Chapter 3

# Meeting the Challenges

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*To develop a partnership with mental health care providers is vital to the success of families in caring for their loved ones – to their providing crisis intervention, case management, counseling, basic needs support, socialization, advocacy and insight into the loved one's illness (NAMI 2006)* .

For those already working in modern comprehensive mental health services, it may come as a surprise that not all mental health programs include all stakeholders. While "patient centred care" has been promoted in general health care, in mental illness, patient-centred care often overlooks that the patient is part of a family and that a family has more than a peripheral interest in the well being of its members.

Despite the large number of evidence-based studies that show the benefits of family interventions, they have not been widely implemented. It is important to understand the reasons for this evidence-practice gap. Understanding the reasons leads to an awareness of the challenges that have to be overcome.

Challenges to the implementation of family work were discovered using one or all of the following methods:

## 1. A Lterature Rview

The literature discusses barriers to implementation and how services that have implemented family work have gone about addressing the challenges (Drake 2001, Fadden 1998, Brooker 2001, Kavanagh 1992, 1993, McFarlane 2001, Burbach 1998).

## 2. A 'Barrier' Aalysis

A barrier analysis first identifies the major individuals/groups that are critically important in making change succeed. Such an analysis can be undertaken by groups of clinicians, family carers and consumers.

Using a tool developed in Australia by the National Institute of Clinical Studies a barrier analysis was carried out as part of a funding submission to implement evidence-based family interventions. The major individuals/groups that were rated critically important for making change succeed were:

- area managers
- directors of clinical services

- team leaders/program managers
- frontline clinicians (interdisciplinary case managers)
- doctors
- 'known obstructors'.

It was critical that 'known obstructors' were involved and that a strategy was devised to manage their opposition, as they had the potential to prevent change from happening at all.

Conduct focus groups with frontline clinical staff to determine what they see as the challenges/barriers to the implementation of family work.

### 3. Consult with experts in family work and interview 'key informants.

Key principles that were emphasized by an acknowledged expert in family work, Dr. Grainne Fadden (2005 – workshop in Melbourne, Australia):

- evolving family work into routine clinical practice is a process that takes time and perseverance
- central funding is needed to get family work started – not necessarily to have it in the longer term
- model of intervention should be relatively simple and part of the workload of all clinicians
- ongoing supervision of clinicians after training is vital
- uptake of the intervention by clinicians will be minimal at first (working in depth with only one or two families if working with a single family model, or one group if a 'multi-family group' model is adopted).

Apart from discovering the challenges to the implementation of family work, these three processes can be important as a way of raising the profile of family work and finding out, in the actual area where family work is to be implemented, what local stakeholders see as the problems.

What follows in the description of challenges in this chapter is the result of using these three identification processes.

## What are the Challenges?

Grol and Wensing (2004) propose that in any area of health service delivery, the challenges involved in a change process can be examined at six levels:

1. **Innovation itself**
2. **Patient (and the family)**
3. **Professional Staff**
4. **Organizational context**
5. **Social context**

## 6. Economic and political context

### 1. The innovation – Family Interventions

- Systemic reviews and research results are making family interventions much better known. Nevertheless recognition of their value and acceptance of their value needs to be constantly emphasized.
- There has been some criticism of the research – e.g. some have highlighted the complexity of translating research into clinical practice. Research studies do not address how it should be implemented (Jones et al, 2002).
- Family intervention has evolved into different models, so there is some confusion about terminology, and which model should be implemented.
- Even though respected research findings are positive, all research findings in the psychosocial area are less likely to be implemented as they do not belong to mainstream psychiatric treatment and are largely conducted by professionals other than psychiatrists.

### 2. The patient and the family

*The patient*

- Symptoms of mental illness (e.g. paranoia, lack of insight), the patient's desire for a confidential relationship with their clinician, cultural and developmental beliefs around independence from one's family in western cultures, can lead to 'disengagement' from the family.
- If a patient commences treatment with the belief that s/he is the sole recipient of the service and that family do not need to be involved, then it less likely that family will be included at a later date.
- Some patients may refuse outright to have their family involved in their treatment; some patients even refuse treatment for many varied reasons.

*The family*

- Some families may not have the practical or emotional resources to become actively involved in more aspects of the treatment of a relative.
- Some families may not see these interventions as 'treatment' and question the value of spending the time and effort in such interventions.
- In the early stages particularly, an inability to acknowledge the mental illness is common. Family members may have different 'explanatory models' about what has happened – what it is, who or what has caused it and how it should be treated. These differences can tear families apart, making optimal management of the illness hard to achieve.
- Previous years of bad experiences with mental health clinicians and services leads to a wariness of the engaging with professionals. It is felt that clinicians

have not helped in the past; it is unlikely that future treatment will be any different.

