



Healing the Stigma of Depression

A Guide for Helping Professionals

A resource for helping professionals of all disciplines serving people who may be affected by depression—and by its stigma.

**Written by Pamela Woll, MA, CADP
for the Midwest AIDS Training and Education Center
and the Great Lakes Addiction Technology Transfer Center**

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**In loving memory of Reggi Marder,
whose great love and brave heart
will inspire us the rest of our days.**

Table of Contents

Preface	v
Foreword	vii
Acknowledgments	ix
Chapter One: Purpose	1
The Purpose of This Manual	3
Defining Stigma	6
The Lure of Stigma	8
Finding Hope	10
Healing the Stigma: This Manual's Approach	11
Chapter Two: Depression	15
Depressive Disorders	16
Who Contracts Depressive Disorders?	19
The Onset of Depression	24
The Timing and Termination of Depressive Episodes	27
When Depression Proves Fatal	28
<i>Jennifer's Story</i>	30
Chapter Three: The Brain	33
Chemical Messengers	35
Brain Structures	37
Implications for Stigma Reduction	45
Chapter Four: Treatment for Depression	47
Stigma and the History of Treatment	48
Diagnosis	50
Treatment	54
One Vision for Treatment and Stigma Reduction	60
Chapter Five: When Depression is Not Alone	63
General Medical and Developmental Disorders and Depression	63
HIV and Depression	66
Substance Use Disorders and Depression	70
Trauma and Depression	76
<i>Louise's Story</i>	80

Chapter Six: Stigma and Depression.....	83
Why People Stigmatize	85
Attitudes	89
Stigma Toward Treatment	90
Stigma and Culture	91
Stigma and Helping Professionals	93
Chapter Seven: The Effects of Stigma	97
Discrimination	98
Effects on Help Seeking.....	100
Self-Stigma	101
Effects on Depression	103
Chapter Eight: Healing The Stigma in Society.....	107
Starting With Ourselves	107
Choosing a Stigma-Reduction Role	110
Choosing Strategies Based on Their Effectiveness	113
Becoming an Advocate	118
Examples: Anti-Stigma Campaigns	121
<i>Fred's Story</i>	125
Chapter Nine: Healing Self-Stigma	129
Countering Self-Stigma	129
Resiliency.....	132
Empowerment.....	134
The Story	136
Recovery	137
In Closing	140
Bibliography	141
Resources for Advocacy and Support	165
About MATEC and the Great Lakes ATTC	173
About the Author	175

Note: The painting on the front cover is Vincent Van Gogh's "Backyards in Antwerp, 1885." The artwork featured on the back cover is a quilt entitled "DEPRESSION IS," crafted by a woman who has lived with depression since childhood. It speaks of the pain and fear engendered by this illness, and of the responsibility and hope associated with treatment and recovery.

Sheep in Fog

The hills step off into whiteness
People or stars
Regard me sadly, I disappoint them.

The train leaves a line of breath,
O slow
Horse the color of rust,

Hooves, dolorous bells—
All morning the
Morning has been blackening.

A flower left out.
My bones hold a stillness, the far
Fields melt my heart.

They threaten
To let me through to a heaven
Starless and fatherless, a dark water.

Sylvia Plath, from *Ariel*

Preface

By Barbara Schechtman, MPH and Lonneta Albright

“Helping professionals.” That phrase describes those of us who have chosen to work with people who need support and services for a variety of challenges. We include medical and nursing providers, counselors who treat Substance Use Disorders, mental health providers, teachers, clergy, prevention specialists, and many others.

The organizations that employ us realize that it is essential that we be continually developed, informed, trained, and educated, to ensure that we have an effective workforce. As important as the science, education, best practices, and application are, we must also challenge ourselves and each other to look at internal obstacles and barriers, including injustice, myths, “burnout” and apathy, and—in this instance—the stigma that we all carry concerning depression. As Directors of training centers for professionals who have dedicated their lives to mitigating the effects of HIV/AIDS and substance abuse, we have seen first-hand the need for this product as a self-help tool for ourselves and our audiences.

It is an honor and a privilege to do the work that we do and to be able to raise awareness, educate, and affect so many people through our network of partners and supporters in the field. Working in an academic institution does not usually conjure visions of people in touch with what goes on in the real world. We are often referred to as the “Ivory Tower.” However, we have had tremendous opportunities to develop meaningful work guided by phenomenal people. And in getting to know people from all walks of life, we also come face to face with the joys, pains, and fears that we all—as human beings—face in our lives.

The motivation for this publication came from our very personal experience of the role of stigma in the illness of our dear friend and colleague, Reggi Marder. A very strong and dedicated “helping professional,” Reggi was not able to keep from embracing the societal stigma of depression that we all see around us. She could not help herself, and, for a “helping professional,” this in itself brought the stigma of failure.

As “helpers,” we have a responsibility to understand all we can about problems, diseases, and research and practice implications, so we can do our part to help people live healthy lives. We must, then, bring the issue of stigma—in the broadest sense—to the forefront of our work, and battle its devastating consequences for ourselves, and for our patients/clients/consumers in our work with them.

For those of us in the fields that treat HIV/AIDS and Substance Use Disorders, and for those in most other human service fields, depression and its consequences—including its stigma—are critical issues. For the estimated 36% of people with HIV who have major depression, and the estimated 26.5% with dysthymia, depressive disorders can complicate treatment, jeopardize adherence, increase the risk of transmission, and significantly impair quality of life.

Mood disorders are also the most common conditions co-occurring with Substance Use Disorders, with estimates ranging (for example) from 20% to 67% among people seeking treatment for alcohol dependence, and from 30% to 40% among people seeking treatment for cocaine dependence. The co-occurrence of these conditions also complicates diagnosis and treatment of both conditions, and significantly threatens the success of treatment and recovery.

We believe that education and information are critical elements for achieving freedom and understanding. Understanding leads to acceptance and a real capacity to be human. In gaining and disseminating these elements, we as “helping professionals” can truly be of benefit to the people we serve.

This publication will give the reader a better understanding of depression; its effects on individuals, families, and the community as a whole; and—most important—the many challenges that people with depression face, including stigma. We hope that we have helped to bring to you, our colleagues, a way to face these issues gently, yet effectively.

It remains to express our gratitude, first and above all, to our author, Pamela Woll—whose talent, skills, passion, and expertise have made this a work of which we are immensely proud. Her uncommon patience and creativity bring many of our products to life. This one is different only in that it was also written with a personal commitment and passion, coupled with what we know as a field and what we have learned from the research that informs our work. She has the unique ability to integrate what we know with what we think and feel.

And we cannot close without expressing our great gratitude and respect for our colleague Reggi’s family, whose courage and compassion have pushed us all forward in our commitment to overcoming the ravages of stigma and depression in our own lives.

Foreword

By Joe Eppstein

Two years ago I lost my wife, Reggi Marder, to suicide. In an instant, our world was turned upside down. A light was extinguished that will never be replaced, and it has left us with a void that will never be filled.

To those who knew her, this was simply unbelievable. How could this happen to such a vibrant, fun-loving, charismatic person who simply loved living life to its fullest?

Reggi's condition started to worsen in March of 2005. Prior to that, she had muscled her way through countless nights of difficult sleep that she attributed to pre-menopausal symptoms, pre-menstrual symptoms, and just plain aging. She had fought her demons in silence, until that March, when she could no longer keep them at bay.

At that point she took a leave of absence from work and concentrated on trying to get better. What neither of us realized was how deeply rooted her depression had become. She was such a strong individual, and so capable, that she simply did not understand what was happening to her.

It is that misunderstanding that I am hoping this manual helps to dispel. If we had understood depression better, and had not suffered from the stigma that our culture places on depression, I am convinced that Reggi could have fought this illness more successfully.

In spite of all she knew about human psychology and all her years in human service, Reggi still viewed her depression as a character flaw rather than an illness. She did not want to admit to anyone that she was struggling until the end, and by that time it was too late. She had said repeatedly that, if this were only cancer, she could fight it. If our society viewed depression as the illness it is, I believe she would have won her struggle.

Severe depression is a disease. It affects the chemical composition of the brain and in many cases becomes fatal.

