

Involving Carers

Carers play an important role in many service users' lives. Their knowledge and expertise represent an enormous resource for statutory and voluntary mental health services. These are reasons why it is so important to include them through sharing information.

This chapter is in two parts. Part 1 is written from a service perspective, and describes how professionals can actively involve carers in different aspects of service development and training. Part 2 is written by a carer and describes the various roles that family members can take on at local levels and also more widely developing into national roles.

Part 1

Including Carers In Staff Training and Service Development In Somerset

Roger Stanbridge and Frank Burbach

The involvement of family members/carers has been a fundamental element of our service development and training initiatives in Somerset. Carers' contributions have been integral to the development of our family intervention in psychosis service (Burbach and Stanbridge 1998, 2006) and our strategy for the development of more family inclusive mainstream services (Stanbridge & Burbach 2004, 2007). Carers' descriptions of their lived experience, together with their feedback and suggestions regarding mental health services have shaped the way in which our services have developed.

Developing Family Intervention Services to Meet Families' Needs

Even when families have been offered family interventions, they have not always felt that this has addressed their needs. (Hatfield, 1983; Reimers & Treacher, 1995). One explanation might be that professional frameworks (e.g. assessment; theoretical models) may sometimes get in the way of listening to families. Assessed needs may not be the same as expressed needs. It is clear from the literature that the quality of the relationships between professionals and family members is a key ingredient for a successful outcome and requires a collaboration regarding the aims/goals of the sessions.

In the approach we have developed in Somerset, our family intervention sessions with each family are based on a shared agreement regarding their needs and goals we have mutually

agreed. At the end of sessions, we ask whether family members have found the meeting to have been useful and plan future sessions. The approach has evolved in the light of this routine feedback from families, as well as a more formal research study (Stanbridge et al, 2003). This study involved semi-structured interviews with fifteen families involved with the first of four teams established in Somerset.

In the study a majority of families described feeling apprehensive on referral to the service. For some, this was based on having had previous poor experiences of mental health services: (To protect privacy where individuals are referred to, false initials will be used.)

“I had a lack of confidence in the process. I was also prejudiced against the service generally because of our first contacts.” (father)

Others felt that sessions would be unhelpful or make things worse:

“Nervous for J- (son) due to his fearfulness and worry about going. Worry that he would feel worse after coming”. (mother)

“I was hesitant as to how I would be treated. A sense of trepidation as to whether or not we would be treated sensitively. Whether therapists would be trained and could be trusted with sensitive issues.” (father)

In spite of this, families were overwhelmingly satisfied with the service they received.

“Surprised and satisfied. The most important thing was that they listened and responded to the family’s needs, not followed their own agenda, and that happened.” (aunt)

What Families Valued

When asked what they valued most about the service, a number of themes emerged:

- **Openness of discussion within sessions**

“Open discussion in a safe and supportive environment.” (mother and son)

“The non-judgmental nature of the service has helped most, but not in a wishy-washy way”. (father)

- **Therapist’s qualities**

“Talking to someone about J- who knows and understands him and is sympathetic.” (mother)

“A feeling of concern and warmth.” (mother)

- **Support offered**

“Knowing someone is there to talk to, to explain or answer a problem in sessions or on the phone.” (mother)

“We liked the flexibility in the timing of appointments which vary depending on what is happening and how much help we need. You only need to pick up the phone to arrange a session.” (mother and father)

- **Managing the burden of care**

“An easing of the pressure, burden at the time. Especially after the meetings. We didn’t feel so much on our own.” (mother and father)

- **Access to the mental health services**

“Another point of contact with the system.” (mother and father)

Therapeutic Relationship

Family members were asked a number of questions about the qualities of the relationship between themselves and their therapists. Most felt understood by their therapists and often described this as a powerful experience.

“I felt very much understood. That was very overwhelming in a way, having come from a place where we weren’t understanding each other at home, to have two people who were empathetic there for me and for our son D”. (mother)

People valued the ongoing evaluation of the usefulness of sessions and the fact that the sessions were mutually agreed.

“They asked at the end of each session if we were happy to continue and if it was useful or not.” (client)

“It felt as if we had the first say and they (therapists) would follow what we wanted, but they might come up with suggestions as well, but it felt as if our needs came first.” (client and wife)

“We agreed together. That was the whole point of the counselling- to get agreement about what you’re talking about, otherwise you’re not getting anywhere.” (mother and father)

All families identified helpful qualities in their therapists. These included:

- **The ability of the therapist to listen**

This was referred to explicitly by seven families and implicit in many families’ reference to other qualities.

