resident of the use of the telephone, or even the right to receive letters from his family. It all boils down to the patients' lack of clout. So, who can supply the clout? Who can provide power for the seriously mentally ill? With strength in numbers, families are filling this role and are speaking out for their relative who needs and deserves the quality treatment and humane care that is the right of every sick person. There is strength in numbers. Only 3/4 million families world wide (at an optimistic estimate) belong to family self/help organizations. The WSF has helped to begin five new groups (this totals 200 families) in the past two years. How great would be our strength if we could include among our membership all the families of all of the mentally ill world-wide. Let us begin this work today.

The families of the mentally ill have not been looked upon as a force to be reckoned with in the past. There is an ancient Irish expression "outside the pale". In a rough explanation it means that one is not included in the protection and care given to a community which is "inside the pale", the pale being a spiked boundary fence. For years many families, dealing with serious mental illness and disability have found themselves "outside the pale". Although they may have had significant information and experience to help with the management of their relative, they remained, and often still do remain, outside the hospital treatment team, outside the out-patient team, even outside the plans of any community worker assigned to the patient. (I am going to use the word patient. I am not going to use the word consumer. The word consumer suggests that there is ability to shop around for services/ doctors, etc., whereas, in reality the people I am talking about are often, like their families, "outside the pale" of the mental health system, put there by their persistent disorder, their confusion, their paranoia, and the disabling effects of these.)

Of course, there are several reasons for families and even patients being "outside the pale". The first is a horrible, historical reason. In the sixties, when no-one could come up with a cause for the schizophrenias, it seemed logical that those frantic people who were trying to look after a mentally ill person were themselves at fault, even to blame. Of course these theories have long since been debunked, but many of the offending text books have not been removed from library shelves of universities, schools of social work, departments of psychology - they often still turn up in public libraries. In addition, quite new text books often impart erroneous messages about the severe mental illnesses. While enlightened professionals have moved on, there still remains a segment of the population who mistakenly believe that the treatment of someone with schizophrenia or depression is best attempted without the inclusion of another complicating factor - the family!

A second reason for excluding families from the treatment and care of their loved ones has come about indirectly. Because of the limited amount of funds made available for the care of mentally ill people, fewer

doctors have been hired in hospitals, there are fewer nurses, and fewer beds. When there is less money to spend on health care, the psychiatric hospitals and departments are the first to suffer cut backs. Governments are pragmatic. They know that the seriously mentally ill are unlikely to offer a serious lobbying threat. They know that the families who look after them are often too burdened to offer serious resistance. They may also be aware that the professional psychiatric community has always been loath to stand up for itself, almost as if it is tarred with the same stigma brush that has touched people with schizophrenia. In the future, however, it will not be so easy for those responsible for treating the mentally ill and the governments who make the laws to ignore family pressure. It is up to the family movement to act as a union fighting for the best possible deal for its members.

As a result of often chronic under-staffing, the last thing doctors want to have to do is to interview the patient's family. An hour long meeting with family and patient may seem an unnecessary nuisance given the doctor's heavy workload. However many excuses are made for not including the family in the treatment of their relative, it comes down to poor medicine and poorer care in the end.

I have been talking to doctors in other clinical areas: to my dismay I find that lack of communication with relatives is common in many areas, particularly among the younger doctors, who are very much "science" and "test" oriented rather than focusing on the patient as a person with a concerned family -- a family who will inevitably have to deal with the patient's problems along with the patient for much, if not all, of their lives.

Separating the patient off from his family in this way has gone a step further in some societies. The family doctor or psychiatrist can be instrumental in worsening the patient's situation by adhering rigidly to the "need for confidentiality". Communication and understanding are brought to a standstill: the family is once again "outside the pale"

We can overcome these difficulties, cross the pale, but the nature of the disorder we are faced with doesn't make it easy. The schizophrenias and some depressions can make the patient literally unable to tell the doctor how he feels about anything. The fluctuating nature of the symptoms may make him say one thing today and another thing tomorrow. The fluctuating nature of his feelings may make him angry or sad, or critical or belligerent all in the same day. He will deny he is ill, refuse to take medication and agree to take it again -- all this is part of schizophrenia. It takes a particularly sensitive doctor, and one ready to hear from both the patient and the family, to sort out the problem and help the patient towards recovery.

Families are involved. They should be consulted.

In Japan, people with serious mental illness often spend years in hospital. In what we choose to call "the west" psychiatric patients spend considerably shorter periods of time in long stay facilities. What we would wish for, is a solution which ranged somewhere between the two. There is no doubt that many people need the protection and safe haven of the psychiatric hospital, some for protracted periods, some for periods of several months. The closure and reduction in size of mental hospitals which is happening and has happened (largely as a result of the human and civil rights movements) in the United States, the United Kingdom, Canada and New Zealand, to name only four countries, has simply moved the problem elsewhere, into the streets and into the jails, rather than solving it. I urge you here in Japan, in the words of Rael Jean Isaac, author of the American book *Madness in the Streets*, to "make your own mistakes, don't copy ours".

It is wrong-headed to treat people with serious mental illness as though their brains were functioning normally. This is what is being done in societies where care outside the psychiatric hospital is being advocated for nearly all psychiatric patients. This notion springs from the idea that all you have to do with someone who is mentally ill is give them a decent place to live, an income and one or two people to keep an eye on them and the problem is solved. This naive notion has taken hold in many areas to the detriment of those with schizophrenia and depression and to their families on whom the whole burden of care eventually falls. In the community with his illness, the person may leave his place of residence, stop taking medications which have kept him relatively well till then, and become disoriented. He will almost certainly neglect his physical health and hygiene. In this vulnerable state he may become the victim or the perpetrator of petty or major crime. And for the large number of people who refuse medication, often because they don't believe they are ill, no amount of social services and good housing will re-integrate them into the community without treatment.

It therefore falls to the family to fight for the maintenance of the psychiatric hospitals while seeking their constant improvement and development. It is the family's responsibility to come up with workable plans that will make new

forms of institutional and community care and rehabilitation a working option for patients. Off-hand I can think of about 20 programs begun and run by families. There are many more - but what we need are many thousands more. Begin working on it today.

IF YOU DON'T – NO ONE ELSE WILL.

**IN A CITY OF 11 MILLION
OVER 50,000 PEOPLE ARE SICK WITH SCHIZOPHRENIA.**

**THE NUMBER OF PEOPLE WHO WILL BE DIAGNOSED
AS HAVING SCHIZOPHRENIA THIS YEAR IS ABOUT 1 IN 4,000.**

**IN TOKYO, 3,000 PEOPLE
WILL BE NEWLY DIAGNOSED WITH SCHIZOPHRENIA THIS YEAR.**

THESE FAMILIES NEED OUR HELP.

[Figures derived from Schizophrenia Simplified by John Thornton and Mary V. Seeman. Published by Hogrefe & Huber Publishers. 160 pp. 1991. Toronto, Seattle, Bern, Gottingen.]

Let us work to lessen the burden on families just now having to face a diagnosis of schizophrenia, the most difficult of all the mental disorders. Let us strengthen our family of families by playing an active role in our own group. Let us volunteer our effort to build a family movement that is truly a global presence to be reckoned with.