

The Role of the Family in Psychiatric Rehabilitation

by LeRoy Spaniol, Anthony M. Zipple, and Doris Lockwood

At Issue



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Abstract

This article describes the multiple roles that families can play in the psychiatric rehabilitation process and suggests ways for professionals to collaborate with them. The authors discuss the family's experience of loss and their process of recovery; their caregiving role; their role in supporting other families; their teaching and educational role; their advocacy role; their role as researchers and research subjects; and some suggestions for supporting family roles.

During the past decade, the literature on helping families of persons with mental illness has broadened considerably. Reported approaches include psychoeducational groups (Hatfield and Lefley 1987), emotional support mechanisms (Byalin et al. 1982), and models for training professionals to be more responsive to the needs of these families (Zipple and Spaniol 1987).

One key to improving clinical collaboration between families who have a family member with a mental illness and mental health professionals is to help professionals understand the family's initial experience and their subsequent role in psychiatric rehabilitation. The onset of mental illness triggers major role changes

in families that are not dissimilar to the role changes experienced by families of persons with other disabilities (Power and Dell'Orto 1980). Few families are prepared to deal with such traumatic role changes, especially when these changes are precipitously forced upon them (Hatfield 1987; Spaniol 1987; Terkelsen 1987; Tessler et al. 1987).

Interestingly enough, professionals are often as unprepared as families to respond appropriately to this kind of profound crisis. In fact, we frequently see a parallel process in the emotional and cognitive responses of the mental health professional and the family: both feel helpless, angry, despairing, and anxious. The scarcity of useful helping models and the relative lack of solid scientific data about mental illness leave the psychiatrist, the psychologist, the social worker, or the mental health practitioner with little confidence to help families. Most professionals have been taught about mental illness and some have been taught about families, but many professionals do not understand families who have experienced mental illness. Indeed, numerous studies have shown a dramatic difference between professionals' perceptions of what families need and the families' own perceptions of their needs (Hatfield et al. 1982; Spaniol and Zipple 1988a).

The training that professionals receive often fails to provide the skills, supervision, peer support, and validation necessary to assist families with coping and adaptation skills (Wasow 1982; Bernheim and Lehman 1985; Minkoff 1987). On the con-

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trary, professionals are frequently still taught that families both cause and perpetuate the illness and decompensation of their family member. These professional beliefs and attitudes, and the lack of appropriate helping skills, coupled with a real sense of inadequacy due to lack of knowledge and a "cure," often lay an extra burden of guilt on the newly traumatized families (Terkelsen 1983).

The Task Force on Families and Mental Illnesses of the California Alliance for the Mentally Ill conducted a survey of California graduate training programs in the core mental health disciplines. They found that 53 percent of all training programs surveyed still teach a theory of family causation for serious mental illness (NAMI Training Matters 1991). Further, 82 percent of the programs reported that they prepare their students only "somewhat" or "not at all" to work with families of people with mental illness. This is in spite of the enormous interest during the last decade in educational and supportive approaches for families with mentally ill members (Beels and McFarlane 1982; Leff et al. 1982; Falloon et al. 1984; Bernheim and Lehman 1985; Anderson et al. 1986). Unfortunately, the training received by professionals does not consistently reflect the value of these educational and supportive interventions.

It is little wonder that professionals fail to understand and value the role of the family in psychiatric rehabilitation. Understanding of the family's complex and highly charged emotional experience can give professionals a basis on which to develop new techniques more helpful to the family. Professionals can help families to see their experience as a natural result of a traumatic crisis, one which requires new coping and adap-

tation skills. This article describes the multiple roles that families can play in the psychiatric rehabilitation process and suggests ways for professionals to collaborate with them. We will discuss the family's experience of loss and their process of recovery, their caregiving role, their role in supporting other families, their teaching and educational role, their advocacy role, and their role as researchers and research subjects.

Coping With Trauma: Loss and Recovery

The families of persons with mental illness experience a very difficult adjustment and recovery process that is likely to last for many years (Terkelsen 1987; Tessler et al. 1987). They go through the normal shock, denial, depression, anger, acceptance, coping, and final affirmation of any person confronted with a traumatic illness (Power and Dell'Orto 1980; Van der Kolk 1987). In addition to the typical stages and tasks of adjustment, we are beginning to discover unique aspects of their adjustment process. For example, the lack of clarity around the process and outcome of mental illness results in many families regularly cycling through hope and then despair. While these shifts in feelings and the resultant behavior may at times seem quite extreme, painful, and confusing to families, the experience is quite normal. Professionals who do not understand the adjustment process of families frequently view these reactions as evidence of pathology.

