

## MINDS OVER MADNESS

### Psychiatric Survivors on the Road to Recovery

by

Peter Stastny, M.D. and Dian Carswell Cox

#### Overview

For years Janice B. did not put food in her mouth fearing that God would punish her. These days she cuts checks for sixteen of her former fellow patients, who deliver food to the homeless. They all work for Share Your Bounty, Inc., a food bank founded and run by psychiatric survivors. Ms. B. spent eight years in a state hospital, prior to her eight years as treasurer of this unique organization. Until she joined this group in their mission to help the less fortunate, she was unable to leave the ward due to her compulsions and fears. Together they put the hospital behind them and established themselves in the community. With their own government funding they opened an office, and have served the destitute of New York City ever since.

Ms. B. is one of thousands who have found new ways beyond the predicament of "mental illness." Most were once deemed "chronic" and incurable; their lives, in spite of all psychiatric efforts, were at best gray drudgery punctured by flare-ups of madness. No work, no homes, no friendships, despairing families and frequent trips to the loony bin - one wonders why so few commit suicide.

Many who broke this vicious cycle, have done so on their own steam. By taking charge of their lives, and, very often, by giving to others, even people like Ms. B., who had lost all hope, become valued members of the community. Realizing this, a rapidly growing number of dissatisfied customers of psychiatry are flocking toward self-help groups like Share Your Bounty. There they find meaningful work, the comradeship of peers and freedom from institutional constraints. In doing so they become allied with a world-wide movement of former mental patients, joining tens of thousands other activists in their fight for equal rights and opportunities.

Minds over Madness is the first book that records and reveals the accomplishments of the survivor movement in mental health. In its roughly 70,000 words and 16 chapters, the book shows how a rapidly growing share of the millions diagnosed as mentally ill are empowering themselves to overcome tremendous obstacles. The main thesis of this book is that individual victories would not be possible without the gains made by the survivor movement. Each chapter will feature unique approaches developed by exponents of this movement in response to the dire dilemmas they face. These approaches have often led to recovery and real solutions where traditional treatment has failed. Personal experiences as told to the authors will be woven into observations, descriptions and background material. No illustrations are planned.

We intend to approach Kate Millett and Kurt Vonnegut Jr. to provide introductions for this book. They each have come forward with accounts of their personal distress and are respected by the survivor movement. Persons who are identified by name will be asked for written consent after review of the salient passages. Others who are essential to the project, but are not available for consent, will be adequately disguised. A literary attorney will be consulted to prevent litigation.

#### Back Matter

Each chapter is followed by notes referenced to numbers in the text. A selected bibliography lists relevant key writings. Finally, an index to topics and proper names complements the book's chapters.

#### **Resources Needed to Complete the Book**



## Chapter-by-Chapter Outline

- I. RECASTING THE DIE
  - 1. We Own Our Minds !
  - 2. Healthy Rage
  - 3. A Biology of Empowerment
  
- II. PAT ANSWERS
  - 4. Recovering Alone
  - 5. Peer Therapy
  - 6. Patient Philanthropy
  - 7. Personal Philosophies
  - 8. Sure Salvations
  - 9. Sane Art in Insane Places
  - 10. Meaningful Work
  
- III. RESTRAINTS OR REMEDIES
  - 11. Chemical Solutions ?
  - 12. Teach Your Parents Well
  - 13. Due Process - Undue Harm
  
- IV. NEW ALLIANCES
  - 14. Grassroots and Umbrellas
  - 15. Psychiatry Revisited
  - 16. A Just System for All ?



In the following we introduce empowerment as the main principle which promotes recovery. Personal statements and vignettes illustrate individual experiences of empowerment. Clifford Beers and Judi Chamberlin, two well known movement protagonists, give the reader a glimpse into the first tidings of personal empowerment. To contrast these authentic moments of assuming power over one's life, we critique the strategy of "consumer involvement", which mental health providers have recently added to their repertoire.

In the final section of this chapter we offer a description of communities built by former patients. The crucial link between individual empowerment and peer support is emphasized through an in depth study of one ex-patient organization. Their family-like network is an example of the new support structures that can emerge in today's social climate. The chapter ends by revisiting the three essential features of the movement -- novel solutions, empowerment and peer support -- and thus sets the stage for the subsequent chapters.