“The therapists didn’t take sides or become judgmental, but listened to the problems we had as a family.” (mother)

- **Non-judgmental attitude of therapists**

This was referred to by five families:

“Parents are concerned about being judged. This didn’t happen. We were not made to feel responsible or judged or put in a box in any way.” (mother and father)

- **Therapist answered questions and shared views**

This was referred to by five families:

“It was possible to ask questions and discuss things. They would give frank answers.” (mother and father)

“They were very open, sympathetic and shared their views.” (mother and father)

- **The therapists worked well together**

This was referred to by five families:

“They had two very clear roles and confidently interacted with us and each other.”
(mother and father)

- **Helpfulness of therapist**

This was referred to by four families:

“It’s helped us to cope with the situations that do arise with A- from time to time when his psychosis flares up.” (father)

- **Interest of therapist**

This was referred to by three families:

“They were very interested in the problems we were having as well as P--’s (son). That was the first time that had happened, they knew that we were having problems, we were worried and we were suffering from stress. They realised that.” (mother and father)

- **Therapists created a calm and quiet atmosphere**

This was referred to by three families:

“The therapists were pleasant, calm, helpful and patient. You didn’t feel oppressed in any way.” (mother)

Most Common Problems

The most commonly identified problems for which families sought help related to the impact of the sufferer’s behaviour on family relationships. Themes identified included:

- **Managing specific behaviours** (e.g. domestic chores, irregular sleep patterns, aggressive behaviour, suicidal ideas)

“Conflicts with my Mum over household chores were a specific problem and stress.” (client)

“J—’s suicidal thoughts were high on the agenda.” (mother and father)

- **Difficulties created in close relationships**

“We were concerned that we might be giving mixed messages to M-, you saying one thing and me saying another, and the impact of different approaches.” (mother and father)

- **Making sense of the experience**

“How best to manage it and how best to understand what had happened and what it meant to my wife and I.” (client)

- **Support for family members’/carers’ own needs**

“It was for us, to carry on trying to live a normal life with A-- the way he was.”
(mother and father)

Many families described improvements in their relatives' symptoms and related concerns/problems. They felt that the family sessions had helped them to cope better and deal more effectively with their relative's symptoms.

A number of themes emerged when people were asked what had helped with their problems or symptoms:

- **Developing improved coping strategies**

“J-- has been able to use her relapse strategy and has not had a full-blown episode.”
(relative)

- **Improved communication**

“Changing our communication between ourselves, improving that. Avoiding certain triggers.” (client and wife)

- **Increased understanding of mental health problems**

“Helping us understand mental illness. I learnt a lot about it I didn't know. (father)

- **Availability of support**

“They were clearly communicating well as a network. Everyone seemed to know what was going on elsewhere in the service and what they were doing and we admire that because it's not common.” (mother and father)

- **Reduced contact with relatives**

“His leaving home, space to get away from us, otherwise I think he would be in hospital again.” (mother)

Timely Referral to Family Services

The study also indicated that early referral was associated with successful engagement in family work. Two families felt that being referred at the point of their son's discharge from hospital was “too late”. They would have welcomed the offer of the family service at the point of their greatest need (i.e. when first contacting mental health services).

Views on Participation in the Research

All those interviewed felt positive about taking part in the research. Many expressed a sense of passion about the service they had received. They felt that carers' needs had been overlooked in the past and were keen that the new family interventions service would continue to be available:

“I think that it is a must to have a service like this. There must be a support service for families.” (mother)

Many saw participation in the research as a tangible way of helping others:

“We're pleased to be of help and will do anything in the future, for all that's been done for us...without the help, I don't think we'd have been in business. I don't think we'd have been able to carry on normally. It was a 24 hour constant worry.”
(mother and father)

Involving Families in Staff Training

In addition to seeking families' views in order to create more responsive services, families also help service development by contributing to staff training programmes.

(1) Family Interventions in Psychosis Course

Like many other courses, families are invited to come and describe their experiences in order to raise trainees' awareness of the stress felt by families and their experience of accessing services. In addition, some families have agreed to take part in family sessions within our one-year training course. Although our clinical approach involves pairs of therapists meeting with families in a variety of settings (e.g. at home), for the purposes of training we have found that it is helpful to use a "live supervision" model. This involves the therapists meeting with the family in one room whilst the observing/supervising team is in an adjoining room, connected by a one-way screen, video and audio-link. This enables the co-therapist to receive messages from the tutor/supervising team, which can then be fed into the session in a congruent manner. The one-way screen/video-link enables trainees to observe family sessions and provides rich material for subsequent discussion/supervision.

All aspects of these somewhat unusual arrangements are fully discussed in advance with all family members. Clearly not all families would feel comfortable with this procedure, but often families are willing to help with the training and see the advantage of having the input of an experienced multi-disciplinary group of staff (the 8-10 observers routinely include doctors, nurses, social workers, psychologists and a range of other therapists).

The advantage of integrating the skills training within the course (as opposed to trainees developing their clinical skills in separate placements) is that our trainees do not have the usual difficulties in putting their newly developed skills into practice. In addition, by delivering the course to the new team in-situ we are able to create a new family interventions service which is fully operational by the end of the course. The families who participate, therefore, also gain the benefit of family work in advance of the new service.

(2) Family Inclusive Mainstream Services

There have been recent changes in policy in the UK which have raised the profile of the needs of carers/families, and have led to the development of education and support for carers. However, this has not addressed the needs of the majority of mental health staff who have not had training in working in partnership with families. It is in this context that we have developed a three-day training programme which we are delivering to existing in-patient and community mental health teams throughout Somerset.(This programme is described in detail below.

Each training course starts with a presentation by a carer. This takes the form of the family member (or sometimes this is two parents) telling their story. We encourage people to talk about both good and bad experiences of services but specifically ask them to comment on the following areas:

- Events leading up to contact with services;
- First experiences/impressions of services/in-patient unit;
- Subsequent impressions/experiences;

- Whether they felt included by staff;
- Quality of the communication with staff;
- Any recommendations they might have.

