

Introduction

I am writing this book for and with my son, David Christopher Ruether. It represents our almost thirty years of struggle with his mental illness that has debilitated him since his late teens. It also is about our struggle as parents with the mental health system in the United States, as we have pursued our son through his vicissitudes of hospitals, nursing homes, and board-and-care homes in the search for better advice and better treatment for his illness.

I have folded David's personal story into the story of the changing face of how those with mental illness have been treated in the United States, from colonial times to the present. I brought in this historical context not only because I am a historian and deeply interested in how ideas and practices have developed historically but also—and more importantly—because of my realization of how little has changed in the treatment of those with mental illness.

The usual view of the history of the treatment of those with mental illness is that while there may have been some barbaric treatment in the past, it has now been overcome. The development of psychotropic drugs and the emptying of mental hospitals in the 1950s to 1970s signaled the dawn of enlightened treatment of these people. It is said that society now realizes that this illness is simply a physical disease like any other; it is treatable with medications, and those who suffer from it can live as valued members of society. However, the reality of the situation

is very different. In fact, Americans have gone from one inhumane solution to another for persons with mental illness. Today, the incarceration of many of those with mental illness has been transferred from mental hospitals to jails. The worse descriptions of the bedlam of prisons and mental hospitals in the eighteenth or nineteenth centuries, where people were chained to their beds, shouting or mute, naked and idle, lying in their own excrement, can now be duplicated in the pretrial mental wards of county jails.¹

Tragically, each of the shifts has been accompanied by great waves of reform led by idealistic reformers determined to rescue those with mental illness from abusive situations and give them a truly humane and dignified life. So what has gone wrong with these reforms? Why do we as a family with a son with mental illness struggle with such poor alternatives today? Answering these questions is an integral part of the story contained here. It also tries to envision better alternatives, to imagine what our society would do for those with mental illness “if we really cared,” and it presents some examples of groups who are doing a better job.

This book is primarily the fruit of my research and writing, but it is also an expression of a family collaboration. Herman Ruether has been a central part of this struggle with David’s mental illness over the years, and he has been a constant consultant on this book, reading and discussing all its chapters. David has also been an integral part, not only because it is his story but also because his own experiences, thoughts, and writings have been brought in at many points. I have consulted him on many issues and at times have quoted verbatim some of our conversations. His own writings play an important role in the narrative. This book seeks to make David’s voice heard. His two sisters have also played a role by reading major parts of the manuscript and giving me feedback and sharing how they want their own experiences represented.

I wish to say a word about terminology in this book. I have avoided the terms *the mentally ill* or *a mentally ill person* since they seem to essentialize mental illness as the identity of the person. Just as we would not refer to a person with cancer as a cancerous person, so we should not refer to a person with mental illness as a mentally ill person. I have

adopted a number of ways of referring to different individuals and groups with mental illness in terms of the context. In the traditional hospital for persons suffering from mental illness, the term *patient* seems appropriate. I occasionally use words like *maniac*, *crazy*, and *insane*, but only as references to past historical usage, and usually in quotes. Several movements, such as Thresholds and the Village, see themselves as communities and call the people who participate in their movement *members*, while Gould Farm refers to them as *guests*, so I use these terms in the context of these movements.

Mostly I just use the term *persons* in varying contexts, such as “persons with mental illness” or “persons receiving mental health services.” I do not use the term *consumer*, which is favored by the National Alliance on Mental Illness. To me, *consumer* is market terminology. It refers to someone who buys goods and consumes products. What are people with mental illness being presumed to “buy” or “consume”? Mental health services? Medications? I think this term masks the involuntary way that medications are being imposed, for the most part, and the underlying medical model that still shapes this relationship.

This book unfolds in six chapters. The first chapter consists of an overview of David’s life from birth in 1959 to the time of the completion of this writing in March 2009. It is organized around six periods: early childhood in the Claremont area of southern California; his youth in Washington, D.C.; young adulthood (with some months spent in Cambridge, England, and then in Evanston, Illinois) and the early onset of schizophrenia; the eight years he spent in Hawaii from 1987 to 1995; the period from 1995 to 2002, when he returned to the Chicago area and bounced around between various hospitals, nursing homes, and board-and-care homes; and the most recent period in which he, with us, his parents, returned to the Claremont, California, area.

This biographical chapter was originally written to help psychiatrists and social workers understand the different aspects and stages of David’s experience with mental illness and the mental health system in the context of his larger life experience. Except for one director of a local clinic, I have never met a social worker or psychiatrist interested in reading it. Apparently, these professional roles can be carried out

without understanding very much about the person whom one is “treating.” I have expanded this biography to put everything else in the book in the context of David’s own experience of mental illness and the mental health system over the last thirty years.

