

First Person Accounts *of* Mental Illness *and* Recovery

Edited by

Craig Winston LeCroy

Jane Holschuh



Praise for *First Person Accounts of Mental Illness and Recovery*

"This book is a stellar resource for educators in social work and other helping fields. While I have in the past assigned single book-length first person accounts, I will use this collection to give my students a broader understanding of the tremendous heterogeneity in the ways that different people experience and cope with mental illness."

Beth Angell, PhD
Associate Professor, School of Social Work and Institute for Health, Health Care Policy, and Aging Research
Rutgers University

"The authors have compiled an important collection of first person narratives of mental illness and recovery. Every course in mental, emotional, and behavioral disorders should seek to give voice to the diverse lived experiences of consumers who want so much that we listen, understand their struggles and triumphs, and truly appreciate their humanity. This book will help us do that."

Kia J. Bentley, PhD
Professor and Director
Virginia Commonwealth University
School of Social Work

"In their book First Person Accounts of Mental Illness and Recovery, LeCroy and Holschub offer the student, researcher, or lay person the intimate voice of mental illness from the inside. First Person Accounts of Mental Illness and Recovery is a wonderful book, and it is an ideal, even indispensable, companion to traditional mental health texts. I am grateful that they have given the majority of this book to the voices that are too often unheard."

John S. Brekke, PhD
Frances Larson Professor of Social Work Research
Fellow, American Academy of Social Work and Social Welfare
School of Social Work
University of Southern California

"This book provides a major new resource for education in the mental health professions and contains an extraordinary range of personal accounts of mental illness in one volume. These are given context and meaning through the introductions and study questions that precede each chapter."

Linda Chafetz, RN, DNSc
Professor, Department of Community Health Systems
University of California, San Francisco

"This is one of the most compelling, comprehensive, and powerful compilations of first person accounts of resiliency and recovery that I've read. It will be an excellent teaching resource for instructors and professionals. The firsthand accounts will engage students in discussions that promote a more humane understanding and less stigmatizing image of mental illness. The book should be required reading in all schools of social work with a strengths-based mental health curriculum. It is a marvelous book and a gift to the reader."

Jan S. Greenberg, PhD
Professor, School of Social Work
University of Wisconsin-Madison

“In this volume, Craig Winston LeCroy and Jane Holschuh have assembled a collection of essays and accounts that are at once inspiring, courageous, and revealing. Reading about people with schizophrenia, bipolar disorder, and the like will allow people to see the ‘real’ side of these disorders and even more importantly, that people with such disorders are people whose lives are not defined by their disorders.”

Ann M. Kring, PhD
Professor, Department of Psychology
UC Berkeley, Berkeley, CA

“First Person Accounts of Mental Illness and Recovery is a gift to all who truly hope to understand people who live with mental disorders. This book is an engaging, informative, and inspiring must read.”

Nadine Nehls, PhD, RN
Professor and Associate Dean
University of Wisconsin-Madison
School of Nursing

“LeCroy and Holschuh have produced a stellar work that will facilitate a deeper understanding of the subjective experience of living with mental illness. This comprehensive collection manages to be scholarly, engaging, and instructive at once.”

Christina E. Newhill, PhD, LCSW
Professor, School of Social Work
University of Pittsburgh

“This is absolutely a must read for anyone who has been touched by someone with a mental illness whether it be personal or professional. It is imperative that this book be required reading in any course dealing with psychopathology and the DSM whether it be in psychology, psychiatry, social work, nursing, or counseling.”

Phyllis Solomon, PhD
Professor in the School of Social Policy & Practice and Professor of Social Work
University of Pennsylvania

“The authors have put together a unique and inspiring collection of personal narratives that will assist readers in learning firsthand what it is like to be viewed and related to as a person with mental illness. Reading these varied and remarkable stories will promote insight for professionals and sensitize them to how individuals with a mental disorder perceive themselves.”

Leonard I. Stein, MD
Professor Emeritus of Psychiatry
University of Wisconsin School of Medicine and Public Health

FIRST PERSON
ACCOUNTS OF MENTAL
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Edited by
Craig Winston LeCroy
Jane Holschuh



WILEY

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To people with mental illness everywhere who struggle, prevail, and recover.