- The mental health system effectively disempowers families. In early stages again, many families are not sure of how to ask for help, nor are they really capable of knowing exactly what sort of help they need. When mental health services do not include them in treatment and care regimes, family carers are left feeling powerless and unsure of an appropriate role.

## 3. Professional staff

### Concentration on the individual patient:

- Professionals are trained to provide individualized care (Furlong 2001) and they often do not know how to work with families.
- Patient confidentiality can be used as an excuse to avoid working with families for reasons of time or preference. Sometimes there is a belief that the patient will no longer trust them if they involve their family members.

### Outdated beliefs and models:

- Families are 'pathologized' by some staff. For example, it is still common to hear clinicians describe families as 'dysfunctional,' rather than appreciating families are experiencing complex difficulties.
- Priority is given to biological treatments at the expense of treatments to improve patients' functioning.
- Serious mental illnesses can still be viewed as chronic and deteriorating, with no prospects for positively changing the course of the illness.

### Professional boundaries:

- Family work is viewed as a specialist area and not part of routine care.
- Certain professions see family work as their area of expertise, and do not want to lose their specialist knowledge and influence.

### Skills

- Clinicians may feel they cannot cope with being exposed to the wide ranges of emotional trauma that family members inevitably experience.
- Clinicians are inadequately trained in the structuring of family sessions, or in the running of a group; they have difficulty keeping discussions focussed, sticking to time limits and keeping control should the session disintegrate into conflict between family members.

## 4. Organizational context

### Work priorities

- Family work is seen as an 'add-on' – an extra task. It is not core business, and is not integrated with case management and other responsibilities.
- Stressful periods in mental health work (particularly acute crises) take precedence over family work which is then neglected.
- Caseloads are considered too large; there is not enough time for patients, let alone their families.

### Existing service structure

- Lack of support, particularly from middle managers.
- Training clinicians and creating programs means more time in the beginning of the implementation of family work. Time in lieu or extra pay, has not been negotiated. It can be difficult to release staff for a number of days in order to receive training. The flexibility of working hours that is needed for families is not attractive to clinicians. Families are often only available at times when clinicians traditionally do not work (evenings, week-ends).
- Often there is an absence of clear policies and protocols to support family work
- There has been a failure to give ongoing supervision immediately after training of clinicians in family work.

## 5. Social context

### Stigma

- Stigma prevents families and consumers from being open about their needs.
- Denial and minimization of problems can lead to delays in accepting psychiatric care, which in turn leads to increased burdens for family carers, greater distress for the person with the illness and increasing disengagement of the family and consumer from normal social life.

### Myths and legends

Myths perpetuate misinformation about mental illness. 'All people with schizophrenia are violent', is a myth that is hard to eradicate especially when the rare case of a murder by an untreated mentally ill person hits the media headlines. Beliefs about the cause of mental illness emanating from the devil, other evil spirits or from God, mean non-medical or unproven forms of help are sought which, in the main, are ineffective. Like stigma, myths and legends delay appropriate treatment and add to social and economic costs.

### Cultural diversity

Cultural Diversity requires mental health services to be sensitive to widely differing social norms and customs. This sensitivity is seriously lacking in most services resulting not only in neglect of the family carers, but in the violation of peoples' customary modes of behaviour.

### Family and consumer disagreements

- Disagreements over priority issues between consumers and family carers, can lead to lack of cooperation and consensus, which can lead to questions about the benefits to all of including family work as core business.
- Disengagement of mentally ill persons from their families often results when the person has been treated individually and his/her family has been excluded. When this has happened, clinicians do not see the need for family work even when such work could reunite the family and reduce risk of homelessness and isolation for the mentally ill person.

## 6. Economic and political context

### Economic priorities do not include family work

- Lack of vision in planning services has resulted in an overemphasis on short-term treatment of individuals for acute episodes of illness. This has happened for a variety of reasons – introduction of medications for acute symptoms, treatment in acute psychiatric units with the emphasis on shorter hospital stays, and the belief that rehabilitation happens in the community (although rehabilitation facilities are few and far between). This emphasis on shorter terms of treatment, while seeming to be less stigmatizing, appears to be driven more by very limited resources for mental health than benefits to patients and their families.
- Emphasis on 'targets, budgets, mergers, restructuring and development of new services often means that clinical priorities do not receive due attention.' (Fadden, 2006, p.31). The failure to implement evidence-based family interventions is a good example.
- Limited government spending on mental health may prevent the scale of implementation needed to produce the benefits found in research studies. The implementation will fail and the programme then deemed to be ineffective.
- Great emphasis is placed on the rights of people with mental illness. This is extremely important. Nevertheless, costly medico-legal provisions and 'risk-averse' management cultures have consumed a disproportionate amount of mental health budgets. Incidentally, the rights of families have received little or only spasmodic attention in most countries.