**Chapter 2: Healthy Rage**

15 pages

This chapter outlines the historical origins of the survivor movement emphasizing the pervasive outrage that characterized its early days. A collage of headlines from Madness Network News, The



recovery through self-healing and empowerment. It is organized in five segments.

At first, the concept of empowerment is translated into the neurobiological realm. The authors then give a rationale for taking this road by showing that the artificial separation of the biological and social spheres has not served the very people it is intended to serve. Indeed, we show, that biological theories have accomplished little other than keeping people from owning the experiences of their minds.

The following section considers the brain as the seat of our selves. This is done to help the reader appreciate the essential role of the brain in mental health, not just in mental "illness". Once this is established, a discussion of brain events reputedly linked to schizophrenia ensues. Without certainty that such a condition truly exists and also that certain brain pathologies can indeed be indentified as its causes, we make the case that empowerment reverses such noxious factors. To accomplish this we first entertain the popular notion that schizophrenia goes along with the experience of loosing central aspects of self, like motivation and direction. These very elements are actually undermined by the practices of biological psychiatry, when just the opposite should occur. The authors then assert that empowerment restores the person's ability to take charge of themselves, which is basic to recovery.



televised outreach is given as an example of the great range of options available outside of conventional treatments.

The second and most substantial segment of this chapter contains testimonials by survivors, who relate specific ways they discovered to counter their mental and emotional difficulties. Thought stopping, distraction, meditation, reality-checks and detection of warning signs are some of the techniques explained by their proponents. Interviews with Esso Leete, a widely published survivor of schizophrenia, and Edward Knight, a leader of the New York self-help movement who copes by meditating, give detailed insight into their approaches. The authors survey other survivor writings about successful self-help methods.

Finally, the chapter shows that many of these solitary strategies can be taught to others in search of solutions. A description of training curricula developed by former patients concludes this segment and provides a link to next the chapter.

**Chapter 5: Peer Therapy - Former Patients as Healers**

15 pages

Chapter five shows that former patients can become healers by blending their experience with a special brand of caring. It begins by discussing how personal experience provides unique credentials for those working as peer counselors. Special

training efforts that build on these experiences are described in contrast to professional education in mental health. The chapter moves on to delineate the nature of this work and brings to life it's principles by capturing their practical applications.

To give the reader a graphic understanding of this new and important form of therapy, we interview both participants, doing away with the patient-therapist distinction. These accounts of counseling sessions provide a striking counterpoint to the familiar rituals of psychotherapy. Complex ethical issues, like friendships, sexual relations, payment and termination emerge as we develop insight into the practice of peer counseling. The chapter closes with a discussion of career paths open to survivors steeped in this method. Working within and outside the mental health system, these new practitioners are a formidable challenge to the staid way of dispensing cures.

**Chapter 6: Patient Philanthropy**

20 pages

This chapter spotlights an essential ingredient of the survivor movement: the desire to help others in need through selfless charity. It begins with a portrait of Share Your Bounty, Inc., an organization of former patients that provides food and clothing for homeless people in New York. This sets the stage for a more general discussion of the relationship between altruism, philanthropy and mental health. The life of Florence Nightingale

as well as personal recollections from the medical practice of one of the authors complement this part of the chapter.

Realizing themselves as philanthropists fulfills the needs of people who have experienced deprivation and is the subject of the next section. Philanthropy is viewed as meaningful work by many former patients quoted here. William Brown, the leader of Share Your Bounty, and Howie the Harp, a prominent activist from Oakland, California, are featured in the last segment of this chapter. Their dedicated work for the homeless is presented as a shining example of how individual victories result in the benefit of many. The chapter traces their altruistic motives back to religious and political origins, approaching two very important foundations of the survivor movement.

In ending, the authors consider the stressful effects of such daring positions on these self-less leaders.

**Chapter 7:        Personal philosophies**

15 pages

The next chapter introduces the reader to new views of the world based on experiences with madness and psychiatry. A brief excursion into the relationship between philosophy and madness provides a backdrop to the main thesis of this chapter: the assertion that experiences as a psychiatric patient can give rise to fresh interpretations of the world, untainted by diagnosable

disease. As an introduction to this potentially dense subject, the chapter acquaints us with the work of Friedrich Hoelderlin, a German philosopher said to have been mentally ill. Contributions of Antonin Artaud, a brilliant thinker and multi-media artist, who perished in an insane asylum, complete this section.