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Our team in various phases consisted of Kim Bingham, Michelle Urban, Andrea Riendl, Aindrea McCammon, Erin McClain, Chris James, Janet Reed-Verdusco, Rich Hinton, Clinton Sandoval, and Mandy Bergstrom. Mandy, in particular, worked on this project while in school and continued with us after graduating. She was essential to the final product we created.

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Introduction

More Than a Diagnosis: First Person Accounts of Mental Illness and Recovery

There is a long history of personal narratives written by individuals who have suffered from a mental illness or mental disorder (we use these terms interchangeably in this book). That history has been traced to the 15th century (Barlow & Durand, 2004), and there are many well-known accounts from the 1800s. For example, Leo Tolstoi wrote his account of suffering from depression in 1887. As such, narrative descriptions of the subjective experiences of mental illness have a lengthy and established presence in the mental health field. Indeed, a major impetus for the current book was the rediscovery of Bert Kaplan's *The Inner World of Mental Illness*, published in 1964. This marvelous book gathered first person accounts that described varied experiences of mental illness. As Kaplan (1964) notes, "there is no better starting point for those seeking to understand ... than accounts of this experience ... we can come into intimate contact with the reality of mental illness itself" (p. vii). This classic book included four sections: the psychotic experience, a variety of psychopathologies, drug-induced states, and historic statements. In the past half-century, the interest in and list of first person narratives has continued to grow.

These many accounts have contributed to an ongoing interest in memoirs. The public is familiar with such first person accounts (FPAs) as *An Unquiet Mind*, *Girl Interrupted* (a major motion picture), *Wasted, A Beautiful Mind* (also a major motion picture), *Prozac Nation*, *Drinking: A Love Story*, *Darkness Invisible*, *Down with the Rain*, *Quitting the Nairobi Trio*, and numerous other stories. And although these particular accounts have achieved commercial success, there are many others written by people who simply want to tell their stories. Gail Hornstein (2008) has created a comprehensive “bibliography of first person accounts of madness in English” current to 2008, which includes 642 separate written accounts (See www.mtholyoke.edu/acad/assets/Academics/Hornstein_Bibliography.pdf). Sommer and colleagues (Sommer, Clifford, & Norcross, 1998; Sommer & Osmond, 1960, 1961, 1983) have created lists of accounts starting in 1960 and published them in highly regarded peer-review psychiatric journals. They list over 150 titles. In 1982, Peterson published *A Mad People’s History of Madness* and listed 305 titles.

There are compendiums of accounts that focus on more specific themes such as depression (*Unholy Ghost*), eating disorders (*Going Hungry*), or mental health professionals telling their own stories (*Breaking the Silence: Mental Health Professionals Disclose Their Personal and Family Experiences of Mental Illness* and *Wounded Healers: Mental Health Workers’ Experiences of Depression*). *Different People, Different Voices* (Fleteren & Fleteren, 2008) is a book of first person accounts written, published, and marketed entirely by Canadians with mental disabilities. Similarly, *Voices of Experience* (Basset & Stickley, 2010) acknowledges the recipients of mental health services as “experts in their own right,” and provides readers with the personal narratives of psychiatric “survivors” in the United Kingdom. People with a story to tell are publishing e-books, and one publisher, Chipmunka, specializes in stories of mental illness and recovery. Beyond this is the World Wide Web, which hosts Internet sites such as the Experience Project, where you can post almost any experience you want to write about. In England, there is Health Talk, which is a database of personal and patients’ experiences where individuals share their stories. The advent of online organizations such as Intervoice, Asylum, MindFreedom, and the Hearing Voices Network represents the development of democratic psychiatry and the hearing voices movement (Gray, 2009; see Gray’s first person account, p. 18, for URLs). In the United Kingdom, Dr. Benjamin Gray is working with Intervoice to publish a book

of first person accounts of hearing voices that invites “all sorts of voices and voice hearers and all sorts of points of view, experiences, and personal journeys” and will include “journeys to recovery” (Gray, 2009, p. 663).

