Copyright © 2009 by Center for Psychiatric Rehabilitation, Trustees of Boston University

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any information storage or retrieval system, without permission in writing from the publisher.

The articles in this text were reprinted with permission from the *Psychiatric Rehabilitation Journal*. Citations for the original publications are included as footnotes at the bottom of the first page of each article.

Published by: Center for Psychiatric Rehabilitation College of Health and Rehabilitation Sciences (Sargent College) Boston University 940 Commonwealth Avenue West Boston, MA 02215 www.bu.edu/cpr/

The Center for Psychiatric Rehabilitation is partially funded by the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Printed in the United States of America

Library of Congress Control Number: 2009922413 ISBN13: 978-1-878512-23-9

Published 2009

Edited by Sue McNamara

Boston University Center for Psychiatric Rehabilitation

i Preface

2 From Psychosis and Alienation to Recovery *Christine Mahoney Holst*

- 7 Photovoice-Anonymous
- 8 Experience with Post-Secondary Education for Individuals with Severe Mental illness *Jennifer M. Padron*
- 11 Photovoice–*Edgar*
- 12 Soul in Search of Self: The Lived Experience of Serious Mental Illness—*Anonymous*
- 17 Photovoice-Derek
- 18 Open Doors-John S. Caswell
- 28 Recovery: The Heart and Soul of Treatment Wilma Townsend & Nicole Glasser
- 32 Photovoice-Catherine Imbasciati
- 33 How I Quit Being a "Mental Patient" and Became a Whole Person with a Neuro-Chemical Imbalance: Conceptual and Functional Recovery from a Psychotic Episode—David J. Fekete
- 40 Photovoice-Karen
- 41 First Psychosis Prodrome: Rehabilitation and Recovery–*Ian Chovil*
- 46 Photovoice-Catherine Imbasciati
- 47 Recovery Commentary: With the Passage of Time *William Stride*
- 50 Photovoice–Gloria
- 52 Marriage and Mental Illness-Valerie Fox
- 56 Photovoice-Helen
- 57 From Darkness to Light: From Turmoil to Serenity *Victoria E. Molta*
- 59 Pivotal Therapeutic Moments: A Patient's Perspective on Surviving Suicide–*Terry L. Wise*
- 65 Photovoice-Michelle
- 66 Hearing Voices and Seeing Pictures J. P. Lee
- 72 Photovoice—Gloria
- 73 A Wellness Approach-Margaret Swarbrick
- 77 My Journey of Spirituality and Resilience Leonard Mulcahy

Chapter 1: Recovery

Chapter 2: Increasing Knowledge and Control

Chapter 3: Managing Life's Stresses

Chapter 5: Building Personal Support

Chapter 6: Setting Personal Goals

80	The Spiritual Meaning of Psychosis Marcia A. Murphy
86	Photovoice-LMV
87	From Depths of Despair to Heights of Recovery <i>Holly Henderson</i>
93	Photovoice-KMH
94	Calculated Risk-Taking and Other Recovery Processes for my Psychiatric Disability— <i>Richard Weingarten</i>
98	Photovoice-Karen
99	Working with Schizophrenia: Personal Insights Into Working with a Psychiatric Disability <i>Francis Gilfedder</i>
102	My Personal Story of Coping-Marjorie Jacobs
106	Photovoice-Diane
107	A Mother's Love–Valerie Fox
110	Photovoice – SQ
III	Therapeutic Alliance – Valerie Fox
113	Photovoice-Ellen T.
114	Nowhere To Go Except Home-Barbara Markwood
116	Photovoice-Catherine Imbasciati
118	Photovoice-LMV
119	Slip Sliding Away: A Journey from Professional to Consumer– <i>Rachelle Weiss</i>
122	Photovoice—Taira
123	Recovery: Always a Work in Progress-Alex Morisey
125	Photovoice-KM
126	Coping with Mental Illness-Gwen Davis
130	Photovoice-Diane
131	Being Bipolar and Dealing with Obesity: Personal Lessons <i>—Melissa Anne Hensley</i>

Preface

In 1994, the Center for Psychiatric Rehabilitation at Boston University published The Experience of Recovery, edited by LeRoy Spaniol and Martin Koehler. It is an anthology of stories and poems by people recounting their own recovery experiences. The book was published at a time when the notion of recovery in the mental health field was a relatively new concept. The Experience of Recovery has been read by consumers, family members, practitioners, trainers, administrators, and members of boards of directors. It is a book that anyone connected to the mental health field would enjoy reading. It has been used in academic classes and has been left on coffee tables in residential settings and mental health programs for anyone to pick up and read. The firstperson accounts are inspirational, and they have helped many people to feel hopeful for their own future and to make progress in their own recovery journey. Customers who have purchased The Experience of Recovery began asking when another book of its kind would be published by our Center.

