What Professionals Need to Know About Families

Module 1:

The Family Experience of a Family Member with a Psychiatric Disability

Trainer'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.

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).

Training Guidelines

Introduce Participants

Begin with introductions. Ask participants to tell a little about themselves—who they are, where they work, and what they hope to get from the training. Trainers should also introduce themselves by telling who they are, what their affiliation/background is, and how they came to be involved in the training. This should take about 15 minutes, depending on the size of the group. If there are more than 20 participants, rather than detailed introductions from each individual, you can address the participants more generally by asking if anyone would like to share why they are participating and what they hope to get from the training.

Pre/Post Evaluation

Before beginning any training, give participants copies of the Pre/Post Evaluation included on the CD and ask them to complete the survey questions. Participants should then be asked to complete this same survey again at the end of the training sessions. If participants receive training from all five modules of the series, the Pre/Post Evaluation should be completed at the end of Module 5. If participants are being trained in select modules from the series, the Pre/Post Evaluation should be completed at the end of the final training session. The purpose of the Pre/Post Evaluation is to measure the effectiveness of the training.

Contract with Trainees

If this is to be a multiple training series, contract with trainees regarding attendance and participation in the training. We have found contracting with trainees is a useful way to support their participation and attendance. The sample contract found at the end of this document is an example of a simple way to structure this step. Have trainees read and sign a copy. This should take about 5 minutes.

This training may arouse some level of discomfort and anger in trainees. Inform participants that this may occur but assure them that if they attend all sessions and talk about their concerns, their discomfort and anger will be resolved. Let them know that these feelings are a natural part of the process. Be clear that the training does not intend to blame professionals but to educate them.

Orient the Training

Present a brief outline of the structure and content of the training. If a multiple module training is planned, it is useful to provide a syllabus with the date, time, location, and description of each of the training sessions. Give trainees a copy of the Participant's Manual for this module. Explain that this contains the exercises, handouts, and assigned readings for the training. This should take about 5 minutes.

Share Family Stories

It is helpful to have at least one family member co-trainer for every eight participants. Ask one or more family members to briefly tell their story. Encourage them to be candid and honest and to provide a clear overview of their experiences with their relative who has a mental illness and the mental health system. They will have time to expand on their story so they do not have to tell every detail. This section should take about 15 minutes. Allow for some questions from the trainees.

Present and Discuss Content Using Overheads and Supplemental Resources

Present the content on the overheads. Incorporate the background information on the stages of recovery presented in the following overview, with information from the readings from your experience. Begin with the historical background and then move on to the stages of recovery that family members experience. Be sure to let trainees know that:

- Stages/phases of recovery are only guidelines. They help understanding but they are not intended to force individuals into any mold.
- Stages/phases are multifaceted and each stage contains many tasks. The process is not linear. People will deal with tasks with varying degrees of success. They may move ahead to another stage but may have to return to a previous stage to finish or rework a task.

It is important to *discuss* the points presented in the overheads. Your own experience and your knowledge of the literature can help you with this. There are also "notes" with some of the slides for elaborating on the overheads.

Co-trainers who are family members should be actively involved in the presentation. Encourage them to share experiences relevant to the discussion of family phases of recovery. When trainees ask questions or make comments, have the co-trainers respond to them as often as possible. Remember, a major goal of the training is to provide trainees with an opportunity to listen to and interact with family members. The presentation of the overheads should be kept to 30 minutes.

Complete Exercises 1.1 and 1.2

Give trainees copies of Exercises 1.1 and 1.2 (copies at end of this document). Ask them to complete them individually. Then discuss their answers in small groups led by the family member co-trainers. The training leader can visit the various groups and be available to support and consult with the family member co-trainers. The exercises and discussion should take about 25 minutes.

Debrief Exercises 1.1 and 1.2

Return to the large group and discuss the key learnings from each exercise. Use a flipchart or chalkboard to record the key points raised in the discussion. This discussion should take about 5 minutes.

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.