

This is an excerpt from *Psychological and Social Aspects of Psychiatric Disability* by LeRoy Spaniol, Cheryl Gagne, and Martin Koehler. Copyright © 1997. 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.

PSYCHOLOGICAL AND SOCIAL ASPECTS OF PSYCHIATRIC DISABILITY

EDITED BY

LEROY SPANIOL

CHERYL GAGNE

MARTIN KOEHLER

CENTER FOR PSYCHIATRIC REHABILITATION

SARGENT COLLEGE OF ALLIED HEALTH PROFESSIONS

BOSTON UNIVERSITY

vii Preface

CHAPTER 1 THE RECOVERY PROCESS

- 2 **The Course of Psychiatric Disorder, III: Longitudinal Principles**
JOHN S. STRAUSS, HISHAM HAFEZ, PAUL LIEBERMAN & COURTENAY M. HARDING
- 14 **A Long and Winding Road: The Process of Recovery From Severe Mental Illness**—WILLIAM PATRICK SULLIVAN
- 25 **Sense of Self in Recovery From Severe Mental Illness**—LARRY DAVIDSON & JOHN S. STRAUSS
- 40 **Self, Identity, and Subjective Experiences of Schizophrenia: In Search of the Subject**—SUE E. ESTROFF
- 51 **Chronicity in Schizophrenia: Revisited**—COURTENAY M. HARDING, JOSEPH ZUBIN & JOHN S. STRAUSS
- 68 **Consumer-Practitioners and Psychiatrists Share Insights About Recovery and Coping**—ANDREA BLANCH, DANIEL FISHER, WILLIAM TUCKER, DALE WALSH & JANET CHASSMAN

CHAPTER 2 THE EXPERIENCE OF RECOVERY

- 74 **Recovery as a Journey of the Heart**—PATRICIA E. DEEGAN
- 84 **Finding Myself and Loving It**—JEANINE M. O'NEAL
- 86 **Maintaining Mental Health in a Turbulent World**—J. F. HOUGHTON
- 92 **Recovery: The Lived Experience of Rehabilitation**—PATRICIA E. DEEGAN
- 99 **How I Perceive and Manage My Illness**—ESSO LEETE
- 104 **The Schizophrenic Inside**—PATRICIA J. RUOCCHIO
- 108 **Schizophrenia: Some Issues**—JILL STAINSBY
- 112 **The History and Outcome of My Encounter With Schizophrenia**
RON B. FORTNER WITH CHRISTINE STEEL
- 119 **My Schizophrenia**—ROBERTA PAYNE

- 123 **How I've Managed Chronic Mental Illness**—RICHARD WEINGARTEN
- 130 **Behind the Mask: A Functional Schizophrenic Copes**—ANONYMOUS
- 133 **Schizophrenia—A Pharmacy Student's View**—ANONYMOUS

CHAPTER 3 COPING AND ADAPTATION

- 138 **Past the Struggles of Mental Illness, Toward the Development of Quality Lives**—DONNA ORRIN
- 145 **Twelve Aspects of Coping for People With Serious and Persistent Mental Illness**—FREDERICK J. FRESE
- 156 **Spirituality and Serious Mental Illness**—KAREN N. LINDGREN & ROBERT D. COURSEY
- 171 **Women: The Ignored Majority**—CAROL T. MOWBRAY, DAPHNA OYSERMAN, CATHERINE LUTZ & ROGEAIR PURNELL
- 195 **Coping With Hearing Voices: An Emancipatory Approach**—M. A. J. ROMME, A. HONIG, E.O. NOORTHOORN & D. M. A. C. ESCHER
- 203 **Involuntary Commitment: A Consumer Perspective**—BARBARA GARRETT & TOM POSEY
- 207 **AIDS Knowledge, Attitudes, and Risk Behavior Among People With Serious Mental Illness**—JIM A. CATES, GARY R. BOND & LINDA L. GRAHAM
- 216 **Women With Serious Mental Illness in the Role of Parent: Characteristics, Parenting Sensitivity, and Needs**—JUDITH K. ZEMENCHUK, FRED A. ROGOSCH & CAROL T. MOWBRAY
- 228 **Dealing With Depression and Manic Depression for People With Mood Disorders and Those Who Love and Support Them**—MARY ELLEN COPELAND
- 240 **A Continuum of Care for People Who Are Elderly and Mentally Ill**
MICHAEL A. BERNSTEIN & SUSAN JENKINS