The second part of the chapter deals with the idealization of madness espoused by R.D. Laing and his school. Rather than attempting an exhaustive discussion of the subject, this serves merely to distinguish between a philosophy inspired by the madness of others, and one that is generated by survivors in the aftermath of altered states of mind.

The last segment is devoted to the life and work of a man who has made his own mental illness the subject of a philosophical dissertation. Whether a philosophy derived from such experiences can promote a healthy adjustment to life is addressed at this juncture. Gleaning from his material, as well as from statements offered by other survivors, the chapter presents insights well worth disseminating. Whether or not these are useful to the general public is left as an open question.

**Chapter 8: Sure salvations**

**20 pages**

The next chapter examines the healing powers of spirituality - untainted by cultism or delusions. It begins by discerning

genuine spirituality from religious ideas associated with mental illness. Here the authors address the practical and social aspects of religion, as opposed to its philosophical underpinnings. In doing so, it places religious beliefs of survivors on a continuum between isolated pursuit, at times termed delusional, and communal celebration. This leads to a description of three forms of practice: alone, but following shared spiritual tenets; as zealots of cultist groups; and finally, as members of established churches.

Many Eastern religions lend themselves to solitary practice. Their place in self-healing is noted in the next segment. Particular attention is given to centers like the Naropa Institute, dedicated to spiritual remedies of serious mental problems. Forms of meditation and bodily exercises are described in some detail, building extensively on reports by those, who have found them useful.

The next section aims at uncovering to what extent popular cults like Scientology, as well as some of the smaller, more marginal groupings like the Symbionese Liberation Army, promote psychosis among its followers. We explore this by reviewing related literature with the intent of contrasting such dangerous exploits to the clearly restorative forms of religion.

Finally, church membership is presented as a widespread and

powerful method to achieve and maintain mental health. While the survivor movement as a whole does not endorse any specific spiritual path, this chapter makes it clear that they constitute an essential element in the recovery of many once termed mad.

**Chapter 9: Sane Art in Insane Places**

20 pages

The chapter defines artistic expression as a road towards new identities beyond patienthood and institution. It begins by challenging the widespread notion that the "artistry of the mentally ill" is a mere byproduct of their maladies. In the following we distinguish clearly between "art therapies" and authentic artistic endeavors. Leaving no doubt about the fundamental role of free artistic expression, the next section illustrates the multitude and power of creative work by psychiatric survivors.

Writers, painters, filmmakers and actors display the many ways in which they have used their work in recovery. Instead of exhibiting the work, the chapter emphasizes their use of the creative process. Each field is touched by a brief survey of it's finest features. While there are scores of artists who suffered nervous breakdowns as well as patients who became artists during recovery, the focus in the following part is on two internationally known projects, where hospital inmates became artists working in the public domain. These are the "Living Museum" at Creedmore

Psychiatric Center in New York, and the "Artist's House" located in an Austrian state hospital.

Two published writers, Laura Ziegler and Beth Greenspan, share their views on the role of writing in their struggle against psychiatric oppression. We include in this last section certain poems and prose excerpts to illuminate their perspectives. Finally, the central role of creative writing in the survivor movement is underlined.

**Chapter 10: Meaningful Work**

10 pages

This brief chapter underscores the importance of meaningful work for people recovering from mental breakdowns. New roles in the survivor movement are affirmed as realistic employment options. A concise discussion follows, contrasting how vocational rehabilitation has failed persons with psychiatric disabilities. Establishing that many former patients make significant contributions to their recovery and to their communities, the chapter asks the cardinal question: can the free market economy provide rewarding opportunities to work? For the time being, the answer is no. This sad state of affairs is affirmed in the concluding passages of the chapter, providing a lead-in to the next section on restraints and remedies.

**SECTION III RESTRAINTS AND REMEDIES**

This section covers situations viewed by many as obstacles to healing and personal freedom. These include psychiatric medication, the family and the law. Rather than simply taking an antagonistic posture vis-a-vis this powerful triad, the chapters presents a range of concerns and solutions articulated by survivors. It shows how medications can be used safely and appropriately; how positive relationships to families can be established through a new kind of dialogue; and lastly, how legal advocacy can be a potent tool in vindicating former patients.

