An Overview

Diane Froggatt

Asked about what single change would substantially improve quality of psychiatric care, Professor Julian Leff replied "Listening to and implementing what patients and their carers want." In answer to a question on what single area of psychiatric practice was most in need of development, he replied "Including the family in any consideration of the patient's problems, needs and strengths"(Fannon 2004).

With the introduction of community-based care and the reduction in the number of beds in both psychiatric and general hospitals, there is no doubt that the responsibility for care falls mainly on the family and the person's social network. We define the family as those in a close personal relationship with the patient whether or not they are blood relatives. The fact that many mental health professionals see patients who are estranged from, or distant from their families is likely to be an indicator of the difficulties families are having holding the family together and providing ongoing support to someone who is unwell and unable to function as previously. Families attempt to care for someone who may:

- have bouts of acute psychosis;
- exhibit little motivation for most activities;
- be self-absorbed much of the time;
- hardly contribute to the household;
- have cognitive difficulties giving rise to forgetfulness, misunderstandings, irritability, frustration, and sometimes outright hostility.

Initially families are completely unprepared to deal with the challenges of this role and need the benefit of professional assistance and resources to help with the care and management of the patient, as well as linkages to self-help support. When these are available, there is a two-way exchange of information that can add immeasurably to the clinical team's knowledge base and help in the patient's recovery process.

While doing research for the guidebook we talked to clinicians and researchers and families. One mother was quite eloquent about family involvement in care:

> "Some years ago my son was admitted to a well-respected psychiatric hospital in a town two hours away from our home by car. Prior to his admission the treating psychiatrist had interviewed our son together with my husband and I. We asked if we could be involved in the care of our

son so that when he left the hospital we would be in a position to aid his recovery. "Oh yes", said the psychiatrist and gave me the number of the hospital social worker. We were unable to see her but spoke on the telephone. She advised us to come to the family session held regularly on a certain day once a month. To our dismay it turned out to be an hour-long session for several families new to the hospital. It described the illness, symptoms, etc. and there were no further sessions. There would be no personal exchanges about the treatment, no directions about how we should look after our son, or concerning the problems that we were constantly attempting to deal with. It was difficult to get anyone to return our calls. It was, indeed, paying lip service to family. If and when the was evaluated, they could answer "yes" to the question "Do you have a family program?"

Out of Research and Into the Community

There is an overwhelming body of scientific evidence in the research literature that confirms the value of family interventions in comprehensive care. It was this information, already long in existence in the 1980s, that was the catalyst for the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) to become another strong voice advocating for family inclusion.

The evidence continues to grow, so that the inclusion of families as a formal part of the treatment team is widely accepted in research circles. The problem has been getting it out of research centres and into community-based care on a large scale. We hope that this guidebook will help with this task.

There has also been a dearth of training opportunities for professionals in mainstream graduate and postgraduate studies. Thus professionals are left to their own devices to develop family programs (McFarlane et al. 1995). According to a personal communication from William McFarlane the weight of evidence is finally tipping the balance as more and more departments, services and clinicians accept, develop and adopt models of psychoeducation. This guidebook aims to accelerate this process.

Throughout this book we will demonstrate that:

- family work is valuable to the treatment team and the family

- the new skills required for mental health professionals can be learned through appropriate training

- it is eminently possible to introduce family work into any department or service

- many of the challenges to family work can be overcome with the right approach

- implementing family work will help improve patient care and make the mental health professional's job more rewarding and fulfilling

The WFSAD Families as Partners in Care me – A View of Family Inclusion

The WFSAD strategy to encourage the implementation of family work as a formal part of a comprehensive approach to treating patients with serious mental illness was launched as the 'Families as Partners in Care Strategy' at the World Association for Psychosocial Rehabilitation Congress in Hamburg, Germany in 1998.

At that time we identified three major problems associated with attempts to care for the mentally ill in local communities.

Systems lacked:

1. appropriate and sufficient community support and rehabilitation facilities;

2. information, education, training, and support for the families or carers who had the emotionally distressing task of caring for a loved one experiencing mental health difficulties;

3. training for mental health professionals to work in community settings, and particularly to know how to include the family as part of the treatment and care plan for their unwell relative.