During the early stages of their recovery process, families often experience severe guilt, embarrassment, and self-blame. Contact with caring and knowledgeable professionals is critical at this time because these feelings and beliefs may be intensi-

fied by contact with professionals who continue to believe that the family is the source of the problem. Families initially exhibit strong reliance on professionals, believing they will provide answers. As the persistence of the illness becomes apparent, pessimism and despair replace the unquestioning faith in the doctor and the mental health system. Professionals may experience angry and assertive families as negative and intrusive, misinterpreting their increasing alliance with other families as resistance to therapy. At this point, however, other families who have been through the same experience often have more to offer than professionals. When families begin to accept the limitations of what can be done, they focus more on the management of symptoms and improving the functioning of the family member with the mental illness. The professional's response at this point is crucial. Professionals often reject the family as its members become more assertive because they fear that this involvement will lead to a breach of confidentiality (Zipple et al. 1990).

As families experience less self-blame and more assertiveness, they show an increased interest in working more closely with knowledgeable and caring professionals. Family members also frequently find that they have changed, that they are no longer the people they were when the initial trauma occurred. They are more confident in the value of persistence and united action over time.

Professionals have dealt with losses just as families have. Understanding the families' experience as a loss experience requiring support, coping, and adaptational skills can lead to greater compassion and new competencies.

Parent and Caregiver

In typical families, parents serve a crucial caregiving role for other family members. While this is particularly evident in the case of supporting young, dependent children, this caregiving role often extends to adult family members who need special support. The special needs of a family member with a mental illness, coupled with a service system that can often be unresponsive, place many families into the role of primary caregiver (Thurer 1983). This is usually not a role families freely choose for themselves. Further, they frequently lack the knowledge, skills, and support system required to provide specialized mental health care (Bernheim et al. 1982). In addition, not all families are equally well equipped to support their family member with a disability. Families who have a member with a mental illness include a broad range from families who are sophisticated and have extensive resources to families who may be struggling with other problems and are less able to offer significant assistance without personal support for themselves.

While families are eager to assist their family member with the disability, they believe that professionals should assume the role of primary caregiver (Fisher et al. 1989). Unfortunately, for many reasons, the mental health system has been unable and sometimes unwilling to provide the necessary services, and these gaps in service delivery have forced families to assume this responsibility themselves (Hatfield 1981).

As professionals begin to assume their role of primary caregivers, families can still provide coaching around daily-living and problem-solving skills. Families can assist in administering medication and moni-

toring its side effects. Family gatherings provide social opportunities and families are also in a position to encourage and support friendships. Families can also support their disabled member's vocational and educational initiatives. Many of these suggestions are simply extensions of the normal parenting/caregiving role of families with any family member. However, they often assume a new level of importance and become more difficult to implement because of the disability.

There are some problems in caregiving that are particularly difficult for families that include a person with a mental illness. These include management of medication, bizarre and abnormal behavior, antisocial and aggressive behavior, social withdrawal and isolation, educational and career deficits, hygiene and appearance problems, and self-destructive and suicidal behavior. These problems require specialized and additional coping strategies, and families often find themselves alone and tormented in coping on a day-to-day basis (Spaniol 1987; Spaniol and Ziple 1988b). Professionals frequently lack the practical experience or training to adequately assist families. It is no wonder then that families who have achieved some stability in these areas quickly become primary resources for other families facing these same issues.

It is difficult and often frightening for families to manage the delicate balance between independence and age-appropriate behavior, such as living away from home, and the functional limitations imposed by the disability. Also, although most families struggle to separate from their caregiving role, they do not trust that their family member will be supported as he/she should be because of the current mental health structure

and the financial climate of our times. Most families prefer to have the day-to-day caregiving provided and managed by an ongoing community support system (Lefley 1990). The family's role should not be abused because of lack of community facilities. Professionals and family members need to find solutions together. Families do not want to take over the mental health system, but they do want to radically change it.

Supporting Other Families

Gartner and Riessman (1982) have written about the profound importance of self-help and mutual aid groups in supporting individuals with special needs. Families of persons with mental illness have organized their own mutual aid groups and have become an essential source of support for each other. The National Alliance for the Mentally Ill is the largest and best known of these groups in the United States; it has grown from a few hundred family members in 1979 to over 130,000 in 1991. These groups nurture and support their members and also promote the roles of family members as advocates and teachers. No one can understand the pain of these families as well as other families in the same situation. Professionals can help families in many ways, but not with the kind of healing that one family member gives to another.

One of the primary functions of peer support is to provide families a place to share their stories about coping with mental illness. Because it is such a profoundly distressing experience, one that leaves them feeling helpless, bruised, alone, and vulnerable, families need to be heard in a nonblaming atmosphere such as their peer group. Through these groups, families can develop more effective

coping mechanisms. They can mourn their loss and feel validated in their experience, and from this their ability to cope begins to grow. Even when there are no answers, families can learn to live better with what they cannot change. Families are the most important resource for one another in developing strategies for successful coping (Spaniol 1987).