In our evaluation of the training we have found that the experience of hearing directly from a family member/carer is very highly rated and has a major beneficial effect on staff attitudes. Staff frequently describe feeling emotionally affected by hearing the carers' experiences and often identify closely with their struggles. In terms of impact on attitudes, these presentations are usually far more effective than the presentation of research findings or policy, although we find that both of these aspects are also important parts of the training. Starting with the carer's story, literally and symbolically puts this at the centre of the training and trainees and trainers often refer back to the carer's experiences throughout the course. Staff appear more receptive to the training package and more willing to consider changes in practice as a result of the carer's contribution.

We are aware that carers could be involved throughout training courses of this kind, or these courses could be run by carers' organizations. We have found, however, that staff appreciate the opportunity to reflect on their practice as a group and that we have been able to facilitate more open communication with the course structure described. This acknowledges that the challenge in this training package is to work with a wide range of staff attitudes. Addressing unhelpful, institutional attitudes is an important part of the training and can only take place in a non-defensive environment. It is for this reason that we also ensure that the families invited to share their experiences have not personally been involved with the staff group that they are speaking to.

Developing Family Oriented Mainstream Mental Health Services through Staff Training

In order to implement Standard Six of the National Service Framework described in Chapter 7 (Department of Health, 1999), which entitles carers to their own assessment and written care plan, our trust, like many other UK mental health trusts, started to employ Carers Assessment Workers. Whilst providing new services for carers is clearly a positive development, we became concerned that this would lead to existing mental health staff becoming less involved with families, if they felt that this was the responsibility of the new carers service. This would not have brought about the change to more family inclusive practice which is advocated by national policy. We therefore began to develop proposals to integrate carers' support services with mainstream clinical practice. In Somerset our mental health trust encouraged the development of a strategy to enhance working partnerships with carers and families (see Table 1).

Table 1

Extracts From Somerset's Strategy To Enhance Working Partnerships With Families/ Carers

Vision:

The Somerset Partnership NHS and Social Care Trust will strive to respond to the needs of families/ carers in all parts of the service. This entails having a social network perspective to all assessments and interventions provided by staff and the involvement of families/ carers in service delivery wherever possible.

In practice this means that our services would need to develop to the point where they **routinely** offer:

- Family friendly units with appropriate facilities and where staff welcome relatives and carers.
- Interventions which consider the client in the context of their relationships, e.g. including a family perspective when working with individuals.
- Involvement of families/ carers in the initial Care Programmes or equivalent assessment/admission process where appropriate.
- Close working between colleagues across specialities and agencies (Adult Mental Health, Child and Adolescent Services, Older Adults, Primary Care, Social Services, non-statutory organisations and education) to meet the needs of all family members.
- Formal carers' assessments and care plans where appropriate.
- Carers' support initiatives e.g. Carer support groups, carers' newsletters, carers' education courses and psycho-educational groups for carers.
- Early referral for specialist forms of therapy offered, when appropriate, to all family members.
- Specialist family/ carer interventions, e.g. Family Intervention in Psychosis Services; Family Therapy Clinics.
- Greater consideration of the needs of children in families; including child protection issues, impact of adults with mental health problems, children as carers.
- Greater consideration of the needs of adults who care for children with severe developmental or mental health problems.

Families/ Carers Steering Group

One of the first steps was to set up a Families/ Carers Steering Group with the aim of supporting the implementation of the strategy. This group brought together a broad ranging membership representing carers, service users, managers, clinicians and those providing services for carers. This multi-disciplinary and multi-agency group had representatives from adult, older people, child, learning difficulties and drug and alcohol services. The setting up of the group provided the first forum in the Trust specifically designed to focus on family and carer issues and has done much to counteract the fragmentation and isolation described by staff and carers working in this area. In its first two years of operation, this bi-monthly group has carried out work in the following areas:

- Improving information and support services for carers
- Increasing the involvement of families/ carers in the assessment and treatment of the people with mental illness
- Raising staff awareness and developing skills for working with families
- Influencing Trust policies and guidelines

For example, the input of the group into the review of the operational policy for all community mental health teams led to the routine invitation of family members/ carers to the initial assessment process. A welcoming invitation to families/carers is now included as standard practice in all initial appointment letters to new service users.

Confidentiality and Information Sharing

Another example of the group's work is in the area of confidentiality and information sharing. Of central importance to families/ carers is their relationship with staff and the ability to share information with professionals involved in their relative's care. Difficulties in this area are well documented both by families (Shepherd, 1994), and professionals (Clarke, 2004), and are raised in most research and national guidelines as a significant impediment to good partnership working. A sub-group explored the issues involved and researched existing work in the area (e.g. Royal College of Psychiatry, 2004; Department of Health, 2006), which led to the production of best practice guidelines on information sharing and confidentiality with families and carers. These guidelines emphasize a **three-way partnership** between service users, families/carers and professionals, stress the benefits of information sharing and use case scenarios to illustrate good practice. They are intended to give families and carers a sense of what they might reasonably expect from services and provide staff with more information on which to base their practice. These are now part of community mental health teams' and inpatient services' operational policies and form the basis of ongoing further training in this area. In addition we have embarked on an extensive staff education and skills training programme.