**Chapter 11: Chemical Solutions**

25 pages

The opening chapter of this section reviews psychiatric drug therapies in light of concerns raised by it's users and outlines novel approaches to medication. Visiting a cross-section of critical positions towards psychiatric drugs, the chapter at first draws attention to the principal conflict between survivors and psychiatrists. It moves on to outline the extreme positions taken by the psychiatric profession reacting to criticism leveled by patients: the majority favors drugs, even forced, as the mainstay of treatment for serious disorders; a small, but vocal minority exposes their toxicity and advocates against their us, particularly under duress.

With this as a backdrop, the chapter's main section explores

a range of personal responses to medication. It begins with those activists, who continue to take medications having found them useful or for lack of a better alternative. In these difficult dilemmas, they must weigh possibly toxic effects against the fear of relapse and incarceration. We assert that self-medication strategies counter psychiatric notions of "non-compliance", illustrating personal struggles with the stigma and side-effects of these drugs. This section also includes a brief appraisal of substance abuse among psychiatric survivors. The common idea of two maladies aggravating each other is refuted by the view that street drugs and alcohol often provide the only moments of "wellbeing" accessible to this troubled group.

The last part of this chapter addresses the obvious need for alternatives to medications, particularly for survivors who are suffering from severe undesired effects without reaping any benefits. The recent controversy on "detoxification" is brought to light by its major proponents. Many survivors spend considerable energy pursuing natural healing options. Homeopathy, herbal remedies and megavitamin therapy are discussed in some depth as promising alternatives being advanced. The chapter concludes by restating the position that drugs are at best imperfect and controversial solutions to vastly complex problems.

**Chapter 12:      Teach Your Parents Well**

18 pages

This chapter depicts the new relationships between survivors and their families, and between family advocates and organized survivors. It is divided into three parts. The first acknowledges the problematic roles that families of psychiatric patients have traditionally played. Moving away from the early ideas which indicted families as a principal cause of mental illness, the chapter lays out how family organizations have rallied to refute such notions.

The chapter then returns from the political arena to the private battlefields inhabited by many families and survivors. In most cases, the process of empowerment has not proceeded at an equal pace for families and their labelled relatives. This situation is exemplified by excerpts from interviews with family advocates and their relatives on one hand, and with survivor activists and their families on the other. Bringing these positions together for the first time, this section establishes that a new kind of dialogue has become possible based on the gains of both advocacy movements.

Finally, the chapter describes unique turns in the relationships between family and survivor organizations. Positions taken by prominent family advocates, like Harriet Lefley, favoring consumer empowerment, are listed side by side with some of the harsh criticism leveled by survivor-advocates against the national family platform. The chapter summarizes its findings in light of

the potential for real change within these thorny relations.

**Chapter 13: Due Process - Undue Harm**

15 pages

The next chapter shows how legal advocacy works in the patient's favor and against questionable practices of psychiatry. We begins by discussing the shift from the use of law to curtail the rights of individuals in crisis to it's more recent applications protecting citizens from psychiatric abuse and neglect. Without spending too much time on the virtually lawless situation that governed early hospital practices, the chapter moves on to review some of the landmark decisions felled in patients' favor. Particular attention is given to the "least restrictive alternative" and the "right to treatment" cases.

This leads us to consider some of the more controversial issues currently under dispute: the right to refuse medication; the right to decent housing and meaningful work; the right to choose treatment options. While only the first of these agendas have received legal backing, they are very much on the forefront of the movement's concerns. As such, the chapter uses them to characterize the legal advocacy efforts currently underway. Examples of class action suits brought against public and private providers illustrate the current state of affairs.

The third section of this chapter examines the work of legal

advocates who are survivors. A small number of their most eloquent representatives, like Ron Thompson from Washington, D.C. and Laura Ziegler from New York, argue their cases in this section. Rather than simply examining their merit, the chapter aims to appreciate the meaning of legal advocacy in the lives of these individuals, who are pursuing unique careers, despite the intrusion of psychiatry. As members of a national network of legal and lay advocates, they raise the question to what extent this kind of work offers viable paths for others to follow.