A final function of the peer support system is to highlight the limitations of the current service system and delineate the family's role in the psychiatric rehabilitation process. Families are keenly aware of the limitations of the service their family member is receiving and they know what techniques, community services, and professional help are required. Peer support and effort are clearly important in implementing any changes that need to be made. As families move into a more active role, they need less support for their own adjustment and more for their outside activities as advocates and teachers.

Teacher and Educator

As families experience less self-blame and become more assertive, they develop an increased interest in working more closely with knowledgeable and caring professionals. In some cases families have become especially knowledgeable and may even know more than many professionals, particularly about some aspects of their own relative's illness. This knowledge is an important resource in the rehabilitation process. For example, they know their family member's reaction to life stresses, strengths and weaknesses, and reactions to the illness and to the interventions of the mental health system. This family knowledge is an important addition to the knowledge professionals gain

from their experience with their client.

Families also need to educate professionals about how they experience the mental illness of their family member and to confront the negative beliefs some professionals hold toward families. Professionals need to see the family's experience as valid and normal. One way in which families can educate professionals is by helping to train professionals to work with other families and with persons who have a mental illness (Zipple and Spaniol 1987).

Families are also important educators for providers of mental health services. They can monitor and provide feedback to programs on how they are functioning and on how well clients are being served (McElroy 1987). They can also be an important source of imaginative ideas about program changes and innovations and encourage providers to maintain their commitment to the most severely disabled.

Advocate

Families have begun to realize that even sensitive professionals and sympathetic legislators have their own interests to protect and cannot adequately speak for them. Families have therefore assumed a much more direct role in changing the mental health system. Advocacy is a healthy response to the hopelessness that families often feel. When families learn to be more helpful to themselves and to their family member with mental illness, when they begin to feel their impact on the mental health system, when they see laws, policies, and legislative practices change because of their influence, then they feel empowered, confident, and truly hopeful about their ability to affect their own lives and those of

their family member who has a disability. Advocacy is also a natural and a necessary stage in the adjustment and recovery process of families.

Advocating for services for individual family members is one aspect of family advocacy. Families are advocating for a balanced service system, including accredited hospitals, improved medications, more enlightened rehabilitation programs, supported housing, supported work, supported education, and other programs which support community integration. Families are also in the vanguard of those advocating for the adoption of new treatment methodologies. They support programs that treat their family members as individuals and prepare them with useful skills that they can present to society.

Because families know that gains for their family member mean gains for other people who have a mental illness, their concern goes beyond their own situation. They have a shared sense of effort and advocacy with one another. Advocacy brings families out of the shadows, making the inherent strengths of families more available to the greater community and building the families' sense of confidence in their ability to make a difference for their family member and for others. Advocacy strengthens the potential for healing within families and within society.

Families want to be seen as partners in the psychiatric rehabilitation process and advocacy is a way to shift the balance of power between families and professionals (Bernheim 1987). This requires a change in the way professionals relate to families (Spaniol and Zipple 1984). Advocacy is fostered primarily by the support process within the family movement, but it is difficult for some profession-

als to support family advocacy when they are often its primary target. Also, some professionals are not prepared to deal with intact and assertive families. The family's shift toward advocacy is why professional support begins to have diminishing returns as families move further on in their own recovery process. It is also one reason why family support groups led by professionals have only limited usefulness (Zipple and Spaniol 1991). As families get better at coping, they need the support of other families to move into personal, organizational, and legislative advocacy.

Professionals can also benefit from family advocacy. Families can bring pressure to bear on the mental health system and its funding sources that professionals alone could never bring about. Families are determined to make major changes in the way clients are served by changing how professionals are trained, how programs are operated, and how systems are funded, planned, and managed. Many professionals have also wanted these changes, but they have not felt sufficiently empowered to bring them about.

Researcher and Research Subject

In spite of the tremendous advances that have been made in the past 20 years, the profession's knowledge of the experience of families coping with mental illness is still in its infancy. Recently, families have been able to recognize the importance of their participation in research projects and have conceived and implemented their own research (Johnson, in press). They have also filled out questionnaires and have been interviewed, both of which take time and often raise painful memories and issues. Even though families

have good reason to be somewhat cautious about participating in research projects because of the risk that some forms of research might simply continue the many myths about families and mental illness (Hatfield et al. 1987), many families are highly committed to having their experience validated. They want to influence the mental health profession's perception of them and thus be involved in making an exceptional contribution to the field. This collaboration requires great humility on the part of professionals because the role of helper often gets reversed. It also forces professionals to come closer to sharing the grief, pain, discouragement, and anger that families often experience.