The odds of successfully fighting depression have been demonstrated to improve when it is treated in its earlier stages—much like cancer. We must fight the stigma our society places on depression, to allow those who struggle with it to seek help openly and comfortably. We should not be ashamed to be on anti-depressants and other treatments used to help depression. In fact, we should support those who are fighting this illness in the same way that we support those going through chemo and other treatments for cancer.

When I am asked how my wife died, and I say that I lost her to suicide, the conversation simply stops. The person with whom I am speaking simply does not know what to say, and the topic of conversation immediately changes. This is what we must fight.

So where do we start? One of the places we started was in our Synagogue. We formed the Reggi Marder Memorial Task Force, committed to working with our community to promote a better understanding of depression, fight the stigma of this illness, and work toward the prevention of suicide. We also made wristbands engraved with the words, "Help fight the stigma; get depression out of the dark," to stimulate conversations and questions about depression. When MATEC approached me about this manual, I embraced the idea wholeheartedly and was glad to participate in the planning process.

But I think the most important place to start is with our children. In conversations with children about suicide, the question of suicide as a sin inevitably arises. We must help our children understand that this is no more a sin than cancer. Suicide is the result of a severe depression that has caused damage to the brain so that rational thought is no longer possible. There is no shame in this.

My children have been the source of incredible strength for me over the past two years, and I am truly in awe of them. In the many discussions we have had in dealing with our loss, a couple of questions continue to be asked.

One of the big ones is, "How can there be a God if this kind of a tragedy can occur?" Fortunately, our spiritual leaders can help us grapple with that question.

Another question my children have asked is, "What is the meaning of life?" I know how Reggi would have answered this one: The meaning of life is making this world a better place. We must struggle to overcome poverty, we must work to overcome injustice, and we must work to protect our environment. We must fight the stigma of AIDS and HIV, the stigma of substance use disorders, and the stigma of racism. And we must fight the stigma of depression. Please help spread a better understanding of depression by speaking of it openly with your children, your friends, and your colleagues.

I am proud to have had Reggi as my wife, partner, and soul mate, and my children are proud to have had her as their mother. We are not ashamed of the way she died. There is no one we respect more. She fought her battle with all her might, and lost because the deck was stacked against her. We are committed to carrying on the work she started, making this world a better place for all of us to live.

We ask you to join us in this commitment.

Joe Eppstein
August, 2007

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This manual was inspired by the life and struggles of Reggi Marder and the much broader need that her struggles illuminated. Her spirit was present in very tangible ways during the planning and writing of the manual, and we trust her to remain with us as we develop and deliver training programs to disseminate it.

Financial and in-kind support for this manual was a mixture of contributions from several sources, including: funds raised by the Midwest AIDS Education and Training Center (MATEC) in the 2005 AIDS Walk Chicago; contributions by MATEC's principal funder, the Health Resources and Services Administration; contributions by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Treatment (CSAT), principal funder of the Great Lakes Addiction Technology Transfer Center; and time donated by the author, Pamela Woll, MA, CADP.

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In addition, two consumers with depressive disorders ("Jennifer" and "Louise" in this manual) told their stories but asked that their names be withheld, due to the lingering effects of stigma on their lives. Thanks to Amy Watson for the idea of providing consumers' stories followed by questions, and to Patrick Corrigan for providing an example of this technique in his 2004 book, *Beat the Stigma and Discrimination: Four Lessons for Mental Health Advocates*.

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Finally, those of us most closely involved in this project—Barb Schechtman, its leader and spearhead; Lonnetta Albright, its loyal supporter; Joe Eppstein and family, carriers of memory and dedication; Chuck Bright, its tireless research assistant; and Pam Woll, the teller of this story—wish to thank one another. This has been a labor of love, steeped in our awe at having a chance to make meaning of a loss so great.

Chapter One: Purpose

She that had no need of me,
Is a little lonely child
Lost in Hell—Persephone,
Take her head upon your knee;
Say to her, "My dear, my dear,
It is not so dreadful here."

Edna St. Vincent Millay, from "Prayer to
Persephone"

One function of the human mind is to figure things out, to make sense and meaning of experience. When children find a phenomenon confusing or troubling, they make up stories that explain it. They use their imagination, the images that surround them, and snippets of stories that others have told. Sometimes these stories last a lifetime, long after other, more rational explanations have come to replace them.

The ancient Greeks explained the seasons with the story of Persephone, daughter of Zeus and Demeter, goddess of the harvest. Persephone was caught collecting flowers one day and abducted by Hades, god of the underworld, to be his wife. Sick with rage and grief, her mother brought famine upon the world.

After a series of negotiations—and Persephone's unfortunate decision to eat the pomegranate seed that Hades had offered—the gods reached a compromise. Every year Persephone would spend nine months on earth, followed by three months in hell that would leave the world dark and barren.

The onset of depression is often very much like Persephone's descent into hell, but without the promise of release in three months' time. Indeed, for many people with depression, it is the absence of hope—the fact that wellness seems so foreign, so far beyond reach—that sears the soul and seals the experience.

For the friend, family member, or helping professional trying to reach and reassure, this effort can seem very much like the attempt to break through to some darker parallel universe. Two people can be in the same room, with the same objects, the same words, but reality is not the same. Reassurance can be kind, but beside the point: It **is** so dreadful here.

Civilizations have made up many myths to explain depression and the other mental health problems that often cause so much pain and turbulence. These have evolved from the very primitive myths that cited demons or “bad blood” to the more contemporary faith in the weakness, laziness, inferiority, or “dangerousness” of people with mental illness. These myths—and the stigma they reflect and perpetuate—may have brought some comfort or sense of order to those who espoused them. But for many people with depressive disorders, stigma has simply helped seal the gates of hell.

In the words of the Surgeon General’s 1999 report on Mental Health, “Stigmatization of people with mental disorders has persisted throughout history. It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance. Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders...It reduces patients’ access to resources and opportunities (e.g., housing, jobs) and leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking, and wanting to pay for, care. In its most overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society” (DHHS, 1999, p. 6).

The 2003 report of the President’s New Freedom Commission on Mental Health characterized stigma as “a pervasive barrier to understanding the gravity of mental illnesses and the importance of mental health” (DHHS, 2003, p. 20). According to Hinshaw (2005), “The stigmatization that surrounds mental illness is increasingly recognized as a central issue, if not *the* central issue, for the entire mental health field” (p. 714). Stated very simply:

- People who make decisions that affect the availability of opportunities and services are less inclined to be fair to those whom they stigmatize, and more likely to discriminate.
- People who stigmatize mental illness are less willing or able to give respect, support, and acceptance to friends, colleagues, or loved ones who have these conditions.
- People who have learned to stigmatize their own disorders experience feelings of shame and worthlessness that worsen their symptoms and make it more difficult—and in some cases impossible—to seek the help they need and the opportunities they deserve.

This manual goes to press in November, 2007, seven months after the tragic deaths of 32 students and the wounding of 25 others at the hands of a student who had been ordered by the court to seek outpatient treatment for mental illness, but had not received the ordered treatment (Schulte & Jenkins, 2007). In the massive media coverage of the event, and speculation about the mental state of the gunman (who had in the end taken his own life), some cable news talk shows presented repeated discussion of the perceived need for greater powers of involuntary commitment for people with mental illness.

At least in this author’s perception, there was little balancing of these discussions with information about the danger that such powers might be abused, the non-violent nature and behavior of most people with mental illnesses, or the possibility that stigma had contributed to the fact that this young man had not received help. Instead, public consciousness of mental illness was raised once again—and promptly steered in the direction of increased stigma and discrimination.

There is an unbroken thread that leads from a society's beliefs about an illness to the individual's ability to find help and relief and lead a full life. It is our job, all of us, to trace that thread and find our part in the problem and the solution. Depression is only one of many mental health conditions targeted by stigma, but it is one that certainly needs and deserves our attention.

Questions for Reflection and Discussion

1. Why did you pick up this manual?

2. What are your strongest beliefs and feelings about depressive disorders? About people with these disorders?

3. What factors do you think might have influenced your beliefs and feelings about depressive disorders and people with these disorders?