MOTIVES AND PURPOSES OF FIRST PERSON ACCOUNTS

Storytelling has become a large enterprise as authors have increasingly recognized its value. There is something fundamental about telling one's story (LeCroy, 2012). In discussing the sociology of illness, Arthur Frank (1997) describes the “wounded storyteller” and notes that the storytelling of people with an illness is guided by a sense of responsibility and represents one way of living for the other. As Frank (1997) notes, “People tell stories not just to work out their own changing identities but also to guide others who will follow them” (p. 17). He puts his finger on a critical aspect of storytelling by recognizing that it has an element of testimony and that such testimony is inherently valuable—even therapeutic. People who suffer need to tell their stories in order to heal.

Frank (1997) began his work looking at illness and the role narrative stories might play in helping people cope and manage their conditions. He classifies three types of narratives that emerge from people who are ill. The *restitution story* is told frequently, but this type of story makes illness appear only transitory. *Chaos stories* are embedded in the crisis of the illness and cannot get beyond that stage. *Quest stories* address suffering directly and are motivated by the person's belief that something is to be gained by the experience. *Restitution* and *quest stories* are found most often in published accounts. Frank (1997) provides an eloquent description of this process: “Realizing who they always have been, truly been, each becomes or prepares to become the re-created, moral version of that self” (p. 131). In this display of character, memory is revised, interruption assimilated, and purpose grasped. “Whatever has happened to me or will happen,” the *storyteller as hero* implicitly claims, “the purpose remains mine to determine” (p. 131).

The use of first person accounts has been supported further by evidence from a study (Banyard, 2000). Reading or listening to the experiences and perspective of someone with a mental disorder can deepen our understanding and empathy. Furthermore, an increased understanding helps the audience grasp the extent of the challenges faced. This can inspire efforts to help the person and his/her family. The study administered a survey to students

in a required abnormal psychology class. Students answered questions that compared the traditional textbook with the readings of first person accounts. Students assessed what they had learned from the textbook and from the first person accounts by answering questions on a five-point scale and through open-ended questions. Results found significant differences on six of eight of the ratings that compared the two learning modes. For example, students rated first person accounts as significantly more useful than textbooks in being able to understand how someone with the disorder feels and in their ability to feel empathy for the person with the disorder. All open-ended responses about the use of first person accounts were coded as positive. Comments included, “it made it easier to understand the disorder,” “helps bring to life what was learned in the textbook,” “makes the information more real,” and “really brought into focus what living with a mental disorder is like.” The author notes that enhancing students’ understanding and empathy may reduce the “stigmatizing of those with mental disorders” (Banyard, 2000, p. 43). Research consistently has found that stigmatizing attitudes were reduced for those who were introduced to or knew individuals with mental disorders or understood their experiences (Corrigan & Gelb, 2006; Link, Yang, Phelan, & Collins, 2004; Penn et al., 1994; Thornton & Wahl, 1996).

Our hope is that this book will inform readers about mental illness/mental disorder and help instructors, students, and the general public talk about their experiences with it whether a client’s, their own, a family member’s, or a close friend’s. Our small city, Tucson, Arizona, experienced the tragedy of multiple shootings targeted at our congresswoman, Gabrielle Giffords, in January 2011. The young man arrested for the killing spree has been assessed to have mental illness that went unrecognized and untreated. As we write this introduction, one of us (Craig) just days ago was deeply impacted by another tragedy indicative of mental illness. His 17-year-old son’s chemistry lab partner committed suicide—by shooting himself in the head. All of us are in disbelief. This young man suffered from bouts of depression. The private high school where this happened has never witnessed such an event. Yet, as we know from putting this book together, often we cannot escape the impact that mental illness will have on any of us. In the wake of these recent tragedies, we and our community are left with many nagging questions.