#### **SECTION IV      NEW ALLIANCES**

The last section of the book assesses the impact of the survivor movement on current and future mental health practice in three chapters. It covers the vast array of self-help groups and national networks that have emerged; describes the changes that psychiatrists and other practitioners will have to make ; and finally, it imagines a completely revamped mental health system as an idealized vision.

#### **Chapter 14:      Grassroots and Umbrellas**

15 pages

The main goal of this chapter is to compose a group portrait of the increasingly complex network of organizations run by and for psychiatric survivors. Instead of conducting a formal survey of the field, the chapter begins with a typology of groups, describing their size, membership and purpose. The themes of

diversity and unity are stressed here, showcasing Recovery, Inc., which espouses a rigidly structured self-help model dating back to the 1930's; Project Release, a radical "underground" group, still devoted to liberating people from the fangs of psychiatry; and diagnosis-specific groups, like the Manic-Depressive and Depressive Association of North America or Schizophrenics Anonymous.

Following these snapshots of individual groups, the chapter maps the national networks of survivors highlighting their differences in representation and agenda. By focussing on the two most prominent groups - the National Association of Psychiatric Survivors and the National Mental Health Consumers Association - the reader gets a sense of the scope and the potential of these networks to further their national agendas. Interviews with their current leadership complement this section of rare insights into a tightly guarded world.

The chapter closes with a synopsis of governmental efforts to promote survivor organizations. The National Institute of Mental Health as well as selected state agencies have made remarkable contributions in this area. Their efforts may set the stage for major policy changes in the not so distant future.

**Chapter 15:      Psychiatry Revisited**

20 pages

This chapter explores the implications of the survivor

movement for psychiatry and envisions a new kind of mental health practice.

Recently, R.Fuller Torrey, Chief Psychiatrist of the famous St. Elizabeth's Hospital in Washington, filed a complaint against the National Institute of Mental Health for supporting "anti-psychiatric radicals." His ire was triggered by a videotape produced by a survivor group in Vermont, discussing safe ways to stop medication. This anecdote leads into a discussion of mainstream psychiatry's responses to the survivor movement. It is rounded out with unexpurgated opinions offered by an elite of today's psychiatrists.

In the next section, the authors offer statements by psychiatrists sympathetic to the gains of the survivor movement. Dr. Dan Fisher, formerly a patient of VA hospitals, became a psychiatrist because he "wanted to get the key" to the room, where he was confined. He is one of the very few who uses his personal experience in his psychiatric practice. Unique as doctor Fisher's background may be, his perspective provides a lead-in to a survey of professionals whose work has changed in response to patient empowerment. It samples some of the new relationships between psychiatrists and survivors.

The final section of this chapter invites the reader to speculate about the mental health practice of the future. It paints

a vision of non-coercive services with peer counselors in the front lines. They in turn are supported by a small group of selected professionals, who have passed muster with survivors. Hospitals are replaced by home-like settings with caring on-site support, mostly by former patients. This section includes a set of criteria professionals will have to meet above and beyond their credentials. A shopping list of alternative services desired by today's consumers concludes this chapter.

**Chapter 16: A Just System for All?**

15 pages

We cannot ignore the changes occurring at the federal, state and local level alongside with the survivor empowerment movement. The Community Support Program, one of the more active branches of the National Institute of Mental Health, as well as some elements in the U.S. Department of Education have begun to recognize the importance of this movement and its potential for changing the entire system. This has led to a few specific initiatives in making funds available to programs that are either run by current or former patients - or persons with psychiatric disabilities in the language of the Department of Education - or dedicated to increasing their involvement in the service system. A few individuals stand out in these agencies who have put their own careers on the line to support these programs. Jackie Parrish and Neil Brown at N.I.M.H. are only some of the outstanding examples that must be mentioned. In addition, an entire new thrust in

research has begun to develop, attempting to gain insights on the workings of self-help and empowerment. Two self-help research centers, one in Michigan, the other in Berkeley, California, have been funded and specialize on persons who are or have been mentally ill. Numerous other research projects utilizing consumers as service providers have sprung up across the country and preliminary results from the should be available momentarily. In this postscript we review these briefly, with the caution that essential information is still forthcoming; we spotlight the potential impact of these initiatives on the lives of survivors and the shape of things to come.