The Purpose of This Manual

Healing the Stigma of Depression is written for helping professionals in the full range of human service fields, from prevention to treatment, street work to social work, primary care to child welfare, research to advocacy. Depression affects many consumers,¹ family members, and community members served by all these fields. And wherever depression goes, stigma and discrimination follow, bringing with them feelings of worthlessness, helplessness, and hopelessness.

Although the Midwest AIDS Training and Education Center and the Great Lakes Addiction Technology Transfer Center are primarily responsible to the fields of HIV/AIDS and Substance Use Disorders (respectively), both organizations recognize that:

¹ Although a number of terms have been applied to people who use or have used mental health services (e.g., person with a mental illness, ex-patient, consumer, psychiatric survivor, client), for consistency, the term "consumer" will be used throughout this manual.

- The people served by these fields grapple with multiple challenges, far too often including depression.
- These challenges often have interlocking causes, symptoms, consequences, and solutions, bringing consumers into the care of multiple human service fields.
- Professionals in each field can provide far more effective help if they have a better understanding of the challenges that fall under the other fields' scope.

Metaphors of light and darkness surround depressive disorders. Advocates often speak of bringing depression “out of the dark,” pulling it up into everyday discourse. Only then can the many systems affected by the stigma of depression begin to function in more respectful, empowering ways, so that the individuals who experience it can:

- Receive the respect, understanding, acceptance, and support they need from loved ones, neighbors, employers, co-workers, educators, and communities
- Learn recovery² skills and engage in consumer-directed recovery services and programs that embody the values and principles of peer support
- Maintain hope and human support while they search for the recovery-oriented services that work for them
- Seek and receive individualized, person-centered professional help, help that is informed by aggressive research and comprehensive education of all who treat depression
- Be treated with respect in treatment and recovery and given self-direction in their care
- Have access to the opportunities they need to pursue their goals
- Achieve lasting recovery that is rooted in: accurate knowledge of their conditions and their options for consumer-centered services and treatments; full support for their true goals; faith in their own worth and capacities; empowerment; and knowledge of their strengths, resources, and resiliencies
- Build the lives that they choose, lives that will take them toward their goals, their hopes, and their dreams

So this manual is designed to help bring both depression and its stigma out of the dark, bearing the message that:

- Depression is a condition experienced by people of all ages, cultures, intelligence levels, economic status, professional levels, personality types, and levels of wisdom and functioning.
- Depression is a complex condition that can have multiple physical and psychological roots, symptoms, and consequences, with wide variation from person to person.
- The co-occurring presence of other stigmatized circumstances (e.g., HIV, Substance Use Disorders, other mental illnesses, poverty, gender, age, sexual orientation, minority status) can complicate and exacerbate both depression and the effects of the stigma that surrounds it.

² According to the National Consensus Statement on Mental Health Recovery, “Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential” (SAMHSA, 2006, p. 1). The concept of recovery is essential to stigma reduction, and is addressed in greater detail in Chapters Eight and Nine.

- Human beings tend to oversimplify complex conditions and stigmatize conditions that cause emotional discomfort, as a primary way of making sense of our experience and coping with our own discomfort.
- The stigma that society attaches to people with depression—and that many people with depression internalize—reduces many people’s willingness and ability to seek and receive the help they need.
- Helping professionals who suffer from depression may be at higher risk of stigma, self-stigma, and the consequent lack of appropriate care and support.
- Depression can destroy lives, families, careers, dignity, and well being.
- People with depression can improve and recover.
- Appropriate recovery-oriented services and treatment can halt the progression of the illness and restore natural processes of growth and healing.
- The consumer is the expert on his or her own life, values, priorities, and goals.
- In recovery, people can learn to manage their mental health and lead the lives they choose.
- Professionals whose words and actions affect human lives have an obligation to understand and normalize both depression and its treatment and recovery—within themselves, within the people they serve, within their helping communities, and within society as a whole.

Questions for Reflection and Discussion

1. Of the “messages” listed directly above, are there any that you agree with strongly? If so, which ones, and why?

2. Are there any of these messages that you disagree with strongly? If so, which ones, and why?

Defining Stigma

In anatomy, a *stigmata* is a small mark, scar, or hole in the skin, but the word has long been applied to a much wider range of human characteristics and circumstances. In 1963 the sociologist Erving Goffman brought the study of social stigma to the forefront with his seminal work, *Stigma: Notes on the Management of Spoiled Identity*. In that book he described stigma as “an attribute that is deeply discrediting” and the stigmatized individual as someone who has been “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3).

Although those descriptions identify stigma with the condition or characteristic that society discredits, the concept has also been expanded to include the entire process of stigmatization, its components, and its consequences. It is this expanded concept that *Healing the Stigma of Depression* addresses.

As researchers, clinicians, advocates, and consumers of mental health services have become more aware of the link between stigma and the perpetuation of stigmatized conditions, they have begun to craft a language with which we can shed some light on this subject. Here are a few examples:

- **Stigma:** “The co-occurrence of labeling, stereotyping, separation, status loss, and discrimination” in a situation in which power is exercised (Link & Phelan, 2001, p. 363)
- **Label:** “The formal label makes the mental illness ‘visible’ to society (i.e., it serves as a mark, or stigmatum) and demonstrates to those so labeled that society has categorized them as being in an ‘out’ group, that of the mentally ill” (Blankertz, 2001, p. 458).
- **Self-stigma:** “The consequences of people with mental illness applying stigma to themselves” (Corrigan & Kleinlein, 2005, p. 12)
- **Courtesy stigma:** Society’s tendency to extend stigma toward those who are associated with a stigmatized person or group (Goffman, 1963)
- **Public stigma:** “The results of a naïve public endorsing the stereotypes of mental illness” (Corrigan & Kleinlein, 2005, p. 12). Three components of public stigma (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003, pp. 163-164):
 - *Stereotypes:* “Collectively held beliefs about the members of social groups”
 - *Prejudice:* “Endorsement of negative stereotypes”
 - *Discrimination:* “A behavioral response based on prejudice that can result in harm”
- **Structural Discrimination:** Discrimination formed by sociopolitical forces, representing “the policies of private and governmental institutions that restrict the opportunities of stigmatized groups” (Corrigan, Watson, Heyrman, Warpinski, Gracia, Slopen, & Hall, 2005, p. 557)
- **Implicit Bias:** Bias that is unintentional or less strategic, often lying outside conscious control and awareness, and therefore more likely to predict discriminatory behaviors. Implicit bias sometimes co-exists with an egalitarian self-concept and a desire to be respectful and “politically correct” (Teachman, Wilson, & Komarovskaya, 2006, p. 78)

Although depression's largely internal symptoms make it a less inviting target for stigma than some other conditions—including the mania that joins depression in Bipolar Disorder—it is still unfair game for a number of stigmatizing statements. A few examples:

- “She’s not depressed; she’s just lazy.”
- “He should pull himself up by his bootstraps!”
- “Good heavens. We all get down in the dumps.”
- “Snap out of it!”
- “I just don’t have what it takes. I’m useless.”

The people who stigmatize depression rarely do so with a desire to hurt. Quite often it is the opposite, a desire to help heal depression by “teaching” the positive attitudes that have kept them afloat. For others, stigma is rooted in the pain and discomfort born of worrying about their loved ones and waiting for life to return to normal. For still others, the stigma simply fits the world view they learned long ago.

Many people with depressive disorders were also raised to stigmatize these disorders. When their symptoms begin, they turn the external stigma into self-stigma, adding fuel and weight to the symptoms of depression. After all, according to Corrigan and Lundin (2001), self-stigma and depression share many symptoms, including:

- Low self-esteem
- Loss of hope
- Loss of confidence in one’s ability to succeed
- Feelings of helplessness
- The “why try?” attitude
- Giving up on goals
- Denying credit for accomplishments
- Self-blame for failures (and perceived failures)
- Problems with sleep, fatigue, eating patterns
- Loss of interest in keeping on living

So how do we combat a social attitude that is part of the very fabric of the disease it seeks to attack? In many ways the healing of stigma, self-stigma, and depression are interdependent processes. Healing must be addressed on several levels, in ways that respect the complexities in all of these processes.