### Lack of political will

Stigma works against the development of the political will that is needed for more resources in all areas of mental health, a strong reason why mental health remains the 'cinderella' of health service provision.

# Refuting the Challenges

All of these challenges are real and have been reported many times, but they are only challenges and are meant to be surmounted. The positive outcomes of **the innovation – evidence-based family interventions –** have been known for thirty years, have been obtained from at least fifteen countries and have included several thousand families. They

are effective in many clinical practice settings and are designed to be used with pharmacological interventions when clinically warranted.

Family interventions promote closer relations between **the patient and the family,** and can be implemented at any stage of the patient's struggle with mental illness. True, some patients do reject it but most welcome it. Similarly, some families reject it but the research has shown that families overwhelmingly welcome these interventions.

While **professional staff** training has emphasized work with individuals, professional attitudes can be changed when newer methods of working with family members are introduced and shown to be effective. Confidentiality can be easily handled in family intervention procedures (see Chapter 9). Outdated beliefs and models are overcome when patients are seen as persons capable of recovery. Not all staff will embrace family interventions. It will, initially, be attractive to only a minority, but that alone will make a big difference particularly when staff are given the training they need to develop appropriate skills.

The **organizational context** presents many difficult issues for already overworked staff. Managers at all levels need to be supportive of family work as a priority. Where it has been recognized that adoption of new methods requires time for training and the establishment of new goals, family interventions have been shown to be successfully implemented.

Difficulties in **social contexts** tend to dissolve when family interventions are effectively carried out. Nothing beats stigma better than the reduction of symptom severity - one of the results of family interventions. Family interventions have been tested in nations with widely differing cultural practices showing that they can be culturally sensitive. Conflict between consumers and families has been exaggerated (and often by psychiatric practice that focuses on the individual). Most consumers are happy to work with their families toward recovery.

Openness and an unstigmatizing attitude are important for mental health clinicians. This type of attitude is a very significant part of what makes family organizations successful. There is a natural empathy and an outpouring of feeling that is devoid of pity, criticism or hostility within family groups. There is also the desire to be helpful and to help solve each other`s problems. This may be one of the reasons that mental health professionals who are, at the same time, family members or consumers are so well respected by families in mental health services.

**Economic pressures** can be found in virtually all psychiatric service centres, but where family interventions have been implemented, money has been found to pay for it. The lack of political will is challenged when an evidence-based psychiatric practice is shown to be highly cost-effective. Reduction of relapse alone makes family work cost effective.

## Implementation of Family Work into Routine Clinical Practice

As we have seen, to overcome the barriers we need to address the different levels as described by Grol and Wensing. In addition, meeting the challenges requires effective methods of implementing family work into routine clinical practice. The remainder of this chapter suggests ways to do this.

## Establishing a Family Work Implementation Group

'Champions' of family work are needed. These people will bring together collect a group (some dedicated to family work, others who need to be convinced) within the mental health service. This group of people work towards having family work implemented into routine clinical practice. From the beginning, the group must include a representative/s from senior management and senior clinical leadership – people who are in positions of authority and who make the decisions.

The group must also include family carers and consumers who understand and support the implementation of family work.

The employment of consumer consultants (someone with a mental illness) and carer consultants (a carer who has had primary responsibility for a relative with mental illness and experience of mental health services) to work alongside clinicians in Victoria, Australia, has demanded the development of job descriptions which clearly elucidate the qualities required to fulfil these demanding family-work positions.

Meetings are scheduled in advance, with agendas, minutes and action plans.

Mueser and Fox (2000) propose that every community mental health service should designate an individual as the director of family services. This director should be expected to:

- identify and train clinicians in family work
- lead and supervise family work
- monitor the delivery of family services
- develop, implement and oversee family programs
- work with a family advocacy organization or family support group in each state, province, county, country. In Japan Zenkaren is an example of such an organization.
- participate in continuing education activities

## What are the Aims of a Family Work Implementation Group (FWIG)?

### 1. To develop a shared vision of family work

This needs to start with an understanding of the rationale for family work as part of routine clinical care. Understanding and agreement about the rationale is essential for the development of a consensus amongst key stakeholders, as it is unlikely that people will be willing to overcome barriers without the support of a group of like-minded people.