We identified a large number of research studies that indicated better outcomes for people with mental illness when their families were involved with the care in an educational and supportive partnership with the treating professionals. There had been twenty-two controlled studies of long-term family psychoeducation integrated with optimal drug therapy and case management that "had shown substantial additional benefits for people with schizophrenic disorders since 1980," according to Falloon, whose bibliography of these studies and their results formed part of WFSAD's first publication: *Families as Partners in Care –A Work in Progress.* The bibliography is available on the WFSAD website.

Having confirmed the importance of family inclusion, WFSAD outlined the following goals and objectives for successful family work:

- maintenance of family integrity: reducing the possibility of family break-up due to the difficult circumstances

- recognition and acceptance of family and consumer/ patient expertise gained through their 'lived experiences'

- respect for each other's views - consumers/ patients, families and clinicians

- understanding the difficulties faced by all parties

- better clinical management through enhanced knowledge about the patient

- reduction in the disability that can result from mental illness

- reduction in the stress levels experienced by families and consumers / patients

- a better quality of life for consumers / patients and family carers

- better functional recovery

From these were developed a set of fifteen principles for professionals that WFSAD published as *Principles for Working with Families* (2001, revised 2007). These were widely distributed and appear as Appendix 1 in this guidebook.

Since then WFSAD has continued to promote family work and has enlisted the support of the major players in the field in order to advance the work. The result is not only this guidebook but continued advocacy for implementation of family work.

A Sea Change for Schizophrenia and Allied Disorders

In the past few years there has been a 'sea change' or 'paradigm shift' in the treatment of mental disorders. Treatment is being considered in much broader terms: gone are the days when stabilizing the patient was sufficient to be called successful care.

1. There are better research tools in the field of neurobiology .

2. Mental Health Professionals have gained more insight into the disorders so that they are ready to go beyond the traditional parameters of treatment.

3. New medications have helped people cope better with their condition.

4. Recovering patients have raised their voices about the inadequacy of treatment that only requires stability and not recovery. Family organizations have requested that their part in care be recognized and valued. Patient organizations have made their voices heard.

5. Community services have been developed that can offer grass roots support. All these changes have made it even more important that all the stakeholders work together.

All of the above have led to more optimism and a "recovery" orientation in mental health care.

These developments, together with strong lobbying efforts, have led to government interest, and in some cases, government action. In many countries, governments are beginning to focus on the provision of comprehensive treatment for those with severe mental illnesses. Frameworks for Mental Health providing standards for care have been introduced in the United Kingdom (1999); in Canada two major reports on mental health as well as provincial task forces have highlighted the issue in the public mind (Romanow 2001, Kirby 2002). In Australia the National Mental Health Strategy affirms the need to improve mental health services (2003). In the United States the Surgeon General's Report on Mental Health (1990), the American Psychiatric Associations Guidelines for the Treatment of Schizophrenia (2003), the PORT recommendations (Lehman 2004) and the President's New Freedom Commission: *Transforming Mental Health Care in America* (2003), have all given a rationale and impetus for the inclusion of families in the provision of comprehensive care.

What is Family Family Work?

In research circles this work is often called "family intervention(s)". Other names are also used: Family Management, Family Work, Family Psychoeducation, Behavioural Family

Therapy and more. Outside research circles the plethora of terms used serve to mystify and confuse lay persons and professionals alike. The names may also have negative connotations for some families for whom "therapy" was an echo of the past, when the families of the mentally ill were thought to need treatment because they were considered responsible for the illness of their relative.

This guidebook clarifies what is meant by family work,specifically focusing on and defining it in easy-to-understand terms. It explains in detail that it is a means to improve patient functioning and recovery, with the added benefit of reducing family and patient stress. Along with a definition of family psychoeducation, Chapter 2 describes the goals and objectives of family work, and the models used to work successfully with families in an integrated care setting. It also addresses the difference between 'family psychoeducation' and 'family education' – a way that families can get support and education for themselves, apart from their relative who is unwell, outside the treatment milieu.

Why it Works

It is only the true involvement of the treatment team with both patient and family that gets the job done. Issues can be raised and dealt with, the patient can have his say in a non-critical clinical atmosphere, the family can express their concerns, and a clearer picture can emerge for the clinicians. The problems of all can be discussed with a view to providing the kind of care that will give the patient the best chance for improvement and even recovery. This type of care can ensure good medical and medication treatment, while helping the patient and family with all aspects of keeping well.