Questions for Reflection and Discussion

1. What conditions/characteristics have you been stigmatized for in your life?

2. What conditions/characteristics do you think you have stigmatized in others?

The Lure of Stigma

Two factors make the myths and stigma seem particularly natural, even comforting. One is the fact that depression is so easy to minimize. The other is its threatening complexity.

Minimizing Depression

Is depression really a disease? After all, it lives on a continuum with feelings everyone has experienced. From the outside, “Low mood and depression have been difficult to distinguish from each other and from related states such as sadness, grief, demoralization, guilt, and boredom” (Nesse, 2000, p. 14). On the inside, the experience may be entirely different.

“Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self—to the mediating intellect—as to verge close to being beyond description,” wrote the novelist William Styron, describing his own experience with major depression in *Darkness Visible: A Memoir of Madness*. “It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode, although the gloom, ‘the blues’ which people go through occasionally and associate with the general hassle of everyday existence are of such prevalence that they do give many individuals a hint of the illness in its catastrophic form.”

Because all human beings have ample experience of negative feelings, we tend to think of these feelings as part of our “territory,” something we have come to understand. And when we consider the experience of another human being, we tend to perceive and interpret it in light of an experience of our own that we consider similar—an experience that may exist at an altogether different point on the same continuum, or even on a different continuum. After all, depression is to a “bad mood” what diabetes is to a “sugar buzz.”

The fact that depressive disorders share the stage with “normal” moods and mood swings draws the person without these disorders toward a strange place, where the lack of experience with depression meets the fear of slipping down toward it. Unacknowledged, either of these factors can foster stigma, making one regard—and want to regard—the person with depression as “other.” Taken together, their pull toward separation can be far more powerful than any rational response.

“Simplifying” Depression

One purpose of myths, stereotypes, and stigma is to try to simplify that which is complex and troubling and therefore threatening or unsettling. Depression certainly fits that description. It combines intertwining genetic, environmental, experiential, physical, neurological, psychological, and spiritual elements—in its contributing factors, complicating factors, symptoms, and consequences.

So far we lack tests that can determine with scientific accuracy the cause or character of a particular individual’s depression, or the most appropriate medications and levels of medication for that individual. This lack of certainty often complicates the diagnostic and treatment processes, leaving these processes open to challenge and dismissal by people with depression,

family members, employers—even public figures who can gain attention by trying to discredit this branch of medicine.

It is equally challenging to balance differential diagnosis with the recognition of common co-occurring conditions. The diagnostician's science becomes almost an art in the face of the fact that depression can either be mistaken for—or co-exist with and be triggered by—one or more of a number of conditions, including:

- Difficult life transitions
- Grieving
- Post-traumatic effects
- Post-partum effects
- Substance Use Disorders
- Nutritional problems
- Hormonal imbalances
- The symptoms of some immune-related chronic diseases and syndromes
- Organic brain dysfunction caused by physical illness or traumatic injury
- The sense of hopelessness engendered by poverty and discrimination

The progression of depressive illness is in many cases neither orderly nor predictable. An individual's illness might progress along a steady continuum, might be cyclical, or might suddenly branch out and join with other mental disorders. There may also come a point at which depression increases exponentially, to the point where it effects organic neurological changes that make treatment, symptom management, and recovery more difficult.

Questions for Reflection and Discussion

1. What are (or might be) some of the complexities associated with depression in the people you serve?

2. How have you seen or heard people oversimplifying depression in the people you serve?

3. How have you seen or heard people minimizing depression in the people you serve?

Finding Hope

One of the tasks of stigma reduction is the raising of consciousness. But we must be careful that, in raising consciousness, we do not destroy hope. Stigma is already doing that very efficiently.

It is easy to learn of the damage depression can do to human bodies, lives, feelings, and families. The literature is full of this information. It takes more effort to find out about:

- The resources people use to cope with, manage, and compensate for depressive symptoms
- The many talents, skills, values, and personality traits that are **not** compromised by depression
- The many people who have lived moral, ethical, spiritual, kind, and successful lives in spite of debilitating depressive conditions
- The families that have lived in great love and mutual support in spite of this illness
- The variety and success of treatments for depressive disorders
- The evidence that successful treatment can restore the neurological growth processes vital to mood and well-being
- The many options for healing the stigma directed at depression
- The many options for healing the effects of self-stigma
- The growing strength of the concept of recovery among people with mental illness
- The importance of empowerment in healing stigma and promoting recovery
- The resiliency of the human mind, body, and spirit, and its implications for recovery

At times it is not possible to be honest about the most painful phases of depression without using words that sound dramatic, and dramatic words run the risk of depleting hope and contributing to stigma. So we must also find dramatic words to describe the strengths, resources, and resiliencies that people use to survive, overcome, and recover from this disease.

If we are to eliminate stigma, we must know what will remain standing in its place. What is the opposite of stigma? We need a vision, so we will not simply try to heal a negative with a negative. Stigma's opposite is difficult to capture, but its components might include:

- Open-mindedness
- Accurate knowledge
- Understanding
- Compassion
- Unity
- Respect
- Self-esteem
- Empowerment
- Opportunity
- Fairness
- Justice

If stigma focuses on a few problematic features and expands them so that they fill the screen, then its opposite must be a much longer view of the whole human being—complete with strengths, capabilities, and complexities. The opposite of stigma might also include all the rights, privileges, and responsibilities that come from that understanding.

Questions for Reflection and Discussion

1. What effects does a sense of hopelessness have on the people you serve?

2. What effects does a sense of hope have on the people you serve?

3. What have been some of the effects of hope in your life?

Healing the Stigma: This Manual's Approach

The approach in the pages that follow will include five components:

- The words, experiences, and knowledge of people who have suffered from depression
- Basic information about depression, psychological stressors and neurological factors, and treatment and recovery services
- Information about stigma and its effects
- Suggestions for healing the stigma
- Questions for reflection and discussion in workbook format, to elicit your reactions to the first four components

It goes without saying that not everyone who uses this manual will read all the chapters. You may come across a chapter or subsection whose topic area you have known thoroughly for a number of years, and want to skip or gloss over it. Or you might find that a chapter or subsection has far more information than you wanted on that topic. Please do not let that keep you from starting again at the next chapter or subsection. This manual combines two or more very different subject areas, with the understanding that not everyone will want the full course.

Words and Experiences

In the novel, *The Heart Is a Lonely Hunter*, Carson McCullers (who also developed depression later in life) told the story of a young girl named Mick and her attempts to share her love of music with the kindly deaf-mute lodger John Singer. And indeed, trying to understand depression without having experienced it is a little like trying to understand music without having heard it. One can observe the symptoms, read the diagnostic codes, and review the studies that have mapped its course. But anyone lucky enough to pass through life without contracting this condition will always know it from the outside.

Finally, though, Mick learned to describe music in terms of colors and shapes and emotions, and some part of the barrier to Singer's experience of music was dismantled, at least for a moment. It is this "translation" role that the words and stories of people who have lived with depression can play, opening up understanding where none would otherwise exist. In many ways the story—told honestly, with dignity, and without analysis—is the opposite of stigma.

Research shows that the most effective remedy for stigma is contact with members of the stigmatized group who are managing their circumstances effectively. This manual attempts to simulate that experience by offering the stories of three people, followed by questions to elicit your thoughts and feelings about their stories

In addition, the manual begins its chapters with the words of poets and other authors who have suffered from depression. The painting on the front cover (*Backyards in Antwerp, 1885*) is also the work of Vincent van Gogh, whose many challenges in life included serious depression. This painting was chosen because of its somber, barren subject matter, including the high walls between neighbors and the empty windows that gape almost accusingly at the unseen artist. The quilt displayed on the back cover provides a more contemporary view of both the pain of depression and the hope of recovery.

There is great beauty in many of the ways people describe the experience of depression—in poetry, in music, in literature, in visual art, in random sentences spoken to a friend, in the glimpse of the soul that we sometimes see in the eyes of one who knows. There is dignity, symmetry, a sense of depth. It reflects the beauty that is inherent in human beings, the dignity of honest expression, the symmetry of order and chaos, the depth of the human experience. Research cannot capture it, much less explain it. For this kind of understanding, we need to suspend for a moment our words, our thoughts, and our analyses.