CHAPTER 4 THE FAMILY

- 246 **Family Burden and Family Stigma in Major Mental Illness**—HARRIET P. LEFLEY
- 254 **Troubled Journey: Siblings and Children of People With Mental Illness**
DIANE T. MARSH, REX M. DICKENS, RANDI D. KOESKE, NICK S. YACKOVICH, JR., JANET M. WILSON, JAMI S. LEICHLITER & VICTORIA MCQUILLIS
- 270 **Successfully Living With Mania: Helpful Hints to Families and Professionals**
MARY D. MOLLER & LAURA GEER KNUDSVIG
- 280 **The Family Recovery Process**—LEROY SPANIOL & ANTHONY M. ZIPPLE

- 285 **Leaving Home: Separation Issues in Psychiatric Illness**—AGNES B. HATFIELD
- 293 **A Father's Thoughts**—ANONYMOUS
- 298 **A Mother's View**—GAETANA CALDWELL-SMITH
- 303 **Schizophrenia Through a Sister's Eyes: The Burden of Invisible Baggage**—AMI S. BRODOFF
- 308 **Meanwhile, Back on the Ward...**—JAY NEUGEBOREN
- 317 **Confessions of the Daughter of a Schizophrenic**—ROXANNE LANQUETOT
- 323 **Growing Up With a Psychotic Mother: A Retrospective Study**—BONNIE DUNN

CHAPTER 5 THE HELPING CULTURE

- 334 **Resistance of Mental Health Professionals to Working With People With Serious Mental Illness**—KENNETH MINKOFF
- 348 **Spirit Breaking: When the Helping Professions Hurt**—PATRICIA E. DEEGAN
- 358 **A Person-Driven System: Implications for Theory, Research, and Practice**
DIANE T. MARSH, RANDI D. KOESKE, PAMELA A. SCHMIDT, DANIEL P. MARTZ & WILLIAM B. REDPATH
- 370 **Recovering Our Sense of Value After Being Labeled**—PATRICIA E. DEEGAN
- 377 **A Pit of Confusion**—ANONYMOUS
- 382 **A Consumer Perspective on Psychosocial Treatment**—ESSO LEETE

CHAPTER 6 SELF-HELP

- 390 **Self-Help and Mental Health**—AUDREY J. GARTNER & FRANK RIESSMAN
- 398 **Consumer-Run Housing in the Bronx**—EVA CONRAD
- 401 **Comparison of Self-Help Groups for Mental Health**—LINDA FARRIS KURTZ
& ADRIENNE CHAMBON
- 411 **Self-Help Programs: A Description of Their Characteristics and Their Members**—JUDI CHAMBERLIN, E. SALLY ROGERS & MARSHA LANGER ELLISON
- 424 **Fostering Self-Help on an Inpatient Unit**—KATHLEEN M. KELLY, FREDERICK SAUTTER,
KAREN TUGRUL & MICHAEL D. WEAVER
- 430 **Characteristics and Service Use of Long-Term Members of Self-Help Agencies for Mental Health Clients**—STEVEN P. SEGAL, CAROL SILVERMAN &
TANYA TEMKIN
- 441 **Professional Underutilization of Recovery, Inc.**—DONALD T. LEE

CHAPTER 7 BARRIERS TO RECOVERY

- 452 **Public Attitudes Toward Persons With Mental Illness**—ANDREW B. BORINSTEIN
- 461 **The Quiet Discrimination**—ANONYMOUS
- 463 **Educating the Public About Mental Illness: What Will It Take to Get the Job Done?**—MARY E. FRASER
- 467 **Barriers to Recovery and Empowerment for People With Psychiatric Disabilities**—PAMELA J. KRAMER & CHERYL GAGNE
- 477 **The Power of Language in the Helping Relationship**
SUSAN SPANIOL & MARIAGNESE CATTANEO
- 485 **Student Perceptions of Persons With Psychiatric and Other Disorders**
MIKE LYONS & ROBYN HAYES
- 497 **The Multiple Effects of Culture and Ethnicity on Psychiatric Disability**
LAURENE FINLEY
- 511 **Empirical Correction of Seven Myths About Schizophrenia With Implications for Treatment**—COURTENAY M. HARDING AND JAMES H. ZAHNISER

