

This is an excerpt from *The Role of the Family in Psychiatric Rehabilitation* by LeRoy Spaniol, Anthony M. Zipple, Diane T. Marsh, and Laurene Y. Finley. Copyright © 2000. Center for Psychiatric Rehabilitation, Trustees of Boston University. All rights reserved under International Copyright Convention. No part of this text may be reproduced, transmitted, downloaded, or stored in or introduced into any information storage or retrieval system, in any form or by any means, whether electronic or mechanical, now known or hereinafter invented, without the written permission of the Center for Psychiatric Rehabilitation, Boston University.

THE ROLE OF THE FAMILY **in Psychiatric Rehabilitation**

A Workbook

Edited by

LeRoy Spaniol

Anthony M. Zipple

Diane T. Marsh

Laurene Y. Finley



Center for Psychiatric Rehabilitation
Sargent College of Health and Rehabilitation Sciences
Boston University

Contents

Introduction	1
<i>Chapter 1: The Family Experience of Psychiatric Disability</i>	9
Diane T. Marsh	
<i>Chapter 2: Changing Family Roles</i>	29
LeRoy Spaniol and Anthony M. Zipple	
<i>Chapter 3: The Recovery Process of Family Members</i>	43
LeRoy Spaniol and Anthony M. Zipple	
<i>Chapter 4: Family Needs</i>	53
LeRoy Spaniol and Anthony M. Zipple	
<i>Chapter 5: Meeting the Needs of Young Family Members</i>	73
Diane T. Marsh	
<i>Chapter 6: Practical Coping Strategies for Families</i>	101
LeRoy Spaniol and Anthony M. Zipple	
<i>Chapter 7: Helping Families to Manage Personal Stress and Burn-out</i>	125
LeRoy Spaniol	
<i>Chapter 8: Confidentiality and the Family</i>	143
Anthony M. Zipple, Susan Langle, and LeRoy Spaniol	
<i>Chapter 9: The Cultural Context: Families Coping with Psychiatric Disability</i>	159
Laurene Y. Finley	
<i>Chapter 10: Family-Professional Collaboration</i>	187
Diane T. Marsh	
References	209

Introduction

Need for Training

The need for training professionals in the core mental health disciplines to work with people who have a psychiatric disability and with their families has been well documented (Anthony, Cohen & Farkas, 1988; Anthony, Cohen & Farkas, 1990; Johnson, 1988; Lefley & Cutler, 1988; Marsh, 1992, 1994; Minkoff, 1987; Zipple, Spaniol & Rogers, 1990). One of the greatest needs is to systematically improve the effectiveness of core mental health training programs, including pre-professional curricula, field experience, field supervision, and post-professional continuing education. This in turn will enhance the effectiveness of mental health professionals in the core disciplines who are working with those suffering from psychiatric disability and with their families. There is a need to:

- strengthen awareness and deepen understanding of the needs, issues, and potential for new curricula in programs designed to train mental health professionals; and,
- encourage and stimulate communication among and between practitioners, academicians, families, and people with psychiatric disability.

The need to train professionals in the core mental health disciplines to work with people with psychiatric disability and their families arises from three factors:

- the magnitude of the problems related to helping those with psychiatric disability deal with their impairment and disability so that they can live, learn, and work in the community with the least amount of assistance;
- the severe burden families face in dealing with this family crisis; and
- the failure of most existing training curricula to encourage, prepare, and sustain core mental health discipline professionals who want to work with those suffering from psychiatric disability and with their families.

Magnitude of the Problem

It has been estimated that in the United States there are approximately 5.4 million people, or 2.7% of the population, who have severe psychiatric disabilities. The policy of deinstitutionalization resulted in an over 56% reduction between 1972 and 1982 in the number of psychiatric patients treated in state hospitals (Jansen & Orly, 1986). However, people in the community who are psychiatrically disabled have not been able to function well in their personal, vocational, educational, and residential roles (Anthony et al., 1990). For example, it has been estimated that there are at least two million Americans in the community disabled by psychiatric disability who could benefit from vocational counseling services (Skelley, 1980). Data, however, suggest that although clients can potentially benefit, they are not currently receiving effective vocational counseling services. Results from a study of 1,471 community support program clients nationwide suggest that only 11% were competitively employed (Goldstrum & Manderscheid, 1982). More recently, a study found a 0% rate of employment for the most severely psychiatrically disabled (Farkas, Rogers & Thurer, 1987).

People with psychiatric disability also have great difficulty maintaining independent living. A multistate sample of clients attending community support programs indicates that 40% live in a private home or apartment, 12% in board and care settings, 10% in family foster care placements, and the rest in other residential categories (Tessler & Goldman, 1982). Inability to obtain or maintain adequate housing options and social and support services has resulted in problems such as inappropriate use of hospital care (Braun, Kochansky, Shapiro, Greenberg, Gudeman, Johnson & Shore, 1981), lack of community integration (Carling & Ridgway, 1985), homelessness (Bachrach, 1984), great dissatisfaction by people with psychiatric disability, and the intractable persistence of acutely disabling symptoms (Talbot, 1984).

