**What Professionals Need
to Know About Families**

Module 1:

The Family Experience
of a Family Member
with a Psychiatric
Disability

Participant's Manual

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Introduction

Module 1: The Family Experience of a Family Member with a Psychiatric Disability is designed to:

- Provide an historical perspective on families and psychiatric disabilities.

- Describe the experiences of family members as they cope with a psychiatric disability in a family member.

- Describe the recovery process of family members as they cope with the traumatic crises of a family member with a psychiatric disability.

Overview of the Family Stages of Recovery

Shock/Denial/Disbelief

In this phase, families often experience an emerging awareness of a difference in their family member and a lack of clarity about what is going on. Families may try to explain away what is happening—to rationalize it. Their anger may get in the way. They may feel deliberately provoked by their family member. They may feel that drugs, alcohol, or bad friends cause the illness. Their relationship with the family member may change as a result of increased tension, frustration, grief, and anger. Previous negative strains in the family may increase. Often attempts are made to find answers through family, friends, clergy, and physicians. Denial can be massive and may linger throughout the other stages. Support and information are needed to help families through this stage.

Recognition

This is the initial awareness of the presence of a mental illness. Labeling may occur, with or without a clear diagnosis. Guilt, embarrassment, grief, and self-blame may also occur, especially during an acute decompensation. Questions such as "What did I do wrong?" are common. Strong dependence on professionals may be present since it is assumed that they know the answers and have the ability to cure and manage. This is a critical stage in which families need high levels of support as well as information related to the causes, treatment, and prognosis of mental illnesses.

Coping

This is an ongoing stage in which the family tries to adjust to the frequent crises and disruptions in normal family life. There is an increased recognition of the chronicity of the situation and a loss of faith in some professionals and the mental health system. Professionals may feel families are intrusive at this stage because families become more angry and assertive. Pessimism and despair may grow as well as a belief in the family's own expertise. The value of support from other families is acknowledged. Many families begin to accept the limits of what families can do

about the illness. Families become more sensitive to their own levels of stress and burnout. More energy is focused on management of symptoms and improving functioning of the family member and there is often an increased interest in working more closely with knowledgeable and caring professionals. While the need for support and information continues, the coping stage is where the need for a wide range of skills is especially apparent.

Advocacy

In this stage the family becomes proactive externally. There is increased assertiveness, less self-blame, less blame of individual professionals, and more interest in educating and training professionals. Time is devoted to working out new roles and relationships with professionals. There is increased confidence in the value of persistence over the long run, an enhanced ability to let go of what families can't change or don't want to change, and focused efforts on the changes that families see as necessary. There is an emphasis on united action and on changing the system. Community organizing skills become crucial in this phase.

Recommended Readings To Prepare for Training

The following readings were used in preparing the training materials and will be helpful to you as you prepare for this session.

Required Readings

Baxter, E. A., & Diehl, S. (1998). Emotional stages: Consumers and family members recovering from the trauma of mental illness. *Psychiatric Rehabilitation Journal, 21*(4), 349–355.

Finley, L. (1998). The cultural context: Families coping with severe mental illness. *Psychiatric Rehabilitation Journal, 21*(3), 230.

Marsh, D. T., Appelby, N. F., Dickens, R. M., Owens, M., & Young, N. O. (1993). Anguished voices: Impact of mental illness on siblings and children. *Innovations & Research, 2*(2), 25–34.

Spaniol, L. & Zipple, A.M. (1994). The family recovery process. *Journal of the California Alliance for the Mentally Ill, 5*(3), 57–58.

Supplemental Readings

Cuijpers, P., & Stam, H. (2000). Burnout among relatives of psychiatric patients attending psychoeducational support groups. *Psychiatric Services, 51*(3), 375–379.

Dixon, L. et al. (2001). Pilot study of the effectiveness of the Family to Family education program. *Psychiatric Services, 52*(7), 965–967.

Fisk, D. et al. (2000). Homeless persons with mental illness and their families: Emerging issues from clinical work. *Families in Society: The Journal of Contemporary Human Services, 81*(4), 351–359.

Laidlaw, T. M., et al. (2002). Caregivers' stresses when living together or apart from patients with chronic schizophrenia. *Community Mental Health Journal, 38*(4), 303–310.

Marsh, D. T., et al. (1996). The family experience of mental illness: Evidence for resilience. *Psychiatric Rehabilitation Journal, 20*(2), 3–12.

Mueser, K. T. & Glynn, S. M. (1996). Family burden of schizophrenia and bipolar disorder: Perceptions of relatives and professionals. *Psychiatric Services, 47*(5), 507–511.

Phelan, J. C., et al. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin, 24*(1), 115–126.

Provencher, H. L., et al. (2000). The caregiver's perception of behavioral disturbance in relatives with schizophrenia: A stress-coping approach. *Community Mental Health Journal, 36*(3), 293–306.

Spaniol, L., Zipple, A., Marsh, D., & Finley, L. (2000). *The role of the family in psychiatric rehabilitation.* Boston: Boston University, Center for Psychiatric Rehabilitation (www.bu.edu/cpr).