CHAPTER 8 ADVOCACY AND EMPOWERMENT

- 522 **Rehabilitating Ourselves: The Psychiatric Survivor Movement**
JUDI CHAMBERLIN
- 527 **The Independent Living Movement and People With Psychiatric Disabilities: Taking Control Back Over Our Own Lives**—PATRICIA E. DEEGAN
- 541 **The Ex-Patients' Movement: Where We've Been and Where We're Going**
JUDI CHAMBERLIN
- 552 **Professional Training for Consumers and Family Members: One Road to Empowerment**—ROBERT I. PAULSON
- 562 **Power, Powerlessness, and Empowerment in Psychotherapy**—JOHN E. MACK

PREFACE

The psychological and social approach to understanding physical disability has a long tradition (Marinelli & Dell Orto, 1991; Shontz, 1975; Wright, 1983). There has been a deliberate attempt in the field of physical rehabilitation to understand how a person is affected by the disability, as well as how the person with a disability affects and is impacted by family, friends, the helping system, and society in general. The focus of research and demonstration efforts in the area of physical disability has been both on the experience of the person and on the barriers in the environment that prevent functioning fully and autonomously in the community. While information and resources have been available to assist the person with his or her disability, the emphasis has been on increasing his or her capacity to function independently.

In the field of psychiatric disability the traditional focus has been on treating the illness, rather than the person who has the illness. Hospitalization, medication, and therapy have been used as the primary interventions to treat the illness and to reduce positive symptoms. Negative symptoms have been seen as part of the illness, or as resistance on the part of the person, rather than as attempts by the person to cope with the illness, medication, and the effects of his or her environment. Traditional treatment approaches have not acknowledged the wholeness and integrity of the person with the disability. They have not acknowledged important dimensions of the internal recovery process that follow the onset of mental illness, as with any significant trauma (Deegan, 1988). They have not acknowledged the impact of the helping system, and society in general, on the person who is struggling to recover. They have not acknowledged the impact on the

families of people with psychiatric disability, including parents, spouses, siblings, and children of parents with psychiatric disability. While there has been some effort to understand the person's experience of the illness, the impact of society on the person's ability to function, and the need for new skills and supports to function more effectively, this effort has not become widespread and has not been effectively integrated into the helping process. Research and service efforts that have been narrowly focused on what seemed to impact on the illness and on the symptoms, have begun to focus on the person's functioning in a variety of environments of choice.

The newly emerging information on psychological and social aspects of psychiatric disability represents an additional approach to understanding people with mental illness. The approach focuses on understanding the experience of the person, the impact of the environment on the person, how the person copes, how the person moves on with his or her life, and what the barriers and facilitators are to this process. We want to present ways to identify and to support the strong and fiercely tenacious spirit of people with psychiatric disability.

Language usage has changed dramatically over the last several years in the field of psychiatric rehabilitation (*Guidelines for Reporting and Writing About People With Disabilities*, 4th edition, 1993; *Information for Writers*, NAMI, 1995; also see Spaniol & Cattaneo in chapter 7 in this book). In most cases, we did not update the language originally used in the articles selected for this book. The articles reflect this gradual change toward language that is more respectful of, and consistent with, how people with psychiatric disability view themselves.

We would like to thank the many students, family members, consumers, and professionals with whom we piloted this book. They shared their experiences will-

ingly and generously, knowing that others might benefit from what they have learned.

We would like to give special thanks to Kristen Cronk for her tireless efforts in scanning and preparing the manuscript and Linda Getgen for her many useful suggestions on the text and for her wonderful design and typesetting expertise.

LEROY SPANIOL, PH.D.
CHERYL GAGNE, M.S.
MARTIN KOEHLER, B.S.

References

- Deegan, P. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 11 (4), 11-19.
- Marinelli, R. P. & Dell Orto, A. E. (Eds.) (1991). *The psychological and social impact of physical disability*, 4th ed. New York: Springer Publishing Company.
- National Alliance for the Mentally Ill. (1995). *Information for writers*.
- Research and Training Center on Independent Living. (1993) *Guidelines for reporting and writing about people with disabilities*, 4th ed. University of Kansas: Author.
- Shontz, F. C. (1975). *The psychological aspects of physical illness and disability*. New York: Macmillan.
- Wright, B. (1983). *Physical disability—A psychosocial approach*, 2nd ed. New York: Harper & Row.