Like other common illnesses such as diabetes and heart disease, mental disorders are part of society. Nunes and Simmie (2002) describe it this way:

There are really only eight kinds of people affected by mental disorder. It's a very small list, but we all know someone on it: someone's mother, daughter, sister, or wife; someone's father, brother, husband, or son. In other words, people just like us. Just like you. (p. 3)

Our hope is that this book will, in some small way, reduce the stigma and discrimination that so many people with mental illness experience in their daily lives.

EMERGING THEMES

An important aspect of first person accounts is that they have brought recognition to and validation of the recovery process that many individuals engage in and achieve. This is consistent with the landmark Surgeon General's Report (1999) on mental health and the report of the U.S. President's New Freedom Commission on Mental Health (2003), which assert that mental health systems should adopt a recovery orientation. Ridgway (2001) notes that "first person recovery narratives are important source materials that can help us refocus our thinking beyond the myopic and outdated deficit perspective" (p. 336).

In studying first person accounts, Ridgway (2001) identified eight core themes:

1. Recovery is the reawakening of hope after despair.
2. Recovery is breaking through denial and achieving understanding and acceptance.
3. Recovery is moving from withdrawal to engagement and active participation in life.
4. Recovery is active coping rather than passive adjustment.
5. Recovery means no longer viewing oneself primarily as a person with a psychiatric disorder and reclaiming a positive sense of self.
6. Recovery is moving from alienation to a sense of meaning and purpose.
7. Recovery is a complex and nonlinear journey.

8. Recovery is not accomplished alone—the journey involves support and partnership.

Her work is significant in that it represents ongoing efforts to shift the field from the language of “chronicity” to one of recovery. Ridgway (2001) claims that first person accounts often challenge the field to critically examine service delivery systems, which can either support resilience and recovery or act as a barrier to restrain recovery. When systems focus on deficits and pathology, strength-based interventions are de-emphasized, and recovery is not promoted (Rapp & Goscha, 2006; Saleebey, 2005, 2008).

Indeed, this cultural shift toward “transformative” narrative story telling is a welcome addition to the mental health field. The field is experiencing a critical movement toward recovery-oriented approaches and toward systems that promote and support the recovery process (see Rapp & Goscha, 2006). Professionals in the mental health field have worked with consumers to develop a broader understanding of the dimensions of recovery (Whitley & Drake, 2010). Our book contributes to this movement by promoting first person accounts to enhance understanding of the recovery process as well as the challenges faced by those with mental disorders. Ridgway (2001) sums up the potential of such accounts, stating that “narratives can engender a ‘contagion of hope’ (Deegan, 1994, p. 159) and reorient both staff members and people with psychiatric disabilities toward alternative and more rewarding life paths, by restorying the possibility for positive growth after destabilizing life events” (p. 342).

Steven Hinshaw’s book *Breaking the Silence* is a collection of first person accounts by mental health professionals who openly describe their personal experiences with mental illness in some fashion. Hinshaw (2008) concludes that, while some progress has been and is being made to increase understanding and counteract stigma, there is a long road ahead. Indeed, mental health professionals themselves can contribute to stigma. He identified a set of core themes that emerged from the first person accounts in his book, and these same themes have emerged from the accounts in our book. They are summarized here:

Confusion: When an individual experiences mental illness, the symptoms can be confusing—for everyone. This is discussed directly in many of the first person accounts in our book. Individuals struggle

to understand themselves: Why did I say that? Why am I hearing voices or seeing things? Often, individuals experience an exaggeration of an aspect of themselves or may begin to act in ways that are inappropriate. This confusion can be the tipping point at which the person either recognizes the need to seek help or family members/others do. Eventually, the person or a family member realizes there is truly something wrong that is not getting better.

Pain: One of the difficult aspects of reading first person accounts is the high level of pain that may be expressed. It can hurt just to read the detailed description of what the person is feeling. The darkness of despair, the hopelessness about the future, the anguish that one cannot escape—these can be painful aspects of having a disorder. Many times they are felt in a direct and even physiological manner. The stories of depression come to mind since often they are filled with the pain of hopelessness. For others, the pain of seeing a loved one afflicted or not being able to help is also present. For many, the loneliness and social stigma that can accompany the disorder are painful.