As a result, *Voices of Recovery* was created as an updated and expanded version of *The Experience of Recovery*. *Voices of Recovery* consists of two different types of "voices" in the mental health field. The first "voice" is a collection of personal accounts that were published in the "Coping With" column of the *Psychiatric Rehabilitation Journal* from the years 2000 through 2008. Since the 1990s, the "Coping With" column was included in each issue of the journal to provide an opportunity for publishing personal accounts of individuals' experiences of recovery. As more and more people write their unique personal stories, this venue for publication allows these articles to be widely read and shared with others publically in a professional journal. Equally inspiring, these articles describe individuals' experiences of coping with mental illness and of leading them to their own personal recovery.

The second "voice" is a collection of Photovoice projects that were part of the Recovery Center classes held at the Center for Psychiatric Rehabilitation. The photovoice concept was developed by Professor Caroline Wang, at the University of Michigan School of Public Health, and Mary Ann Burris, from the Ford Foundation. Photovoice is a process that has been used for research, education, social change, and the development of more healthful public policy. Cameras were provided to individuals with serious mental illnesses, and they used photovoice to amplify their visions and experience. Short stories or messages were written to explain the person meaning behind the image from the photographer's point of view. By uniting the immediate impact of a photograph and the story, it contextualizes and enhances it. Through the power of the visual image, photovoice offers an innovative way to break the silence that often surrounds the experience of mental illness. Photovoice has three main goals:

- To enable people to record and reflect their community's strengths and concerns.
- To promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs.
- To reach policy makers.

To these ends, the photovoice process lays out multiple stages for defining the goals of a project, anticipating an audience, taking pictures and telling stories about them, evaluation, and presentation. While photovoice can be done on a more individual basis, one of the most powerful aspects of the technique is the group reflection on and discussion of the photographs. The storytelling aspect of photovoice follows the acronym *SHOWED*:

- What do you See here?
- What's really *Happening* here?
- How does this relate to Our lives?
- *Why* does this problem/condition/strength exist?
- How could this image *Educate* the community, policy makers, etc.?
- What can we *Do* about it (the problem, condition, or strength)?

By stimulating critical dialogue of the issues raised in the photographs, photovoice participants generate awareness, not just of problems or concerns, but also of potential solutions and areas of strength with respect to their lives and communities. The images and stories can be shared with an audience in numerous ways including: presentations, exhibits, books, videos, CD-ROM, and on the Internet. Two advances in photography, disposable and digital cameras, offer inexpensive ways of generating images and a wide range of formats for presenting those images. Thus, photovoice can be carried out in almost any setting with almost any group of people.

Voices of Recovery was created with the purpose to be read on its own or to accompany the Recovery Workbook: Practical Coping and Empowerment Strategies for People with Psychiatric Disability (1994) written by LeRoy Spaniol, Martin Koehler, and Dori Hutchinson. The Recovery Workbook is used by individuals or in groups to help people understand and navigate their own recovery process. The articles and the photovoice projects in Voices of Recovery have been organized to supplement the chapters of *The Recovery Workbook*. These chapters include:

- Recovery, which outlines the phases and aspects of the recovery process.
- Increasing Knowledge and Control, which discusses the impact of serious mental illness and the services and values of a recovery-oriented mental health system.
- Managing Life's Stresses, which talks about the symptoms and sources of stress as well as coping strategies.
- Enhancing Personal Meaning, which promotes the idea of acknowledging our accomplishments and personal enrichment.
- Building Personal Support, which discusses connecting with others, basic communication skills, asking for support, and setting boundaries on our relationships.
- Setting Personal Goals, which outlines a stepby-step guide for setting personal goals and developing a plan for achieving a personal goal.

When reading *Voices of Recovery*, we believe that the personal accounts and the photovoice projects will inspire hope and optimism for recovery for individuals with psychiatric disabilities, their family members, and mental health professionals. In addition, given the heartfelt nature of the articles and photovoice projects, we believe that this book will appeal to anyone in the general community and could be used as an educational tool to help reduce stigma and stereotypes of mental illness.

We would like to acknowledge and thank all of the people who contributed their articles and photovoice projects to this book. We appreciate their bravery and strength they have shown through their lived experiences, their willingness to share their stories, as well as their hopes and inspiration to others. When we asked permission to have their articles and photovoice projects published in this book, most people said that they felt honored to have their experiences shared and felt hopeful that their messages might be helpful to someone else. We appreciate this type of caring, giving, and community spirit.