Information about Depression, Neurology, and Treatment

Although it cannot compare to direct contact in its impact upon stigma, information is absolutely necessary to counter the myths, unravel the confusion, and replace fear with perspective.

Because many readers will be helping professionals and others who do not specialize in therapy or psychiatric services for people with depression, this manual contains a moderate amount of basic information about:

- Depressive disorders (and mood disorders in general)
- Vulnerability and risk factors
- Depressive episodes
- Neurological factors

- Co-occurring disorders
- Treatment for depression

For the same reason, the manual does not pretend to include anywhere near enough information to prepare the reader to counsel or prescribe medication for people with depressive disorders. It is designed merely to promote understanding. The bibliography provides an ample supply of titles for those who wish to delve deeper into the literature.

Information about Stigma and Depression

Even more important than an understanding of depression is an understanding of stigma, including:

- The scope of the stigma directed at people with depression
- Why people stigmatize in general, and why we stigmatize depression
- Some of the ways in which stigma manifests, including common forms of discrimination
- The effects of stigma—including self-stigma—on people with depression
- The stigma that may exist among some helping professionals, and toward helping professionals who have depressive disorders

It is the intention of this manual **never** to stigmatize people for harboring stigma against depression, or to create an “us-and-them” conversation in which “they” are the bad people who stigmatize and “we” are the good people who do not. Nor is this manual written only by or for the “unscathed” helpers who have never experienced depression.

In this manual, the word “we” is used to include all of us—people who have had depression, people who have never had it, helping professionals, consumers, families, friends, policy makers. We have all been raised with stigma, and—except for a few who have worked very hard for its healing—we can all fall into patterns of stigma or self-stigma.

And—what is most important—we all suffer from the presence of stigma, stereotypes, prejudice, and discrimination in a society that is supposed to be larger, more rational, more compassionate, and more enlightened.

The author has tried to take great care in crafting this manual. However, even the careful study or discussion of stigma carries within it the potential to stigmatize. The very acknowledgment of the harmful psychological effects of stigma can be mistaken as evidence that people in stigmatized groups are passive, helpless victims of the stigmatization process. It is essential to emphasize again and again that each person's experience is different, that there are as many combinations of mitigating factors as there are human beings, and that the strength and resilience of the human spirit will always exist, under whatever degree of weight the stigma places upon them.

Suggestions for Healing Stigma

Like any true human quest, our search for a solution to stigma begins on the inside, works outward, then returns to the human soul. The final chapters include:

- Considerations for identifying and healing our own stigmatizing attitudes and actions

- Ways of choosing roles and strategies for public education and advocacy
- A few examples of anti-stigma campaigns
- Ways of countering self-stigma through resiliency, empowerment, and recovery

One central belief is that there are many ways of healing stigma, many places it must be healed, and many different roles to suit different personalities and levels of commitment. The last two chapters are designed to provide a suggestion of the range of options available, to give readers a little guidance in plotting their course. The list of “Resources for Advocacy and Support” (Page 165) also provides contact information, so no one will have to walk this journey alone.

Questions for Reflection and Discussion

At several points in each chapter, a boxed-in section will ask you to reflect on the material you have read. You will not be asked to remember or repeat any of the information presented, but rather to give as much as you choose of your thoughts, feelings, insights, and ideas.

If we are going to counteract stigma, we must engage the mind and the heart—and something more besides. It is the mind that unravels the myths and replaces them with facts, and the heart that hears the pain and responds to it with love. And it is a higher set of skills that helps us put away our fears, our resentments, our need to make everything simple and understandable.

Only then can we meet our questions, our doubts, our fallibility—our fellow human beings—in an attitude of openness, fairness, and respect.

Questions for Reflection and Discussion

1. Of the elements of the manual listed above, which ones interest you most, and why?

2. What do you think might be your greatest challenge in reading a manual on stigma and depression?

3. What impact would you like this manual to have on you?

Chapter Two: Depression

...and rain it did—the wettest June for more than a century, and the first time since 1909 that Wimbledon was completely rained out for two days in succession. I felt the rain dissolving my skin, rotating my bones, washing me into the gutter. When the sun returned, brutal and unforgiving, I huddled in doorways where moments before others had sheltered themselves from the rain.... And then, as the last of me dissolved, I ceased to exist altogether, a terrifying state of affairs, and one I felt compelled to keep on testing. I would step without warning into the road to see if the cars would stop, pour boiling water over my arms to see if I could feel anything.

Clare Allan, from “Summerscapes: A Midsummer Day’s Nightmare”

As we recognize the human body’s extraordinary capacity to heal and regenerate, so have we seen in some disease agents and processes an extraordinary capacity to turn our own faculties against us. Addiction, for example, is known as “the disease that tells you that you don’t have a disease.” HIV is a virus that uses our own immune cells to reproduce itself and launch attacks against us. And depression whispers to us, through the cognitive and emotional circuits that were designed to help us navigate and preserve life, that there is no hope and we are not worth saving.

“Indeed,” wrote Snyder (2004), “the severely depressed person is swamped with catastrophizing thoughts. Everything seems bad through the lens of depression, as relationships, work, and other life arenas are covered with a shroud of darkness” (Snyder, 2004, p. 347).

How do we begin to describe something so powerful and so puzzling? Perhaps by guessing at its dimensions. The National Institutes of Health (NIH), National Institute of Mental Health (NIMH) describes Major Depressive Disorder as “the leading cause of disability in the U.S. for ages 15-44,” affecting “approximately 14.8 million American adults, or about 6.7 percent of the U.S. population age 18 and older in a given year” (NIMH, 2006, p. 1). In 2001 and 2002, the Centers for Disease Control and Prevention (CDC) estimated the number of ambulatory care visits for depression at 21 million (CDC, 2006).

In a 2003 replication of the National Comorbidity Survey (the NCS-R), 16.2% of people interviewed had suffered from depression at some point in their lives, and 6.6% within a 12-month period. The average length of time for a depressive episode was 16 weeks. The people surveyed described their role impairment during these episodes as “substantial.” Of the people who had experienced depression within the past 12 months, 59.3% said that these episodes had caused “severe” or “very severe” impairment (Kessler et al., 2003).

Of course, impairment is not the end of it. According to the American Psychiatric Association, “Major Depressive Disorder is associated with high mortality. Up to 15% of individuals with severe Major Depressive Disorder die by suicide. Epidemiological evidence also suggests that there is a fourfold increase in death rates in individuals with Major Depressive Disorder who are over age 55 years” (American Psychiatric Association, 2000, p. 371).

On a broader scale, “The World Health Organization reports that depression is the leading global cause of years of life lived with disability and the fourth leading cause of disability-adjusted life years, a measure that takes into account premature mortality” (Neumeister, Young, Stastny, 2004, p. 512).

The numbers are large, the impairment can be significant, and the illness as a whole adds much to the toll of disability, in the United States and around the world. It can also be fatal. The implications for stigma reduction are clear: Depression is real, it is common worldwide, and it does significant harm. If stigma is contributing to its symptoms, keeping people from seeking or receiving help, and further punishing those who have it, then stigma is a serious problem.

Questions for Reflection and Discussion

1. What has been your impression of the experience of depression up to now?

2. How well does the information on prevalence and vulnerability factors in this chapter fit your experience and observation?

With a general sense of the scope of depression, the next step is to seek a grounding in the terms used to describe and classify it.

Depressive Disorders

In the American Psychiatric Association (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (APA, 2000), Depressive Disorders live in the larger category of Mood Disorders. This category begins with Mood Episodes, followed by Depressive Disorders and Bipolar Disorders. For each episode or disorder, the APA provides a wealth of information on

diagnostic features, associated disorders, cultural features, prevalence, course, family patterns, and differential diagnosis. This information is followed by concise diagnostic criteria.

Reading through a list of depressive symptoms is a bit like driving past an accident site, where the tow trucks and ambulances have left and only the broken glass tells of the suffering that has taken place. These lists are full of words like “worthlessness,” “guilt,” “irritability,” “body aches and pains,” “recurrent thoughts of death,” “inability to think,” “distractibility,” “melancholic features,” “psychotic features,” and “suicide.” And any of these symptoms might fill the experience of an individual for an hour, a day, a month, or far longer.