Developing a Continuum of Training

Most professionals' basic training does not include specific skills for working with families. We therefore decided to develop a range of awareness/basic skills training packages tailored to the needs of specific clinical teams (Stanbridge & Burbach, 2004, 2007). We envisaged the workforce being able to access a continuum of training from basic awareness/skills to specialist skills. We approached this in two phases.

The initial phase has been to provide a series of education and awareness raising sessions to clinical teams accompanied by a survey of staff involvement with families and their training needs. The results of this survey highlighted a lack of confidence and prior training of staff in working with families and a wish for further training. In addition, a three-day package of education, awareness and skills training was piloted with new Assertive Outreach, Home treatment/crisis resolution and Eating Disorders teams. The second phase consists of the systematic implementation of the training programme throughout the mental health service.

Training to Raise Awareness, Change Attitudes and Develop Skills

The balance of theory and practice provided within these short courses depends upon the needs of the particular part of the service. For some staff, an increased awareness of issues facing families/ carers, and how to access further help and resources, may be sufficient; for others, with more direct contact, developing skills in conducting family meetings will be required.

We have found that when training extends over a day or more it is possible to include some skills development (e.g. holding a family meeting which includes the patient), however a

focus on staff attitudes is always paramount. (For initial family meeting format used in training see Table 2.

Table 2

Initial Family Meeting	
Aims	
<ul style="list-style-type: none"> • To create a rapport with the family • To identify and value the role of the family, and to encourage the maintenance of family relationships • To create a platform for future collaboration (3-way partnership); including discussions around confidentiality • To develop a shared understanding/aims • To understand the context of the individual's problems • To provide information on services, support networks (including carers assessment) and services. 	
Content	
<ol style="list-style-type: none"> 1. Contact details; problem free talk (eg. did you have to take time off work; occupations); rationale for meeting (working together; family's expertise/knowledge); procedures/plans for session. 2. Family's account of development of client's problems <ul style="list-style-type: none"> ~ Initial onset of problems (what, when, triggers) ~ How did family members respond (what helped/didn't help)? ~ Experience of (accessing) services ~ Who else has been involved? ~ How have things developed? ~ How have they made sense of what has happened? 3. Impact of the problem on the family/family members. 4. Expectations regarding treatment, including family's goals. 5. Family members' attitudes to working collaboratively <ul style="list-style-type: none"> ~ Discussion around confidentiality and information sharing ~ Involvement in care planning process 6. Provide information about support and practical help for carers <ul style="list-style-type: none"> ~ Offer carers assessment 7. Genogram (family tree) <ul style="list-style-type: none"> ~ Who is in the family/what do they do/how do they get on? ~ Family history of mental health problems 	

Many staff welcome the shift to more family orientated services. However, some staff view family members either as a cause of the client's difficulties, or as interfering, and thus resist contact with families, while many others might not see a need to involve families in the clients' care. There is thus a need to inform staff members about the benefits of involving families and carers and to explore their attitudes and beliefs. This training is informed by both the theory and evidence for family work as well as an awareness of families' views on mental health services and our increasing knowledge of the stress of caring for someone with a mental illness. We have found that involving carers in the provision of the training is an effective way of achieving the required shift in attitudes.

The training also focuses on helping staff to extend their commonly held client-centred values and therapeutic skills to working with families. The qualities of empathy, warmth, genuineness, and a non-judgmental approach also make up the therapeutic stance required to develop collaborative working partnerships with families and carers. In addition, the training explores the challenging practical and theoretical implications involved in making services truly family/carer friendly (e.g. confidentiality and information sharing issues).

Inpatient Staff Training Programme

Having piloted the three-day package with new teams this was then provided to all trained staff on all five of our inpatient units. A team training approach was used to maximise the impact on clinical practice with follow-up consultation to teams. Day three was held approximately one month after days one and two. An important aspect was the building in of evaluation processes throughout. For content of the three training days see Table 3.

Table 3

Three day inpatient staff training programme	
Day one	<ul style="list-style-type: none"> • Carer’s story and discussion. • Introduction to National Policy and Trust Strategy for Partnership Working with Families and Carers, including exercises discussing current practice and personal/organisational obstacles. • Focus on information sharing and confidentiality using best practice guidelines and case examples.
Day two	<ul style="list-style-type: none"> • Introduction to systemic thinking and interaction cycles (including case scenarios). • Presentation by the Carers Assessment Worker: assessments and resources for carers and Electronic Patient Records demonstration. • The initial family meeting (introduce format and role-play). • Development of a unit action plan.
Day three	<ul style="list-style-type: none"> • Discussion of team progress and implementation of action plan. • Genograms (family tree). • Young Carers video and discussion of services for young carers. • Values Questionnaire. • Clinical discussion with examples from the group. • Evaluation of the training.

Evaluation of Inpatient Training

The project has been evaluated in a number of ways. Staff responded positively to the training programme which they rated highly in terms of the appropriateness of its level, teaching methods and whether they would recommend it to colleagues. In a pre- and post-training survey they reported a significant increase in confidence in their own skills in working with families. In terms of changes to clinical practice a pre- and post- training casenote audit, which involved two separate randomly selected groups of ten current inpatient’s case records from each inpatient unit, showed an increase on all the dimensions

measured (see Table 4). This was accompanied by a modest increase in the average number of families seen.