The second chapter details the symptoms of schizophrenia as defined by the DSM, the *Diagnostic and Statistical Manual of Mental Disorders*, the official manual published by the American Psychiatric Association to diagnose mental illness. The chapter compares these symptoms with David’s experience with such phenomena as voices, obsessions and paranoia, incoherent speech and thought, and passivity or lack of motivation. It traces the overlap of much of such phenomena with “normal” human experience and explores the problematic labeling of such experiences as “illness” caused by a “brain defect.” The hearing of voices and visual hallucinations is discussed in terms of their widespread appearance in religious experience, both in the origins and ongoing experience of Christianity and also in Islam and in African-Latin American religions, such as Santería and Condemblé. It compares David’s verbally rich and complex writings with the theories of “incoherent speech” and “poverty of thought” in the DSM diagnosis. Finally, it asks how much of the patterns of passivity and lack of motivation are manifestations of an illness and how much is medication induced and socialized through a mental health system of care designed to produce dependency.

The third chapter traces the pattern of continual oscillation and tension between mental-psychological theories and somatic theories of the causes of schizophrenia. It looks at these conflicting views in three historical stages in Western (especially American) culture: (1) the Christian and classical views inherited by colonial America that saw mental illness alternatively as caused by demonic possession, on the one hand, and by the imbalance of the humors of the body, on the other; (2) the drift between “moral treatment” in the early asylum movement in the early nineteenth century and the increasing focus on somatic causes or “brain lesions” and on somatic treatments like hydrotherapy, shock treatments, and lobotomy that continued into the mid-twentieth century; and (3) the Freudian psychoanalysis and the antipsychiatry movement of the 1960s that challenged these somatic theories and treatments but was

followed by a return with a vengeance to purely somatic or “chemical” theories of the defective brain and a preference for drug treatment of mental illness to the virtual exclusion of any “talk” therapy in contemporary psychiatric theory and practice. The chapter also discusses several new developments of thought that question the mind-body dualism underlying this opposition of mental-psychic versus somatic theories. It lifts up the need to see the interaction of mind and brain, the social and the somatic. It concludes with some of David’s own reflections on the causes of his “problems.”

The fourth chapter asks why those with mental illness have so often been treated so violently and abusively, based on assumptions of what is good for them. It suggests that part of this abusive treatment lies in the need to separate ourselves as “normal” and “rational” from those with mental illness, to deny the continuity between us, and to repress our fears of those “others” as potentially “us.” It sketches the history of abusive treatment from chaining, beating, and extreme neglect in prison-like hospitals or “bedlams” to the shock treatments and lobotomies that became favored in the early to mid-twentieth century, and takes up the question of the new neuroleptic medications developed from the 1950s and the increasing use of them for more and more categories of human experience pathologized as “mental illness.” The chapter also explores the work of Peter Breggin, a psychiatrist whose writings and legal activism have challenged the reign of the chemicalization of treatment of psychic experience, including that of younger and younger children, in preference for any tradition of guidance in a “soul journey” toward maturity and wisdom. This questioning of the reign of “meds” includes a brief exploration of the way in which the psychiatric establishment is being corrupted by big money through drug companies. I conclude by reflecting on our own dilemmas as a family trying to make our way in the midst of this cacophony of conflicting voices about what to do.

Chapter 5, on living arrangements, addresses not just physical housing but the various environments that our societies, from colonial times to the present, have set up for the domiciling of those with mental illness. The chapter addresses the vision of moral treatment that arose in response to the abusive treatment of those with mental illness in prisons,

asylums, and poorhouses in the late eighteenth and early nineteenth centuries. The development of moral treatment by the Quakers at the Retreat in York, England, an institution that still exists, is discussed in some detail. How this vision of moral treatment deteriorated into the new snake pit of the state mental hospital from the mid-nineteenth to the mid-twentieth centuries is then discussed. The last half of the chapter focuses on the critique and emptying of the state mental hospitals in the 1960s and 1970s as a result of a new reform movement that favored “community care.” It discusses how this movement—what has been called “deinstitutionalization”—has deteriorated into the relegation of those with mental illness to a new set of inhumane institutions, the nursing home, and the board-and-care home. Many of those who would formerly have been hospitalized are now found in the street as homeless people or in the jail.

The last chapter seeks to provide some vision of an alternative to this grim picture. It details four much-more-adequate and hopeful therapeutic communities and movements that David and we, his parents, have experienced over the last twenty-five years: the Duck Island experiment, Gould Farm, Kahumana, and Thresholds. It also discusses a fifth very helpful effort to provide an integrated network of services for those with mental illness in Long Beach, California: The Village, with its focus on recovery, not just maintenance. This perusal of more hopeful alternatives with a real vision of recovery is followed by an effort to imagine what a more adequate system of mental health services might look like. I speculate on how we might bring together the hospital, housing, and the community clinic, with work, education, recreation, and social life organized on the county level.

Finally, the book concludes with a brief reflection on what a *spirituality for recovery* might mean both for advocates and for those struggling with mental illness. How do we commit ourselves to long-term advocacy for someone with mental illness and not overwhelm our own lives? How do those with mental illness nurture ongoing hope and not be overwhelmed with sadness for all that has been lost? The chapter ends with a poem by David on the journey through the “storm” and back to the “light.”