It bears repeating that an important factor in the promotion of innovation in clinical services is to develop the shared vision simultaneously with those who have managerial and administrative responsibilities.

## What is the rationale for the implementation of family work?

- The strong evidence base that has resulted from randomized control trials over the last 27 years, has shown the efficacy of including families in treatment and care regimes.
- This evidence base and the development of non-government Family Organisations that have raised the carer voice, has led in many countries to the development of clear health policies and guidelines on the need to include families and other carers in treatment and care.
- Since deinstitutionalisation, families have taken on the caring role formerly carried out by the mental institution. It is not economically sensible to continue to ignore the vital importance of families as a valuable (but undeveloped) resource to underresourced mental health systems.
- It is not morally defensible to continue to allow families to carry the burden of care without giving them the information, training and support necessary to bring about better outcomes for the patient, as well as better outcomes for the carers themselves.

There is growing evidence that clinicians who have undertaken family work report far greater job satisfaction and less burn-out.

## 2. To plan a broad implementation strategy

Having reached a consensus, the next task of the implementation group is to work towards a staged action plan for the introduction of the chosen family work model.

What is needed?

### a) Training of clinicians to work with families

The details of how staff are trained is described in Chapter 4. FWIG should plan how training in the chosen model of family work will happen. Below are some points that need consideration:

- The training program should present the elements of successful training as identified by Joyce and Showers (2002), viz: presentation of information, demonstrations, and opportunities to practise key skills. Training is often most effective in small groups with low participant to trainer ratios. For example, the Meriden Programme uses ratios of 1:5 in all of its training.
- Staff need to understand at the outset that they will be expected to put this training into practice immediately, but that they will be supervised and supported from the outset and at regular intervals thereafter.
- Decide between block training (training on consecutive days with staff released for this period of time); or training spaced out over several weeks (one day a week, for example). The advantages of block training: a longer period of dedicated time allows a more easily accumulated sense of skill mastery; clinicians are freer from the distractions of their caseload; allows a better sense of collegiality to develop. Shorter periods of time over several

weeks is less difficult for the service as it is not such a problem to release staff and to find replacement staff.

- Organizers of the training program need to be aware of any negative staff attitudes and/or high levels of anxiety that will lead to resistance to learning, let alone implementing the program once training has been completed. Staff lack of confidence in working with families is often a huge barrier if it is not recognized, sympathetically understood and training methods found to overcome it.
- Rewards for staff. Although increased remuneration is one incentive, it is not the only one and not necessarily the most important. The work should be rewarding, and should be recognized and acknowledged in the service. Accreditation for training and practice in family work should be given official status.

### b) Key changes needed within the service

- Time-in-lieu. Staff should be given time off during regular working hours to compensate for time spent working with families after hours on evenings and/or week ends.
- Use of the problem-solving process by the key stakeholders in the mental health service can identify ways to overcome the perceived barriers to implementation within their service.

**An example of a problem-solving process to find 'time-in-lieu.'**

On the final day of the training programme, staff from a continuing care team in an area mental health service (Melbourne, Australia 2006) were asked to problem-solve the issue of finding time-in-lieu for seeing a family once every week for two hours in the evening. The problem-solving process allowed many pros and cons to be discussed, but eventually the clinicians agreed to approach their manager and suggest that the number of meetings they were asked to attend could be reduced without deleterious effect. This would allow the time-in-lieu needed for the commencement of family work. Note also that, in the beginning of the introduction of this model of intensive individual family work, staff were being asked to begin with just one family when they went back to work after the training sessions, so the amount of time-in-lieu needed at the beginning of the commencement of family work, was not seen as excessive.

- Caseloads

Clinicians are coping with heavy caseloads, but some of the work presently done by clinicians has no evidence base. Clinicians need to look at what their sessions actually achieve. The emphasis on individual work (see the patient first, then see the family separately, and then perhaps see them together for a few minutes) is still a common 'modus operandi.' This often results in confusion (families wonder what the patient

tells the clinician. Or patients worry about what family members have said about them). If clinicians are trained to work with all family members together (as the research studies have shown), it is likely that outcomes will be better, more efficient and that heavy caseloads can be reduced. Some sessions can still be scheduled for issues that the consumer wishes to remain confidential. Family carers are usually only too respectful of the consumer's wishes for privacy.

- Supervision.

Time is needed for ongoing supervision; how will this be found? What kind of supervisory processes will be used?