Many studies have tried to break down the exact elements of family work that make it so successful for patients and families alike. No one has come up with a definitive answer, but many have made efforts to define what constitutes an evidence based family approach. This will also be covered in Chapters 2 and 3.

In addition to tangible definitions there is an undefinable personal element that must be considered: this is the confidence that all the stakeholders give to each other that has a direct influence on the success of the treatment. Regular and kindly communications and meetings, as well as genuine enthusiasm and belief in the work, are of value to all. Aspects of this will be covered in Chapters 3, 4 and 5.

What the Guidebook Covers

The guidebook will provide practical guidance on how to understand and implement family work. It will address many of the issues raised by both professionals and families as they set about making family inclusion a reality:

- Having a clear definition of family interventions
- Clarifying the different models of family intervention to enable providers to choose a model that suits their circumstances
- Identifying and overcoming the reasons given for not doing family work
- Offering an introduction to training for professionals in psychoeducation

- Providing policy to guide and mandate comprehensive programs in mental health systems in order to increase such services

- Highlighting methods of serving the needs of families in countries where there is a dearth of professionals

- Recognizing stigma in our midst and ways to reduce it

- Issues of confidentiality and denial of illness

Who Should Read this Book?

There is no one profession or group that should have a monopoly on the knowledge associated with family intervention and inclusion. It has to be imparted and shared by all. Patients themselves, their families, health care providers of all professions, government personnel wishing to become more involved in comprehensive mental health care, managers of services and anyone working with patients in a health-care setting – all have a stake in improved mental health care.

A Guide to Training Therapists

The issue of training professionals to work with families is paramount to implementation of family work. At present mental health professionals have little access to such training in undergraduate or postgraduate mes, since it is available in only a few centres. For the most part mental health programs set up their own in-house training.

The book will guide mental health professionals already working with families as well as those just beginning. Traditionally mental health professionals are trained to work with patients in a one on one relationship. They are unused to the different dynamic of working formally with both family members and patients, and finding the means to make it work well.

Psychiatrists, psychologists, psychiatric nurses, social workers and other mental health professionals who have worked with families within their services say they would not go back to a time where families were only briefly consulted on anything regarding the patient. They find working with both patient and family rewarding, particularly when family work is considered as a core service of their program, and they see this method of treatment reaping results. Practical help to make this a reality as well as examples of working services are found throughout the text.

Not just Mental Health Professionals

Not only clinicians but legislators, policy makers, service managers, strategic planners and administrators will also benefit from the information in the guidebook. Their good will, foresight and knowledge, will be the catalyst for implementing the evidence-based best practice programs they will learn about. Legislators and strategic planners who are well informed can be involved in the advocacy work necessary to persuade governments and departments of health of the benefits, and to provide guidance as to the legal framework needed to mandate these family services. Psychiatric researchers can assist lobbyists with their knowledge of the large research base of positive findings.

It is efforts such as these that will continue to turn the tide in favour of fully comprehensive services in which families are included and valued. Governments and their health departments need to know about the compelling evidence in favour of these mental health services and they need to invest in them. With knowledge they can address the lack of best practice standards and the need for consistently appropriate services throughout mental health systems. The challenge will be to offer family psychoeducation in comprehensive care on a large scale: province, state or nation wide - and that is where formal policies around mental health care that mandate family involvement will be necessary. These issues are addressed in Chapter 8.

Examples of Services Working in the Community

Nothing convinces people more than the proof that something is working in communities similar to their own. Chapter 6 gives examples in different parts of the world where successful initiatives in providing psychoeducation services in the community are well established. Some of these services provide their own training while some have experts come to do the training and maintain consultation afterwards.

Low Income Countries – Where There Are Few Professionals

The need to give families formal status in the care of their relatives is nowhere more necessary than in the developing world. Sadly the absence of mental health professionals means that other ways of improving care for patients and relieving stress for families must be found. The development of family support and advocacy organizations in these countries is an important conduit for information about illness and care, as well as a source of family leaders. The future may hold the possibility of the implementation of family led models of psychoeducation in these countries. Chapter 7 focuses on India, a country in which the World Fellowship for Schizophrenia and Allied Disorders has long been active, and describe the progress made in this country towards this goal.