There are enough similarities from person to person to make reliable diagnosis possible, but enough differences to remind us that we are still dealing with an enigma—and with unique individuals whose lives are not defined by their disorders. Nevertheless, the DSM is the sourcebook on what constitutes a depressive disorder, so this is where we start.

In the very brief descriptions that follow, Manic Episodes and Bipolar Disorders have also been included, because of their close and frequent relationship with depressive episodes and disorders. Although the main focus of this manual is on the smaller category of depression, its larger intent is to inspire efforts that will help heal the stigma directed at a wide range of illnesses, including the Bipolar Disorders that so often include depression as their most painful component.

Mood Episodes

Some think of Mood Episodes as the “building blocks” for mood disorders. These include:

- **Major Depressive Episode:** A period of at least two weeks during which there is either depressed mood or loss of interest or pleasure in nearly all activities, accompanied by at least four other symptoms (e.g., changes in appetite or weight, sleep, or psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating, or making decisions; recurrent thoughts of death or suicidal thoughts, ideation, plans, or attempts).
- **Manic Episode:** A period of at least one week (or less, if hospitalization is required) during which there is an abnormally and persistently elevated, expansive, or irritable mood, accompanied by at least three other symptoms (e.g., inflated self-esteem or grandiosity, decreased need for sleep, seemingly compulsive speech, flight of ideas, distractibility, increased involvement in goal-directed activities, psychomotor agitation, excessive involvement in pleasurable activities with a high potential for painful consequences).
- **Mixed Episode:** A period of at least one week in which the criteria for a Manic Episode and a Major Depressive Episode are met nearly every day
- **Hypomanic Episode:** A period of at least four days with symptoms similar to those of a Manic Episode, but not severe enough to cause marked impairment in social or occupational functioning, or to require hospitalization

Depressive Disorders

Depressive Disorders are somewhat simpler to describe once their component episodes have been identified:

- **Major Depressive Disorder** (MDD, also called “Clinical Depression”): A clinical course characterized by Major Depressive Episodes, with no history of Manic, Mixed, or Hypomanic episodes. The DSM also names three subtypes:
 - *Depression With Melancholic Features* (also called “Melancholia”): Characterized by a loss of pleasure in most or all activities (called “anhedonia”), inability to respond to pleasurable stimuli, sadness more pronounced than that of grief or loss, a worsening of symptoms in the morning hours, early morning waking, psychomotor retardation, and excessive weight loss
 - *Depression With Atypical Features*: Characterized by the ability to react to stimuli with pleasure or sadness, significant weight gain or increased appetite, excessive sleep, leaden paralysis, and hypersensitivity to perceived rejection by others (an interesting note: “Atypical” Depression is actually more common than Melancholia)
 - *Depression With Psychotic Features*: Characterized by delusions or (less often) hallucinations that may be consistent with the major themes of the depression
- **Dysthymic Disorder (also called “Dysthymia”)**: A chronically depressed mood, more days than not, for at least two years.

Bipolar Disorders include:

- **Bipolar I Disorder**: A clinical course characterized by the occurrence of one or more Manic Episodes or Mixed Episodes, often combined with one or more Major Depressive Episodes
- **Bipolar II Disorder**: A clinical course characterized by one or more Major Depressive Episodes accompanied by at least one Hypomanic Episode (Bipolar II causes less impairment in functioning than Bipolar I)
- **Cyclothymic Disorder** (also called “Cyclothymia”): A chronic, fluctuating mood disturbance that includes many periods of hypomanic symptoms and many periods of depressive symptoms

Questions for Reflection and Discussion

1. If you were not already familiar with these episodes/disorders and their diagnostic characteristics, what is your “gut” response in reading through them, and why?

Who Contracts Depressive Disorders?

Depressive disorders clearly do not discriminate in terms of age, gender, culture, or socioeconomic status. However, epidemiologists do their best to paint an ever-changing picture that includes prevalence data, risk and vulnerability factors, age of onset, and triggers for depression. The brief descriptions of these that follow offer, not a definitive look at the circumstances in which depression surfaces, but a hint of the diversity that exists among people with depressive disorders.

Demographics

According to the National Epidemiologic Survey of Alcohol and Related Conditions (NESARC), the largest U.S. survey to-date of the co-occurrence of psychiatric disorders, the risk of Major Depressive Disorder is higher among middle-aged people; women; Native Americans; people with low incomes; and people who are separated, divorced, or widowed. Asian Americans, Latinos/Hispanics, and African Americans have lower levels of risk. Of the 43,000 adults surveyed, 5.28% had experienced Major Depressive Disorder (MDD) in the past 12 months, and 13.3% had experienced it at some point in their lives—with the highest lifetime risk among middle-aged adults. The weight of risk among middle-aged adults was a relatively new phenomenon: In the 1980s and 1990s, the highest risk was among the younger adult population (NIAAA, 2005). The DSM, too, had noted a particular increase in MDD among people born between 1940 and 1950 (American Psychiatric Association, 2000).

Other studies have shown that women are twice as likely as men to be diagnosed with depressive disorders (Narrow, 1998) and more likely to inherit a genetic predisposition to major depression (Kendler, Gardner, Neale, & Prescott, 2001). Women's lifetime risk of developing MDD is estimated between 10% and 25%, compared to a 5% to 12% risk for men (American Psychiatric Association, 2000). However, medical and mental health clinicians may also be more likely to diagnose depression in women than in men with similar sets of symptoms (Potts, Burnam, & Wells, 1991). At any given time, an estimated 5% to 9% of women, and 2% to 3% of men, suffer from this disorder.

In terms of age, one study identified the risk of depression as very low through age 14, increasing during adolescence (15-19) and young adulthood (20-24), peaking between 45 and 55 years, and decreasing with increasing age, to a level of zero at age 80 and above. Between ages 9 and 69, women had higher rates of depression than men (Lewinsohn et al., 1986).

In the National Epidemiological Survey cited on the previous page, "About 60 percent of persons with MDD received treatment specifically for the disorder, with mean treatment age at 33.5 years—a lag time of about 3 years between onset and treatment" (NIAAA, 2005, p. 1). As later chapters will explore in greater depth, far too many people who need treatment for depression do not receive it—or wait until the symptoms are farther progressed and more difficult to treat. Many clinicians, researchers, and advocates believe that some of these people choose the pain of untreated depression over the loss of face and freedom that might follow an admission of their need for help.

Genetic Vulnerability

The concept of genetic vulnerability is a double-edged sword for anyone who would seek to reduce stigma. If greater vulnerability to developing an illness can be inherited, then:

- People who would blame others for developing the illness lose some of their credence
- People who want excuses to separate and discriminate against people who are more vulnerable to this illness have another weapon
- People who simply want the truth will continue to seek evidence regardless of its implications for stigma or discrimination

In the case of depression and other mental disorders, it is not the illness, but a greater vulnerability to the illness that can be inherited. The general public does not always make this fine distinction, and so the myths might gain some power. The human tendency to want single, simple answers also makes it more difficult for people to juggle the fact that a number of factors often combine in leading an individual toward one or more of these disorders.

Nevertheless, “Major Depressive Disorder is 1.5-3 times more common among first-degree biological relatives of persons with this disorder than among the general population...A family history of Bipolar Disorder may also be suggestive of subsequent development of Bipolar Disorder” (American Psychiatric Association, 2000, p. 373).

According to Shumake & Gonzalez-Lima (2003), epidemiological data indicate that 40-50% of the risk for depression is based on genetic factors, but that the genes have not been identified. The genes that increase vulnerability to depression are also believed to be many and varied, reducing the impact of any single gene. Certain personality traits (e.g., “neuroticism,” a tendency to feel negative emotions) can also increase an individual’s vulnerability and even predict some aspects of the onset and course of the illness, though even these personality traits may share some genetic factors with depressive disorders (Shumake & Gonzalez-Lima, 2003).