Aloneness and Isolation: Many individuals who have a mental disorder experience loneliness and isolation from others. Certainly, unusual behaviors push people away, scare people, and are misunderstood. Symptomatic individuals often are preoccupied with and overwhelmed by their “inner world” and lose touch with the surrounding social world. Sometimes people with a mental disorder lack the social skills needed to maintain consistent social connections. As symptoms worsen, individuals can be stigmatized in a manner that leads to blame, decreased social interaction, and isolation. Yet, it is also important to know that people with schizophrenia might engage in withdrawal as a strategy to manage their exposure to stimuli. Social stigma and self-stigma remain serious issues that have not been addressed adequately in the mental health field (Corrigan & Watson, 2002).

Vulnerability: Individuals with serious mental disorders sometimes may have limited decision-making ability, and their capacity to be fully informed about therapeutic choices can be compromised. At times, they are vulnerable because of inadequate social and coping

skills as well as difficulties in communication. As people with mental disorders process their experiences, they sense and are aware of their vulnerability. This has been reflected in the way institutions have treated people with mental disorders in the past and can be true today in how they are treated by mental health professionals and systems.

Everyday Lives and Experiences: Many of the accounts you will read here depict not only the big events of the disorder but what everyday life is like living with it. What happens when you get up in the morning? What are the challenges you face today? Living with mental illness is about the everyday effort to cope, work, and live your life—just like it is for all of us. The more we understand what this is like in the everyday sense, the more likely we are to develop a deeper level of understanding and empathy. This increases our ability to identify with others and can reduce stigma by shortening the distance between us and those with mental health problems (Angermeyer, Beck, & Matschinger, 2003).

Strength and Courage: Too often, our understanding of mental disorders is based on the tragedies and failures of individuals. Increasingly, the mental health field is focusing on the strengths and courage of people with these disorders. Indeed, the recovery movement is about helping people identify their strengths, assets, and talents. Most individuals who experience the worst symptoms have times when symptoms abate and functioning improves. The most popular memoirs are testimonies to strength and courage, and they inspire hope and remind us of the resilience that is possible.

Shaping Identity and Career: Frequently, these accounts describe the all encompassing and overwhelming nature of mental illness. Yet many of our authors have written “transformative” narratives in which they have accepted their illness and understood its value in shaping their identity and career. Often, people “give back” as they recover, and this has encouraged the field to recognize the strengths, not just the vulnerabilities, of those with such experiences.

Stigma and Treatment: Too many of the first person accounts in this collection recount the devastating impact of stigma and the inadequate services that our authors have received. Indeed, one of the

most frustrating aspects of reading these accounts has been coming face to face with the disrespect and inappropriate treatment that our authors divulge. Fear of discrimination and stigma often prevent people from seeking critical mental health care. We hope one clear message from reading these accounts is that people with a mental disorder, like all of us, deserve to be listened to, understood, helped, and provided access to quality care. Today, there is no excuse for those needing treatment not to get it.

DEFINITIONS AND DIAGNOSIS

Putting together a book of first person accounts of “mental illness” immediately calls into question what constitutes a mental illness. Although our book educates about and conforms to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, Text Revision (*DSM-IV-TR*) categories, it should not be perceived as an endorsement of the *DSM*. A common understanding of psychiatric disorders is that a person is undergoing extreme distress, is experiencing something that is rare, is engaging in behaviors that might violate social norms, and/or is suffering from a disability or has an impairment in functioning. Yet the *DSM-IV-TR* (American Psychiatric Association, 2000) itself acknowledges: “although this manual provides a classification of mental disorders, it must be admitted that no definition adequately specifies precise boundaries for the concept of ‘mental disorder,’” which “lacks a consistent operational definition that covers all situations” (p. xxx). Wakefield (1992) discusses the idea of “harmful dysfunction analysis” in understanding mental disorders. He defines a disorder as existing when “the failure of a person’s internal mechanisms to perform their functions as designed by nature impinges harmfully on the person’s well-being as defined by social values and meanings” (Wakefield, 1992, p. 373). Wakefield’s harmful dysfunction analysis combines scientific fact with socially constructed values. More specifically, the scientific facts describe the biological process that is not functioning normally, while the social values define the harm that results from that dysfunction.