Table 4

5 INPATIENT UNITS: PRE AND POST TRAINING AUDIT (N=50)		
	PRE	POST
1. Is there a carer registered?	24%	44%
2. Family or friend recorded in 'contacts'?	92%	94%
3. Is there a reference in the care programme approach (CPA) to carer need, roles or contribution to care? (<i>family history, support network, carer's views sections of CPA focused upon</i>)	46%	84%
4. Is there Carer involvement in relapse prevention plan?	06%	18%
5. Any carer 'responsibility' for issues identified as problems within care plan?	12%	20%
6. Systemic issues identified and referral to specialist services		
a. Carer's assessment	14%	44%
b. Carer's support group/education group	06%	30%
c. Family therapy/Family Support Service	04%	09%

In addition a range of actions were initiated to improve communications, visiting arrangements, consideration of children and young carers, provision of leaflets and resources, and the inclusion of families and carers in the assessment/admission processes. This is being followed up by a questionnaire survey of families, carers and others visiting all inpatient units during the six months following the training programme asking about their satisfaction with the level and quality of their contact with staff on the unit.

Discussion

Many mental health services are in the process of developing information and support services for carers. Although this is a response to the needs expressed by families, we would argue that this alone is insufficient to change mainstream clinical practice. If staff are to be encouraged to work in partnership with families in all aspects of assessment and intervention, rather than simply adding-on services for carers, then they will require additional training.

Those professionals with more specialist training in family work are particularly well placed to provide staff with the required training in attitudes and skills for working with the social support network. This brief, broad-based training of large numbers of staff might enable the less complex needs of a large number of families to be met (Pearson et al., submitted for publication). However, this would require family work specialists to seek wider organizational roles and to work in partnership with colleagues who are developing services for carers. In addition to offering training, they will need to draw on their understanding of organizations in order to influence the management system which has the responsibility for the delivery of services. We have found that taking on these wider roles in

addition to direct clinical work enables more people to benefit from family-based approaches.

It is not the aim of our training strategy to train large numbers of staff to be family therapists, but rather to increase awareness of the needs of families/ carers and to create more family-sensitive mainstream services. Organisations also need to support the training of a smaller number of specialist-level qualified therapists in both systemic family therapy and family interventions in psychosis in order to meet more specific needs. This group would also be well placed to provide much of the training required by the broader training strategy.

Specialist family workers should also contribute to the routine supervision of staff in order to encourage the incorporation of systemic ideas in case formulations. Staff usually welcome supervision/consultation following team-based skills training and this can be an effective way of consolidating the application of systemic ideas.

Conclusion

In summary, we would argue that in order for more family inclusive ways of working to move from aspiration to a reality they will need to become embedded in routine services. In the UK the national policy guidelines already support this direction, but it will require mental health services to develop strategies and ‘champions’ to take this forward. In addition to providing resources, education schemes, and support for carers it will also require a higher level of family inclusion and a comprehensive staff training program in order to bring about the shift from a culture based on the individual to one which sees the individual in the context of their social network.

Our experience has been that a team training approach is most effective in bringing about the cultural change required. In providing this training it is important for trainers also to be aware of the current working context of mental health staff. Training needs to be carried out in a positive way. It needs to take into account the pressures and conditions in which both staff and carers work on a daily basis and provide support to staff through education and skills development to enable the setting of achievable personal and organisational goals.

Part 2

INVOLVING AND TRAINING CARERS

Peter Woodhams-- a carer from the West Midlands of the UK

Carers play an important role in many service users' lives. Their knowledge and expertise represent an enormous resource for statutory and voluntary mental health services. These are reasons why it is so important to include them through sharing information.

Introduction

This chapter is about the role carers can have in being involved with services in many different ways. It starts with my own story in becoming a carer and then how I have developed into becoming a carer actively involved in many different aspects of the world of mental health both as a volunteer and in a paid capacity. Inevitably the early part of the chapter relates my own personal experiences but the second part attempts to give more general guidance on how other carers might make a similar journey.

Clearly I have to use my experiences in the UK as my knowledge base, but I believe that similar opportunities to become involved exist for carers (or caregivers) in most parts of the world. Indeed mental health services throughout the world need to receive the input of carers as stakeholders because it is the carer alone who has the unique perspective of knowing the person before and after illness strikes and of the difficulties in accessing services, particularly in the early stages of mental ill health.

I do appreciate that many carers will not have the time, background experience or opportunities that I have had but I do hope that in reading this chapter, they may feel encouraged to get involved even if it is just in a small way.

Becoming a carer

As with most carers, my wife and I knew nothing about the world of mental health when our son first developed mental health problems in 1994 nor did we know the implications of the word carer. Until then our lives had been fairly straightforward.

It is not relevant to this chapter to detail the roller coaster that then ensued for all of us particularly as I know that readers who are carers will have been through a similar phase, but it is relevant to explain that my wife and I felt very helpless and removed until we were offered psycho-educational family therapy some five years later. This gave us the support and knowledge we needed, and the skills we learned helped us to contribute to our son's care and recovery. There is absolutely no doubt in my mind that I would not have become so actively involved without the benefits of Behavioural Family Therapy. Most important of all, my son started to improve and at the time of writing he has made really good progress and is living a relatively normal life.