Neumeister and colleagues suggested that “...virtually all neuropsychiatric disorders, in particular mood and anxiety disorders, are genetically complex and that they are basically a result of the combination of environmental factors and multiple genes and gene variants that may modify the risk of an individual to develop depression” (Neumeister, Young, Stastny, 2004, p. 513).

Many of the studies of genetic vulnerability have focused on the passing of vulnerability from parent to child. But the effects of a parent’s depression on a child’s vulnerability to depression may also depend on whether or not a grandparent also suffered from this illness. Weissman et al. (2005) conducted a 20-year multi-generational study of children of parents with Major Depressive Disorder. They found that in children with two previous generations of depression in the family (i.e., a parent and a grandparent):

- Children with two previous generations of depression were more likely to develop the disease than children with only one previous generation of depression.
- The child’s depression was likely to be more severe if the parent’s depression was more severe.
- If children with two previous generations of depression did develop depression or other mental disorders, anxiety disorders often appeared first.

Genetic vulnerability may also combine with other factors in affecting the long-term success of recovery. People with familial risk factors, and people with early first onset of depression, may also be at great risk of recurrence of Major Depressive Disorder after remission (Keller, 2003). Here again, clinicians, consumers, and advocates must remember that information about vulnerability exists to help us understand these conditions and shore up the recovery process, rather than to predict an individual's chance of success.

Vulnerability in Human Experience

The concept of resiliency—the ability of human beings to “bounce back” and rise above their circumstances—is a source of great hope and wonder. It helps us understand the fact that so many people have survived and succeeded in spite of adversity, yet it always remains a little mysterious. Far less mysterious is the fact that some painful life experiences and circumstances can raise our vulnerability to illness and social challenges.

But when we speak of vulnerability, we must always remember resiliency. The fact that people develop depressive disorders does not mean the same people are not also strong and resilient in many ways. This resilience may have contributed to their survival of these disorders, and it may tip the scales toward lasting recovery.

It is equally important to remember that not all people who suffer from depressive disorders have a history of any of the vulnerability factors discussed in this chapter. Some people simply contract the disease, and to insist that their illness must be linked to genetic vulnerability or “bad experiences” might seem stigmatizing, or even insulting.

Among the many experiences and circumstances that can leave people more vulnerable to depression, three in particular stand out:

- Abuse and trauma
- Poverty
- Racial prejudice and discrimination

Abuse and Trauma

Along with the obvious psychological effects of exposure to abuse and other traumatic circumstances, there are also a number of physical effects that take an equal, if not greater, toll on the body's defenses. As later chapters (“The Brain” and “When Depression is Not Alone”) will show, the experience of stress can set in motion a number of processes that can affect the brain chemicals that regulate moods. Often it is not only the pain and fear generated by traumagenic circumstances (e.g., experience of and/or exposure to violence, threat, or extreme stress) that creates trauma, but also the fact that the pain and fear are not adequately validated, comforted, and resolved after the crisis subsides. The extreme and/or prolonged levels of stress that people experience in traumatic situations can have profound effects, raising their vulnerability to a variety of mental and physical disorders.

According to Hill (2003), the research has made it clear that a childhood history of sexual abuse, parental neglect, or a parent's antipathy toward the child can raise the risk of depression. Studies on physical abuse, and of the interactions of abuse with genetic factors, are less

prevalent, or less clear (Hill, 2003). And “The data strongly suggest that greater severity, frequency, and duration of abuse results in an increased likelihood of subsequently developing depression” (Weiss, Longhurst, & Mazure, 1999, p. 820).

One study of inpatients with alcohol dependence disorder found that men who had experienced both physical and sexual abuse as children had higher rates of major depression, while women who had suffered both forms of abuse had higher rates of anxiety. People with a history of dual abuse also reported higher lifetime numbers of suicide attempts, compared to those who had experienced only physical abuse (Windle, Windle, Scheidt, & Miller, 1995). In another study, men who had been the recipients of unwanted sexual contacts reported more depressive symptoms than men who had not (Larimer et al., 1999).

The implications of this information for stigma reduction are complicated by the fact that people are often stigmatized for being the victims of childhood abuse, partner abuse, or sexual assault. It is sometimes difficult to untangle the symptoms, external stigma, and self-stigma that follow these experiences from the many similar effects surrounding depression.

Poverty

One of the most vulnerable targets of stigma is the population living in poverty. Powerlessness tends to magnify stigma, and poverty breeds powerlessness. The psychological effects of poverty should also never be underestimated. It takes enormous resilience to generate or maintain hope in the midst of hunger, overcrowding, lack of opportunity, lack of proper medical care, violence in the community, and barren or dilapidated neighborhoods.

Turner and Lloyd (1999) found that subjects with lower socioeconomic status tend to have greater stress and access to fewer resources for coping, and pointed out the likely correlation between these patterns and the increased level of depressive symptoms and disorders among people with fewer economic resources.

“Results from the STAR-D project, one of the nation's largest studies of depression, show that chronic depressive episodes are common and are associated with poorer physical health, lower quality of life, socioeconomic disadvantage and minority status” (Crown, 2006, p. 1). Investigators in that study found that “21 percent of the study participants were experiencing chronic major depressive episodes on enrollment in the study” and that “Chronic episodes were associated with older age, less education, lower income, no private insurance, underemployment, larger number of general medical illnesses, lower physical quality of life, concurrent generalized anxiety disorder, fewer prior episodes of major depression and history of suicide attempts.... African Americans, Hispanics and patients receiving care in primary as opposed to psychiatric care settings experienced more chronicity” (Crown, 2006, p. 1).

In any given year, an estimated 12% to 36% of women on public assistance suffer from Major Depressive Disorder (compared to between 4% and 10% of the general population), with high levels of depressive symptoms in 25% to 57% of study samples (Lennon, Blome, & English, 2001). And all of these figures become more concerning if we consider the possibility that many people living in poverty might not seek help for depressive disorders, considering their symptoms normal and necessary responses to their circumstances.

What of the effects on children? Slack and Yoo (2005) assert that the link between food hardship and child “behavior problems” may have two mechanisms, the first due to physiological

responses to hunger (e.g., anxiety, irritability, lethargy), and the second to parental characteristics that poverty tends to exacerbate. They cite a number of studies that associate:

- Low income and food insufficiency with increased levels of depression and other mental disorders
- Higher levels of parental stress and maternal depression with harsher, inconsistent, and less responsive parenting

One lesson for stigma-reduction advocates: In our desire to show society that depression affects many highly successful and well educated people, it is essential not to forget the value and viability of people with fewer advantages who suffer from this illness—or the critical importance of making services available to all who need them.

Racial Prejudice and Discrimination

As noted in Chapter One, stereotypes, prejudice, and discrimination are key components of stigma. So the effects of racial prejudice and discrimination can render people particularly vulnerable, both to depression and to further stigmatization because of depressive disorders.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), several studies have linked the experience of discrimination to symptoms of depression in many members of minority cultures in the United States. SAMHSA (1999) cites a number of reasons for this connection:

- Internalized racial stereotypes and images can damage people's sense of self-worth.
- Racial discrimination can contribute to poverty, violence, lack of health care, and other living conditions that raise stress and affect mental health.
- The stress of discrimination itself can add significantly to people's psychological burdens.

Racist incidents (defined as cognitive/affective assaults on one's ethnic self-identification) are common in the lives of many people in ethnic minorities. According to Bryant-Davis & Ocampo (2005), these incidents can:

- Generate trauma and post-traumatic symptoms
- Serve as an ongoing source of stress
- Lead to survivor's guilt
- Increase the risk of physical and psychiatric symptoms, including depression

Effects of these incidents in many ways parallel those of rape and domestic violence (Bryant-Davis & Ocampo, 2005).

Hammack (2003) identifies the experience of oppression as a key catalyst in the development of depression among African-American youth. Hammack suggests a unified theory that synthesizes a number of theoretical perspectives, including socioecologic, cognitive, family stress, and biopsychosocial theories. The first of these perspectives, the socioecologic, emphasizes the importance of racism, discrimination, economic oppression, and powerlessness as threats to psychological well-being.