Hope for Recovery

Mueser and Gingerich in their recent book: *A Complete Family Guide to Schizophrenia* (2006) describe the hope for recovery well:

> "Viewing recovery as a process rather than an outcome is a major shift in thinking that has provided many people with a renewed sense of hope and optimism, largely because it involves focusing on goals and aspirations instead of symptoms and limitations."

This view of recovery makes providers and society alike begin to think of those with mental illness as people like any others, with mothers, fathers, brothers, sisters and lives like anyone else. For once they are seen in context with their surroundings, and not as the embodiment of difficult symptoms and behaviours. Providers and funders of services are now beginning to take this into account, so that, where once there might have been exclusion of families – a remnant left over from the disgraceful decade of family blaming – there is now inclusion and respect.

WFSAD is careful to recognize that this view of recovery is very different from recovery viewed as a return to life as it was before illness. Families will agree that while in their hearts they will always want a cure, an optimistic view of living with mental illness and achievement of "the best one can be" is an attitude that will make for better relationships all round. Chapter 9 gives a view of recovery as it relates to family interventions.

The chapter also draws attention to stigma, denial of illness and confidentiality. This last topic is a pressing issue for families who have often been denied information about their relative's care. It has been a poorly understood issue which will benefit from the attention that it is now receiving, particularly in the United Kingdom.

We believe in a philosophy that supports a good quality of life for both patients and family, and one that views the care of people with psychiatric conditions as a community responsibility, bringing together professionals, families and representatives of society. It is a philosophy that goes beyond just keeping patients out of hospital and which offers patient, family and professional carers a shared approach to treatment. We hope that this guidebook goes further than the literature on this subject by giving readers tools they can use to make this a reality for patients and families; and that it will give those embarked on family psychoeducation some tools to avoid the pitfalls of those who have gone before, giving practical assistance in the implementation of best methods of family work, and ultimately optimum care.

References

Government Documents

AUSTRALIA. Department of Health and Ageing. 1999. *The National Mental Health Strategy*.

AUSTRALIA. Department of Health and Ageing. 1999-2003. The *Second National Mental Health Plan*.

AUSTRALIA. Department of Health and Ageing. *National Mental Health Plan 2003-2008*.

CANADA. *Commission on the Future of Health Care in Canada*. Head of the Commission: Roy Romanow, 2001.

CANADA. Standing Committee on Social Affairs, Science and Technology. Chair: Hon. Michael J.L. Kirby. 2002.*The Health of Canadians – The Federal Role Final Report*.

UNITED KINGDOM. National Institute for Clinical Excellence (NICE) 2002. *Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care.* London: NICE.

UNITED KINGDOM. Department of Health. 1999. *Frameworks for Mental Health*.

UNITED STATES**.** US Department of Health and Human Services. 1990. *Mental Health: A Report of the Surgeon General,*. Chapter IV: Interventions.

UNITED STATES**.** President's New Freedom Commission on Mental Health. 2002. *Achieving the Promise: Transforming Mental Health in America*. Goal 2.2: Involve consumers and families fully in orienting the mental health system towards recovery.

Journals and Other

American Psychiatric Association. 2004. *Practice Guidelines for the Treatment of Patients with Schizophrenia,* 2nd edition.

World Fellowship for Schizophrenia and Allied Disorders.1998 *Families as Partners in Care – A Work in Progress. Annotated Bibliography by Falloon, I.H*. http://www.world-schizophrenia.org/activities/fpc/index.html

Fannon, D. 2004. An interview with Julian Leff. *Psychiatric Bulletin,* 28 (3):112, 2004.

Lehman, A. F., Kreyenbuhl, J., Buchanan, R. W., Dickerson, F. B., Dixon, L. B., et al. (2004). The schizophrenia Patient Outcomes Research Team (PORT): Updated treatment recommendations 2003. *Schizophrenia Bulletin*, 30, 193-217.

McFarlane W.R., Lukens E., et al. 1995. Multiple-Family Groups and Psychoeducation in the Treatment of Schizophrenia. *Archives of General Psychiatry* 52 (8): 679-687.

Mueser, K. T., Gingerich, S. 2006. *The complete Family Guide to Schizophrenia.* New York: Guilford Press.