Early stages of carer involvement

The Social Worker who delivered our family therapy often reminds me of the time I said to him: ‘Do you think there is anything I can do to contribute to mental health?’. Ever since then I have become a totally involved carer. I was just about to take early retirement and I was wondering about what to do with my time. We discussed this question in some detail and as a result three things happened;

1. The Social Worker passed my name forward to the Meriden Family Programme and my wife and I were invited to speak about the benefits we had gained from Behavioural Family Therapy at an awards ceremony when certificates were presented to professionals who had successfully completed training in this approach to helping families.
2. I was put in touch with a local carer who was trying to start a local Active Carers Group.
3. A meeting was arranged at the local psychiatric hospital to discuss the possibility of me becoming an Associate Manager (someone who sits on a hospital panel to hear appeals under the Mental Health Act).

In each case one thing led to another and opportunities to become more involved opened up on all fronts.

It is important to emphasise that neither my wife nor I had attended local carer support groups. For both of us respite was in our work and at the end of our busy working days, a support group was not attractive to us. However for me the concept of involvement was much more appealing in that it meant trying to do something positive. I had spent a lifetime in meetings and trying to influence decision takers. I found the idea of using this experience to try and improve mental health services for patients and carers very challenging and exciting. Indeed since becoming an involved carer I have never had a boring day. I look forward to every day.

Becoming an involved carer locally

The early days of my involvement ‘career’ were very much in my own local area as a volunteer helping to facilitate the development of a local active carers group. I am indebted to a highly respected local carer who taught me so much about mental health services and about pathways to involvement. We worked together to develop our group and were encouraged in this by our local authority which has a statutory duty to carers. This group is now well established as South Warwickshire Carers in Partnership and it co-ordinates all aspects of carer involvement in the area. We are fortunate that the local health Trust set up groups called Service Development groups which enabled stakeholders including patients and carers to contribute to the way mental health teams were run. In the U.K., health services are divided into areas known as Trusts, with each Trust covering a particular geographical area. Some Trusts provide services while others commission services.

I joined the Acute Care Forum which reviews practices in the local psychiatric hospital. Here I began to understand the way in which mental health services are run. I am still a member of this very important group and feel confident about the way I contribute. I also

became a member of the Service Development group for the Assertive Outreach team, spoke at training courses for professionals and sat on interview panels.

I was energised by the fact that I was gaining an understanding of mental health services. This in turn helped me be a more effective for my son particularly in being able to speak to his clinicians more confidently. By this time I had been appointed as an Associate Manager at the local hospital. I was paid a small fee when I sat on an appeals panel. At this time hospitals were required to have their own internal appeals procedure under the Mental Health Act.

From local to regional

When my wife and I gave the talk to the Meriden Family Programme (described in Chapter 4) clinicians and trainers, we met the Chair of Carers in Partnership (CiP) in the West Midlands. This group promotes carer involvement in the way services are planned, set up and delivered. It runs a network of carers and carer support workers with an interest in involvement, and has one part time staff member. Carers attend meetings on an entirely voluntary basis. I accepted an invitation to join this group.

Soon, I was asked to join the Meriden Advisory group as the CiP representative. I also attended conferences as a carer representative and contributed to training courses. I enjoyed the involvement with CiP as a volunteer and was rapidly gaining confidence in my knowledge of mental health infrastructures.

CiP was able to get funding for another part time staff member whose principal role would be to promote the development of active carers groups in each area of the West Midlands. This in effect was a 'field worker' role. I applied for this post, and was successful. I joined initially as a staff member contracted through the mental health charity Rethink in August 2003. Since then carer involvement has become a substantial and rewarding part of my life.

Regional involvement

Carers in Partnership has been fully funded by the Care Services Improvement Partnership, which has been commissioned by the Department of Health to help implement national policies for local benefit. Whilst I contribute to all aspects of the work programme my particular focus has been on the development of:

Local Active Carers Forums

For such a forum to evolve, two ingredients are essential:

1. A small group of carers willing and eager to get involved
2. An ally within the local mental health service. Carers cannot easily access involvement opportunities without a supporter

Each group works in a different way. Some are exclusively made up of carers whilst others invite professionals to attend as appropriate. They are all working towards having a carer as chair and ensuring carer representation at all key strategic meetings within the locality so that the views of carers can be taken forward. Other activities include arranging for carers

to sit on interview panels and contributing to training and generally being available for consultation on strategic issues. Once local mental health managers know of the existence of the Active Carers Forum then they will channel requests and invitations through to it.

It is helpful if a carer worker from the local mental health service is linked to the forum to provide access to an administrative resource. The running costs of such forums are very small and in most cases the local trust or local authority will provide financial assistance. It is important that carers are paid an appropriate fee when attending strategic meetings.

Carers with Special Needs

There are particular groups of carers who may have special needs, for example, children with caring roles. I will use as an example carers from black and minority ethnic groups. It has been a priority of CiP to try and build up a group of supported and engaged carers from minority ethnic groups.