### c) Resources needed to carry out the implementation strategy

- Services can implement some work with families by rearranging present ways of working and establishing that family work is a priority. Costs in time though, will need to be very carefully negotiated; for example, backfilling to cover for staff who go off to be trained.
- In any changeover period, there are extra costs up front. Seed funding, special project grants, will need to be found and secured. In the long run though, when family work has become routine practice, it should be part of the overall mental health budget.
- Integral to this process of finding and securing funds will be the evidence from many studies that, in the long-term, evidence-based family interventions are very cost-effective. The following evidence of cost-effectiveness needs to be disseminated at all levels of government, to clinical services and to the family non-government organizations. The latter can have a strong political influence.

A recent Australian study (Mihalopoulos 2004) concluded that Family Interventions were cost-effective ($28,000 per Disability Adjusted Life Year averted), and considered 'value for money' within an Australian context. DALY – the disability adjusted life year is an indicator of the time lived with a disability and the time lost due to premature mortality. The DALY is the only quantitative indicator of the burden of disease that reflects the total amount of healthy life lost, to all causes, whether from premature mortality or from some degree of disability during a period of time. (Homedes N (1995)

Carr and associates (2002) found that Family Interventions were cost-effective even without calculating costs saved by relieving family burden. This was due to reduction of high costs (0.36% of Australian Gross Domestic Product for psychosis in 2000) associated with inpatient care and the reduced productivity of persons with psychosis and their carers.

Falloon and associates (2002) also argue that although there are small additional costs involved in the delivery of family intervention programmes, these are dramatically offset by reductions in the need for expensive intensive crisis care

McFarlane and associates (1995) conclude that psychoeducational multiple family groups were effective in reducing relapse rates especially in patients at higher risk for relapse,

with a cost-benefit ratio of up to 1:34; that is, for every dollar spent on multiple family groups, $34 was saved on the costs of rehospitalisation.

### d) Ongoing processes to ensure sustainability:

- Ensure that supervision is provided for as long as it is needed; supervision for the supervisors needs to be considered.
- Record changes that occur in clinical practice through:
    - Maintenance of records: of families who have been receiving Family Work (for example, numbers of sessions, which professionals gave the sessions, development of desired outcome measures for families, use of routine outcome measures for consumers).
    - Feedback: family feedback questionnaires and satisfaction scales.
    - File audits: evaluation within the specific service. File audits can monitor changes in staff-family contacts. Once family work is implemented, it would be expected that file audits could show an increase in contacts with families. More importantly, if adequately designed, file audits could indicate the content of work with families and collate this with consumer outcomes.
    - Observations from 'key informants': This is important as a recognition of the value of the contribution made by people who believe in family work and are working hard to achieve it. It is a personal approach that acknowledges their value as people vital to the success of these new ways of working.
- Development of a programme for training of more clinicians in each service (for example, the Meriden train-the-trainer scheme).
- Promotional material circulated around the organization and to consumers and carers
- Consultation and advocacy with other agencies, bureaucracies, policy makers and politicians (see chapter eight).

## 3. To take the first steps

Once the service staff have decided that they want to implement a particular family work programme, they invite the key people who have developed/implemented this programme to come to the service and carry out an orientation workshop.

The Meriden example:

- Meriden Family Programme runs workshops for services that request this.
- They ask for a link person from the service to provide Meriden with details of who the service wishes to invite. This should include representatives from the

most senior levels in mental health service delivery, middle management, clinical leaders and interested clinicians, carers and consumers.

- Practicalities are given careful consideration – a list of possible dates and times are provided allowing the service to arrange the workshop for maximum benefit of the service (to ensure that the important 'movers and shakers' are able to attend).
- Two representatives of Meriden with help from the local facilitator then conduct the workshop – with special emphasis on:
    - the evidence-base, and rationale for family work
    - details of the training programme
    - a proposal to the service of how Meriden could be involved with them - asking for clinicians to be sent to do the Meriden training programme, and detailing the ongoing process of supervision of the clincians who have undergone the training. This training is well-planned and well-resourced with training manuals, training videos, and a training process based on adult learning principles.
    - asking participants about the barriers they feel they will encounter, and discussions around how these barriers can be overcome.

## Conclusion

Family carers must be given much better consideration than they have received in the past. The inclusion of family carers as an effective resource for mental health services is becoming widely accepted, and we now have the evidence-base from research for its effectiveness. There is emerging evidence that where family interventions are being implemented in routine clinical care, the outcomes for families, for patients (consumers, service users), and for clinicians are far more positive (Chapter 6). We are overcomiing these challenges.

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