Suggestions for Supporting Family Roles

Professionals play a crucial role in supporting families in these new roles. This is not always a comfortable position. Previous training (Minkoff 1987), concerns about confidentiality (Zipple et al. 1990), and their own feelings of frustration as they attempt to assist their clients can interfere with the professional's ability to be helpful. While each professional will want to develop his or her own ways to support families in their roles, the following are some general guidelines (Spaniol et al. 1984):

- Clarify roles. Professionals can be open to negotiating and clarifying with families the varied roles that they play. These roles can change over time for the same family. Professionals can be observant of the changing needs, abilities, and willingness of families and assertive in suggesting and encouraging their assumption of new roles.

- Work as a team. Consider developing a team approach to working with families. Utilize families as collaborative adjuncts to a professional practice. Most families want to work cooperatively, and both the professional and the disabled family member will discover valuable benefits from such a collaborative relationship (Lefley and Johnson 1990).

- Use educational approaches.

Families often feel comfortable in the role of "learner" and are anxious to assimilate all of the information and advice professionals have to offer them. They can then go on to act as educators for peers, professionals, and their own family member with a mental illness.

- Include families in planning and system monitoring groups. Family members can provide input into program evaluation, system planning, human rights issues, and monitoring. Inviting family members to assume these positions and supporting their roles at this level will be very helpful to both the family and the mental health system.

- Learn to respond to intense feelings. Families often report a long history of frustration and even abuse by mental health professionals. Their feelings are deeply felt and may be expressed at unexpected times or with great intensity. Families need professionals to listen with understanding and compassion, rather than defensiveness, to what they are saying.

- Meet local support groups. Professionals can get to know families in their area by visiting their meetings and finding out what their concerns and strengths are. These groups are a great resource for recruiting family members who are interested in new roles. Some professionals have compiled lists of family groups in their area and distributed them to other

professionals. If you are part of an agency, consider an agency liaison for the family groups. This person can help to update other professionals in the agency on the needs, concerns, and availability of family members. Make yourself available as a resource to a local family group. Volunteer to share information through formal presentations or group discussion. Ask family members in to talk to your staff. Invite their comments on your program and how it might better serve their needs. Join the National Alliance for the Mentally Ill as a professional member.

- Acknowledge diverse beliefs.

Learn to acknowledge that there is a wide variety of beliefs and needs in the mental health field. Families may often disagree with you just as other mental health professionals often do! The professional's learned assumptions, allegiances, and loyalties may be regularly challenged as he or she begins to get more involved with families. Learning to accept these challenges is an important part of supporting families in new roles.

- Point out family strengths. A major part of supporting families in new roles is letting them know that they have a great deal to offer. Be specific in acknowledging their abilities and in describing how these competencies will support them in new roles.

- Develop your own supports. Because of new stresses and challenges that they will likely encounter working in new ways with families, it is important for professionals to develop their own support network. Working with families in their varied roles will not come easily, and professionals will need their own support resources to debrief their experiences, share successes and failures, gain new knowledge, and learn new skills.

- Be clear about your limitations. Be clear with families about the complexity of the disability and the limitations of current knowledge and resources to treat it. Let families know that you are also struggling to help their family member. This awareness will help families come to terms with their own hopes, fears, and limitations. Awareness will also prepare them to be partners in developing workable expectations and plans for programs, the mental health system, and their own family member's rehabilitation.

Conclusion

Families play a crucial role in the vital area of psychiatric rehabilitation, and professionals can learn to work more cooperatively with them. The different roles of families in the psychiatric rehabilitation process have the potential to benefit the family member with the disability, the family itself, and the mental health system.

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In Memoriam

It was with great sadness that we at the National Institute of Mental Health learned of the death of Dr. Gerald L. Klerman.

Dr. Klerman, who was Professor of Psychiatry and Associate Chairman for Research at Cornell University Medical College, and a former Administrator of the Alcohol, Drug Abuse, and Mental Health Admin-

istration (ADAMHA), helped bridge the gap between psychopharmacologic and psychotherapeutic research and practice, a synthesis of still-growing importance to the field.

Dr. Klerman will be remembered for his major scientific contributions in the areas of clinical treatment and investigation.

An Invitation to Readers

Providing a forum for a lively exchange of ideas ranks high among the *Schizophrenia Bulletin's* objectives. In the section *At Issue*, readers are asked to comment on specific controversial subjects that merit wide discussion. But remarks need not be confined to the issues we have identified. *At Issue* is open to any schizophrenia-related topic that needs airing. It is a place for readers to discuss articles that appear in the *Bulletin* or elsewhere in the professional literature, to report informally on experiences in the clinic, labora-

tory, or community, and to share ideas—including those that might seem to be radical notions. We welcome all comments.—*The Editors*.

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