Working through a black and minority ethnic sub group, two very successful events have been run for those carers to raise their voice and encourage involvement. A major achievement has been facilitating the commissioning of a Black and Minority ethnic specific Carer Education Programme delivered by the Meriden Family Programme. This was a training trainers course attended by five teams from different services (including carers) with the objective that each team gained the knowledge and skills to deliver an 11 week modular (2 hours per module) education programme to these carers within their respective areas.

Hosting events that highlight Carers' needs

One of the key targets for CiP has been to try and influence improvements to the services delivered to carers in each of the localities in the region. Examples of good practice in carer services were showcased in workshops presented by selected teams from within the region. The target audience was a delegation of 4-6 representatives from each of the fourteen areas in the region. Eleven of these areas sent delegations and attended workshops on:

Carers Assessments	Carer Involvement
Carer Support	Carer Education
Information for Carers	Family Work
Services to BME carers	Carers of older people
Young carers	

The event proved to be very successful and raised the profile of carers throughout the region.

Royal College of Psychiatrists

My initial involvement with the Royal College of Psychiatrists came through a campaign called 'Partners in Care' which promoted a working partnership between psychiatrists and carers/family members. I was invited to join the regional Steering Committee and helped to facilitate Partners in Care events in each area of the region. I was asked to speak on carer perspectives at many of these events and whilst I was initially quite nervous at this prospect, I soon got used to the idea of giving presentations.

This involvement resulted in me being invited to join the West Midlands Executive Committee of the Royal College as a carer representative and at the time of writing I believe that I am still the only carer representative on any of the regional executive committees. I am allocated time at each meeting to present carer issues and with the cooperation of the regional Chair, I enlisted other carers to contribute to a leaflet 'A message to psychiatrists from carers'.

Working with the Meriden Family Programme

Behavioural Family Therapy helped our family so much become an active supporter of family interventions and of the work of the Meriden Family Programme in particular. This has led to very active involvement in the work of Meriden, both on their programmes in the West Midlands and throughout the UK and Ireland. I do some of this work on a carer consultancy basis. This involvement includes;

- Chair of the Meriden Advisory Group - a group of Meriden stakeholders which meets three times a year to review the work of Meriden
- Regular speaker on the benefits of Behavioural Family Therapy to all family members on many Meriden training courses. I also speak occasionally on this topic within mental health Trusts when they are training their own therapists.
- Completed a Meriden Training Trainers course with particular emphasis on the development of facilitation skills
- Worked as a Trainer on all deliveries to date of the Carer Education Training Programme particularly in contributing a carer perspective to this initiative. I also taking a lead in marketing this programme because it is so beneficial to carers
- I consider that I am the carer member of the team and in this capacity there are several other activities that I contribute to.

National Involvement

In England, the way in which carers are involved nationally is very ad hoc. There are groups such as rethink and the Manic Depressive Fellowship that support the needs of family members. However, there is no national mental health carers forum as such, so there is much work to be done to develop mechanisms which enable carers to be involved in national initiatives and to have a representation 'constituency' enabling them to seek views on national issues from other carers. As a result the opportunities outlined below are the only groups I have been able to contribute to at national level and these have come through my own contacts.

National Psychosocial Intervention (PSI) Group

This is a multi disciplinary group including service users and carers which promotes the development of psychosocial interventions including family work. I have spoken on the benefits of Behavioural Family Therapy at a national PSI conference (as indeed I have done at a World Fellowship of Schizophrenia and Allied Disorders conference in India).

Royal College of Psychiatrists

My involvement in the Partners in Care campaign led me to give a number of presentations to national meetings promoting the importance of carer involvement in the training of psychiatrists. I produced a paper which outlined proposals on how best this new training concept could be implemented and I presented these proposals at the Annual Meeting of the Royal College in 2006.

I have also joined the National Patients and Carers Committee of the Royal College.

A summary of involvement outlets for carers

My own involvement has been extensive and varied. This is because I have been fortunate to have had the opportunities for involvement. My earlier career may have helped me acclimatise quickly to this new world of meetings and presentations. Most important of all, I had the time and I wanted to be involved because of the satisfaction and sense of achievement it brings.

This is not going to be the case for all carers and it is really important that carers find involvement outlets that suit them and that they are comfortable with. Everyone has different strengths they can contribute. It is not essential that to be an involved carer you have to go to lots of meetings or give lots of talks. I have summarised below in very general terms the different types of carer involvement in services in England:

Local Mental Health Services

All local authorities will have meetings which carers can attend to review different strategies to do with improvements in these services. It is important that carers explore all local opportunities for involvement. A good example is where carers sit on interview panels for which training should be provided by the local -authority.

Regional Forums

There will be new health and social care initiatives that are introduced on a regional basis. Sometimes collaborative groups will be formed by the relevant health service agency which carers will have the opportunity to join. There will be regular regional conferences at which carers can often get a free place.

Involvement in the training of professionals

This is a growth area of carer involvement in England and it divides into two main categories of training:

- Staff Induction and Staff Development training. Carers should give their perspectives on induction courses for new staff or when existing staff are being re-trained to implement changes in areas such as mental health legislation, family work, or new mental health teams developments
- Professional training within universities. Many courses being provided to train new mental health professionals now include an element of carer involvement. Tutors will often look for carers who are prepared to have a regular involvement with courses for which a fee should be paid. In the West Midlands

we have established a ‘Helping Professionals Learn’ sub group and members of this group have each developed a working relationship with a particular university in the region and are working closely with tutors.