We also would like to acknowledge and thank Bill Anthony for his recovery vision, his leadership in the mental health field and at our Center, and for his encouragement to develop this book; LeRoy Spaniol for his inspiration in developing our first recovery products and for founding both the *Psychiatric* Rehabilitation Journal and the "Coping With" column in the journal; Kathy Furlong-Norman for her support of this project as the current managing editor of the Psychiatric Rehabilitation Journal; Dori Hutchinson for her guidance with this project as director of our services division; Alexandra (Sasha) Bowers for introducing us to photovoice; Derek Fuller for his work in facilitating photovoice classes at our Recovery Center and for his assistance in providing photovoice projects for this book; Andrea Bengston and Jake Briggs for their assistance in gathering contact information for the photovoice authors; and Linda Getgen for her endless support and for her creativity in designing and publishing this book.

Sue McNamara

Center for Psychiatric Rehabilitation

References and Resources

- Anthony, W. A. (2007). Toward a vision of recovery form mental health and psychiatric rehabilitation services, 2nd edition. Boston: Center for Psychiatric Rehabilitation, Boston University.
- Booth, T. & Booth W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society*, 18(4): 431-442.
- Davidson, L., Harding, C., & Spaniol, L. (Eds). 2005. Recovery from severe mental illnesses: Research evidence and implications for practice. Volume 1. Boston: Center for Psychiatric Rehabilitation, Boston University.
- Davidson, L., Harding, C., & Spaniol, L. (Eds). 2006. Recovery from severe mental illnesses: Research evidence and implications for practice. Volume 2. Boston: Center for Psychiatric Rehabilitation, Boston University.
- Harrison, B. (2002). Photographic visions and narrative inquiry. *Narrative Inquiry*. 12(1): 87–111.
- http://www.bu.edu/cpr/photovoice/index.html
- Johnson, D., Russinova, Z., & Gagne, C. (2009). Using Photovoice to fight the stigma of mental illness. *Recovery & Rehabilitation Newsletter*, 4(4). Boston: Center for Psychiatric Rehabilitation, Boston University.
- Killion, C. M. & Wang, C. C. (2000). Linking African American mothers across life stage and station through photovoice. *Journal of Health Care for the Poor & Underserved*. 11(3):310–25.
- LeClerc, C. M., Wells, D. L., Craig, D., & Wilson J. L. (2002). Falling short of the mark: Tales of life after hospital discharge. *Clinical Nursing Research*. 11(3):242–263; discussion 264–266.
- Lykes, M. B., Blanche, M. T., & Hamber, B. (2003). Narrating survival and change in Guatemala and South Africa: The politics of representation and a liberatory community psychology. *American Journal of Community Psychology*. 31(1-2):79-90.
- Mertle, A. (Producer). (2007). *Beyond the shadow of stigma* [video presentation]. Cambridge, MA: Cambridge Community Television, Crazyant Films. Retrieved February 10, 2009 from http://www.cctvcambridge.org/node/1695
- Spaniol, L., Bellingham, R., Cohen, B., & Spaniol, S. (2003). *The recovery workbook II: Connectedness.* Boston: Center for Psychiatric Rehabilitation, Boston University.
- Spaniol, L., & Koehler, M. (1994). Experience of recovery. Boston: Center for Psychiatric Rehabilitation, Boston University.

- Spaniol, L., Koehler, M., & Hutchinson, D. (1994). The recovery workbook Practical coping and empowerment strategies for people with psychiatric disability. Boston: Center for Psychiatric Rehabilitation, Boston University.
- Spaniol, L., & Spaniol, S. (2003). *The recovery workbook II: Connectedness: Leader's guide*. Boston: Center for Psychiatric Rehabilitation, Boston University.
- Wang, C. C. (1998). Project: Photovoice involving homeless men and women of Washtenaw County, Michigan. *Health Education and Behavior*, 25 (1): 9–10.
- Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, 8(2):185–92.
- Wang, C. C. Using photovoice as a participatory assessment and issue selection tool: A case study with the homeless in Ann Arbor. (2003). In M. Minkler & N. Wallerstein (Eds.), Community based participatory research for health. San Francisco: Jossey-Bass.
- Wang, C. & Burris, M. A. (1994). Empowerment through photovoice: Portraits of participation. *Health Education Quarterly*, 21(2): 171–186.
- Wang, C. & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3):369–87.
- Wang, C., Burris, M. A., & Xiang, Y. P. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science and Medicine*, 42(10): 1391–1400.
- Wang, C.C., Cash, J. L., & Powers, L. S. (2000). Who knows the streets as well as the homeless?: Promoting personal and community action through photovoice. *Health Promotion Practice*, 1(1): 81–89.
- Wang, C. C. & Redwood-Jones, Y. A. (2001). Photovoice ethics: Perspectives from Flint Photovoice. *Health Education & Behavior*, 28(5): 560–72.
- Wang, C. C., Yi, W. K., & Tao, Z. W. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International*, 13(1): 75–86.
- Wang, C., Yuan, Y. L., & Feng, M. L. (1996). Photovoice as a tool for participatory evaluation: The community's view of process and impact. *Journal of Contemporary Health*, 4: 47–49.