The literature on the educational status of this population serves as a reminder of the advanced educational status of many people with psychiatric disability. For example, a National Alliance for the Mentally Ill survey (Spaniol, Zipple & FitzGerald, 1984) indicated that 92% were high school graduates, 59% had also attended college, and 17% had graduated. In a study of 505 persons with severe psychiatric disabilities who were discharged from hospitals in Toronto, Canada, it was reported the 72% were high school graduates, including 16% who had attended college (Goering, Wasylenki, Farkas, Lancee & Ballantyne, 1986). It appears that a majority of persons who attend psychosocial rehabilitation centers have a high school education or beyond. Yet few go on to successfully complete post-secondary schooling.

Families in Crisis

One key to improving collaboration between families who have a family member with a psychiatric disability and the mental health profession is to help the professional understand the experience of the family as they attempt to deal with this crisis in their family's life (Byalin, Jed & Lehman, 1982; Hatfield & Lefley, 1987; Lefley, 1996; Zipple & Spaniol, 1987a). The onset of psychiatric disability triggers a major role change in families, which is not dissimilar to that experienced by families of people with other disabilities (Power & Dell Orto, 1988). Few families are prepared to deal with such traumatic role changes when they are precipitously forced upon them and when they frequently continue for many years (Hatfield, 1987b; Spaniol, 1987; Terkelsen, 1987; Tessler, Killian & Gubman, 1987).

Interestingly enough, professionals are often as unprepared as families to respond appropriately to this kind of profound crisis. In fact, we can 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.

If we look at the training professionals receive, it often fails to provide the appropriate skills, competent supervision, peer support, and validation to assist families with coping and adaptation skills (Bernheim & Lehman, 1985; Minkoff, 1987; Wasow, 1982). On the contrary, professionals are frequently still taught that families cause and perpetuate the illness and decompensation of their family member. These professional beliefs, attitudes, and 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).

It is important to note that this situation is not the result of ill will on the part of professionals. In our experience, the vast majority of mental health professionals are dedicated and caring professionals who genuinely want to help. An understanding of the families' complex and highly charged emotional experience can supply professionals with new constructs and beliefs with which to develop approaches 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 adaptation skills.

Lack of Training Curricula

Criticism has been leveled at the field of mental health for not providing specialized training in working with people with psychiatric disability and with their families (Anthony, Cohen & Farkas, 1988; Bevilacqua, 1984; Hargrove & Spaulding, 1988; Lefley & Cutler, 1988; Talbot, 1984). While there is little survey research data on this subject, it is apparent from the informed comments of the former NAMI Curriculum and Training Committee, training program directors, and professionals within the core

mental health disciplines that not only are training programs often unavailable, but specialized course work, field experience, and supervision designed specifically for those interested in psychiatric disability is also lacking (Johnson, 1988, 1990; Lefley, Bernheim & Goldman, 1989; Minkoff, 1987; National Deans Conference, 1987). The vast majority of programs in the core mental health disciplines are “generic” in nature and do not provide specialized training in work with people with psychiatric disability and with their families. It has been reported that training programs 1) lack experienced and enthusiastic faculty; 2) fail to provide adequate courses, appropriate opportunities for field placements, and experienced supervision for interested students; and 3) are unable to attract students interested in working with those suffering from psychiatric disability (Anthony, Cohen & Farkas, 1988; Johnson, 1988; Lefley & Cutler, 1988; Minkoff, 1987). Deficient training programs fail to address the helplessness, hopelessness, despair, discomfort, disgust, and stigma that psychiatric disability often provokes (Minkoff, 1987).

While program and curricular gaps remain, and social obstacles, like stigma, continue to divert professional attention away from the need to improve training programs focused on psychiatric disability, it is also true that the knowledge and research base about how to best help people with psychiatric disabilities has expanded exponentially during the last several decades (Anthony & Liberman, 1986). Effective work with this population requires preparation in relevant core clinical skills that are integrated through appropriate practicum and internship experiences as well as supervision by knowledgeable professionals (Hargrove & Spaulding, 1988). Strengthening the working alliance between theorists and practitioners will benefit everyone, in the same way that the utilization and interdisciplinary dissemination of knowledge must improve research and enhance the effectiveness of services.

There is a need for professionals in the core mental health disciplines to rethink assumptions underlying existing training programs, selection procedures, course design and content, field experiences, and clinical supervision; and to develop innovative approaches to working with people with psychiatric disability, who are so frequently underserved. Unfortunately, many training professionals in the core mental health disciplines lack the essential awareness, encouragement, support, and information to begin this needed work.

Your participation in this training marks you as a professional who wants to be more helpful to the families of your clients who have a psychiatric disability. This workbook contains all of the exercises that you will need to do during the course of the training. In addition, master copies of the overhead transparencies that are used by the instructors are included. This will reduce the amount of note taking that you will need to do. However, feel free to write any notes that you need anywhere in this workbook. It is your personal workbook and will be seen by no one else. For your convenience, blank pages for notes are included at the end

of each chapter. Before reading on, sign your name on the cover of the workbook.

Best wishes with your training experience. If you come to each session, read the material, and participate in the exercises and discussion, we believe that you will be more comfortable and more effective in your work with your clients who have a psychiatric disability and with their families.

Good Luck!