How mental illness is defined has been the target of controversy since psychiatry emerged as a medical specialty. It continues today and is the subject of Richard McNally’s (2011) new book, *What Is Mental Illness?* As

with many others (Corrigan, 2007; Hagen, 2000; Kendell, 2002; Kirk & Kutchins, 1992; Wakefield & Spitzer, 2002; Wylie, 1995), McNally is not content with the traditional *DSM* definitions and understanding of mental disorders. His book begins: “Nearly 50 percent of Americans have been mentally ill at some point in their lives, and more than a quarter have suffered from mental illness in the past twelve months. Madness, it seems, is rampant in America” (McNally, 2011, p. 1). As a critique of the *DSM*, his book is an attempt to bring a greater degree of the scientific perspective to our understanding of mental disorders. Many have wondered how the *DSM* can include what would seem to be very nonpsychiatric difficulties such as mathematics disorder and caffeine intoxication. While our book often will be used side by side with the *DSM* in the classroom, our intent is to provide a broader understanding, that people with a mental disorder and their first person accounts are *more than a diagnosis*.

In identifying the first person accounts for this book, we used a multi-pronged approach. First, we searched the Internet, read blog entries, and googled specialized Web sites to see who might be writing narrative accounts of their experiences with mental illness. This yielded some excellent contributions. However, in spite of the great number of written memoirs, assembling a comprehensive collection was challenging. In the end, our efforts resulted in a varied and interesting set of accounts. Some were written on request, some were reprinted from well-known sources, some were derived from self-published books, and a few historic accounts that demonstrate consistency over time were included. We hope the reader appreciates the diversity represented in the collection.

LIMITATIONS AND A NOTE TO STUDENTS

As you will learn from reading these accounts, mental disorders affect all types of people everywhere—urban and rural, rich and poor, young and old, male and female, educated and uneducated, happy people and sad people. In these pages, you will find the stories of individuals who have much to share about their diverse experiences, ranging from extreme frustration at the mental health services delivery system to incredible gratitude for the help they received. Some authors describe family members who were essential to their recovery, and some describe family members who seemed essential to their demise. Each first person account can teach you something different.

Your challenge is to discover what each story offers to further your understanding.

The chapters in this book are organized by *DSM-IV-TR* categories so that students (and other readers) can relate the first person accounts to what they are learning about diagnosis and mental disorders in the classroom and internship settings. We have taken a teaching approach in the introductions to the chapters for each category of disorders. We intentionally included well-written memoirs that have inspired an entire field of writing and more common accounts that have not made the *New York Times* bestseller list. Sometimes, the well-written memoir is strikingly effective at describing the disorder and does so in an especially engaging manner. Other times, a simple account is basic but establishes a clear and meaningful everyday story. Our goal was to obtain a good mix of personal narratives for the reader.

This book includes subjective firsthand accounts, and as such it is biased, not objective; it does not attempt to represent the true or complete range of experiences that individuals may have. The account is not tantamount to the experience of mental illness itself. It reflects the limits of communication, memory, and potential distortion. Yet it is this subjective experience—the inside view—that we want to present and honor. One challenge for students is to look across these accounts for lessons that can be learned and then applied to their general understanding of the various disorders.

Some of these accounts may, indeed, be accurate representations of a particular disorder. However, in many cases the disorder is not clearly identified and symptoms may overlap with other disorders. We believe this contributes to a greater understanding of the complexity of symptoms and disorders—psychiatric classification is far from perfect, and these accounts should provide indirect evidence of this fact. We have taken our contributors' stories as they were written, and as such they stand. Our goal has been to provide the reader with the subjective viewpoints of people who have experienced living with a "mental disorder." Promoting a broader, more humane perspective is central to an enhanced understanding of mental illness in our society. We hope that reading this collection of first person accounts promotes greater compassion and empathy; an increased commitment to quality services and treatment; reduced stigma, pain, and suffering; and an expansion of hope and recovery.

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