Participating in consultations

On a national level there will be many consultation processes to which a group of carers will have the opportunity to contribute. It is important that carers organise themselves into a group, review the proposals and put their suggestions and comments forward in accordance with the procedure laid down in the consultative document. From time to time individual professions will review their ways of working and the relevant professional body will instigate a consultation process. In recent times Carers in Partnership has contributed to two major consultations, Nursing and Occupational Therapy in which each body was reviewing its role in mental health. The Carers in Partnership submission for Occupational Therapy was included in full in the final report, and can be viewed at <http://www.westmidlands.csip.org.uk/carers-in-partnership.html>

Local health authorities will also often have a formal consultation process when introducing a new method or strategy which affects the way mental health services are delivered.

Speaking at conferences and mental health promotion events

Public speaking is often found daunting by many people and carers are no exception to this. However as many have found, the more practice you get the easier it becomes and very often the key is in preparing a talk that the presenter is comfortable with. Many carers will have put together a talk on their own experiences and although this is an emotional experience, it will often have a profound impact on the audience. Carers who have developed a presentation should make known their availability to trainers within health trusts, local authorities, regional agencies, universities and professional bodies. An appropriate fee should always be paid.

The Written Word

Letter writing to local health trusts is a common communication method for carers with a grievance although the appropriate complaints procedure is probably the best method of taking a grievance forward.

Some carers find that they can best express their experiences in poetry.

Increasingly authors and editors of clinical mental health books will be seeking contributions from carers and other mental health publications will be keen to include an item on a carer perspective on a specific topic.

Involvement with mental health charities

Mental Health charities in England always welcomed the involvement of carers in many aspects of their work and for some carers this is the type of involvement they feel most comfortable with. The involvement can include;

- Working as a volunteer in services provided and run by the charity
- Fundraising activities—organising or attending such events

- Serving as a trustee of the charity
- Being a committee member of a working or governance group
- Participating in lobbying activities of the charity. In England charities such as Rethink have been successful in campaigning on particular issues such as mental health legislation, and raising awareness of the risks of cannabis. They have been actively supported by carers who have highlighted their personal experiences
- Attending meetings such as support groups

A few suggestions for further carer involvement

There is no prescriptive formula for effective carer involvement. Much depends on the number of carers with an interest in being involved, their own particular skills, the availability of funding and the attitude taken by the local services to carer involvement. If the local services are supportive then very often carers will respond appropriately. These are just a few ideas that may be helpful.

Active Carers Group

- Forming an Active Carers Group will enable carers to be recognised as a stakeholder group by mental health services and involvement opportunities will then be channelled through to this group
- The group will then share the different involvement opportunities taking into account individual interests, knowledge and capabilities.
- The group can also be used as a means of seeking the views of other carers on issues and will be a reference group for carers to report back to
- It may also wish to facilitate training for its members, particularly new ones. A training course might cover an explanation of local services, a talk from a clinician such as a psychiatrist, accessing involvement opportunities, and the attitude of local services to carer involvement and how it can be made more effective
- Develop members' skills through courses on inter-personal relations, skills needed to understand meetings procedures, negotiating and influencing and how to give presentations.

Carers Need a Positive, Objective Approach

- Using personal grievances should be avoided in general carer involvement as these should continue to be handled on a personal basis or through the proper mechanisms
- A negative carer attitude or approach will not endear carers to a mental health service. Every effort should be made to keep a positive approach by making constructive suggestions. Managers tire of hearing negative comments all the time and may well switch off or at least move the agenda on.

- angry carers can often be very effective if they can harness their anger and add a constructive element to their contributions

Carer participation in Meetings

- even if carers have a difficulty in contributing to formal meetings it is important to remember that their very attendance at the meeting will often increase staff awareness of carer issues
- it takes time to develop an understanding of what meetings are about and who is who at the meeting. Carers therefore need to be patient as eventually an appropriate understanding will develop
- carers should be paid for attending meetings run by the local services and they should also ensure that appropriate means of communicating meeting papers, minutes, agendas are agreed e.g. email or post.
- it may be helpful for new involved carers to be mentored by more experienced involved carers
- an open meeting for carers when carer involvement is explained is often a successful way to recruit carers into involvement particularly if the meeting includes a subject of specific interest such as understanding medications
- a question that can help to motivate carers become involved is ‘are you satisfied with local mental health services? If not do you want to do something to try to improve these services?’
- involved carers should also identify and build up relationships with key allies in the local services—effective involvement is very difficult without the assistance of allies who can help prepare the way
- it is important to remember that carers can speak for those who might not otherwise be heard.

Is it worth the effort? What are the benefits?

- the knowledge and confidence gained through involvement helps carers become more effective and less stressed. They feel less isolated and more supported. In particular they feel far more able to speak to professionals in their caring role
- carers find involvement challenging but also very satisfying. They feel they are trying to do something positive
- carers can influence mental health strategies locally, regionally and nationally
- involvement helps carers to be seen as genuine stakeholders
- as carers gain knowledge, they can pass this knowledge on to other carers
- carers have a mechanism to take their concerns forward
- for some carers involvement is a form of respite as indeed it has been for me

SO PLEASE ENCOURAGE CARERS TO BECOME INVOLVED

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