If racial stigma increases vulnerability to depression, which in turn increases vulnerability to still more stigma, then the dominoes are arranged in a downward spiral. There is only the hope that

the efforts to reduce stigma, stereotypes, prejudice, and discrimination in each area will inform and help sustain similar efforts in the others. At heart, the will to reduce stigma is the will to learn how to accept and respect all people.

Questions for Reflection and Discussion

1. How well does the information on demographics and cultural and experiential vulnerability factors fit your experience and observation?

2. How would you balance the need to be able to discuss vulnerability factors with the need to avoid “labeling” people as having high risk for depression?

The Onset of Depression

Another important step toward understanding depression is to look at when and how depressive disorders and their episodes arise in people's lives. Research provides a number of clues about the ages at which these symptoms begin and the experiences that seem to trigger them. Like the information about prevalence and vulnerability, data concerning the onset of depressive disorders seem to form a sort of patchwork picture.

Age of Onset

According to the American Psychiatric Association, the age of onset for depression is decreasing for those born more recently. Atypical Depression is also more common in younger adults, and Melancholic Depression is more common in older adults (American Psychiatric Association, 2000). In one large community-based sample of people with Major Depressive Disorders, researchers found that one fourth reported onset during childhood or adolescence, and half reported onset by age 25. Women were more likely to have earlier age of onset, and non-Latino/Hispanic whites and Mexican-Americans born in the United States had earlier ages of onset than Mexican-American immigrants. Age of onset did not appear to affect the probability of recurrence or the number, type, or severity of symptoms during the worst episodes (Sorenson, Rutter, & Aneshensel, 1991).

On the other hand, the National Epidemiologic Survey of Alcohol and Related Conditions (NESARC) identified 30 as the average age of onset for depression. This study also suggested that the risk of onset increases sharply between ages 12 and 16, then rises more gradually until it begins to decline in the early 40s (NIAAA, 2005, p. 1).

In their study, Galambos and colleagues found that depression rates among boys and girls were similar until age 11. Gender differences in prevalence of depression began to emerge in early adolescence (ages 13-15) and continued to increase into late adolescence (ages 16-19). By ages 14-16, girls showed rates of depressive symptoms twice as high as those of boys (Galambos, Leadbeater, & Barker, 2004).

Of course, a number of experiences can affect age of onset. In one study almost three-fourths (73%) of homeless youth with depression reported experiencing their first episodes of depression before they left home. Rates of current depression in the homeless youth studied were 12.2% for MDD, 6.5% for dysthymia, and 17.6% for depression (Rhode et al., 2001).

One clear implication for stigma-reduction efforts is the need to reach out to children and adolescents with messages that will help “normalize” the experience of depression and the need for help. Especially during the teenage years, many children have such an intense paradoxical need to combine independence with “fitting in” that they can be ashamed of almost anything—up to and including the fact that they have parents.

Children can also be vicious in their playful or aggressive attacks on anyone who seems different, and many lack the restraint that would keep them away from highly stigmatizing terms (e.g., “nut job,” “wacko,” “basket case”). When the stigmatization process meets the bullying that is so common among children of all ages, the results can have severe effects on self-stigma, isolation, and depressive symptoms.

People whose depression begins in older adult years sometimes have neurological changes (called “white matter hyperintensities”) associated with cerebrovascular disease (damage to the blood vessels in the brain resulting in stroke). Older adults with this “vascular depression” tend to have higher levels of impairment and lower levels of response to standard therapies (American Psychiatric Association, 2000).

Triggers for Depression

Sometimes major depression is clearly triggered by stressful life events, and sometimes it is considered “autonomous” or “endogenous”—starting with no external provocation. However, cautioned Carol Goldbaum in an interview for this manual, “Even when depression is endogenous or biologically based, there are usually triggers, and people should not assume they know what the triggers are.”

“Episodes of Major Depressive Disorder often follow a severe psychological stressor, such as the death of a loved one or divorce. Studies show that psychosocial events (stressors) may play a more significant role in the precipitation of the first or second episode of Major Depressive Disorder and may play less of a role in the onset of subsequent episodes” (American Psychiatric Association, p. 373).

The “kindling hypothesis” holds that early depressive episodes are more likely to be triggered by stressful life events, but that the chemical effects of the early episodes increase people’s

neurological vulnerability to future episodes that may have no triggers (Post, 1992). And Kendler and colleagues (2001) found that people at higher genetic risk of depression are more likely to have autonomous early episodes of depression, even without external stress factors or the vulnerabilities left by previous episodes (Keller, Thornton, & Gardner, 2001).

The life experiences that trigger depressive episodes also seem to differ between the genders. Men who are widowed are more likely to develop depression than women who are widowed (Lee, Willetts, & Seccombe, 1998), and women are less likely to develop depression if they have strong social support networks (Kendler, Myers, & Prescott, 2005). In a study of stressful life events that may have triggered depressive episodes, women tended to report more interpersonal stress, and men to report more legal and work-related stress (Kendler, Thornton, & Prescott, 2001).

Giving birth can also be a trigger for a variety of MDD called Major Depressive Disorder with Post-Partum Onset, beginning within four weeks after the baby's birth. Not to be confused with the milder, more transitory "baby blues" that up to 70% of women experience in the first ten days after giving birth, post-partum depression is often characterized by common depressive symptoms, plus other symptoms that might include severe anxiety or panic attacks, lack of interest in the baby, fear of being alone with the child, or a tendency to pay intrusive attention that interrupts the child's sleep patterns (American Psychiatric Association, 2000).

Trauma and tragedy are common triggers for depressive episodes. In a telephone survey of 1,008 Manhattan residents after the September 11, 2001 tragedy, researchers at the New York Academy of Medicine found that 7.5% reported symptoms of Posttraumatic Stress Disorder and 9.7% reported symptoms of depression, rates that were two or three times higher than those reported in a national mental health survey in the early 1990s (National Institute on Drug Abuse, 2002).

The significant life changes that people undergo during immigration processes can also trigger depression. Kim and colleagues found that the experience of immigration profoundly affects "living conditions, occupation, SES [socio-economic status], language use, family structure and function, social networks, and political attitudes," thus increasing the risk of depression and other disorders. However, in their sample of Korean immigrants, "...the negative effect of life stress on depression was buffered by higher levels of sense of mastery and social support" (Kim et al., 2005, p. 217).

Even seasonal changes can trigger depressive episodes. Researchers have identified seasonal patterns of depression (sometimes called Seasonal Affective Disorder), usually (in the Northern Hemisphere) beginning in the Fall or Winter and ending in the Spring. In these cases depression is often characterized by a lack of energy, hypersomnia, craving for carbohydrates, overeating, and weight gain (American Psychiatric Association, 2000). This may hearken back to some ancient ancestors' need to hibernate during the colder Winter months.

And finally, as this manual has emphasized before and will emphasize again, stigma itself can be a significant trigger for depressive episodes and symptoms. Mickelson (2001) found that perceived stigma, even directed at other circumstances (e.g., having a special-needs child), was related to a strong increase in symptoms of depression.

The Timing and Termination of Depressive Episodes

Sometimes people experience anxiety and mild depression for a few weeks or months before the onset of a full Major Depressive Episode, and sometimes the episodes appear without these warnings. An episode might develop in a few days or a few weeks. Untreated, a depressive episode usually lasts at least four months, but episodes have been known to last up to two years (after which the depressive disorder is considered “chronic”) (American Psychiatric Association, 2000).

Keller (2003) cited the following definitions of outcome levels after treatment of a depressive episode:

- Response: Some relief, but more than minimal symptoms remain.
- Remission: No longer meeting diagnostic criteria, with minimal symptoms or an absence of symptoms.
- Relapse: Return to full symptoms during response or remission.
- Recovery: Extended remission, marking the end of a depressive episode.
- Recurrence: A new episode that begins during a period of recovery.

About two thirds of people with Major Depressive Episodes reach complete remission and return to full functioning. The rest experience partial remission, with some depressive symptoms remaining months or years after the episode and causing some disability and distress. People who have partial remission after one episode are more likely to have partial remission after future episodes (American Psychiatric Association, 2000).

Some people’s episodes are separated by many years with no symptoms, some experience clusters of episodes, and some have more frequent episodes as they grow older. Someone who has experienced one depressive episode has a 60% chance of having another. That risk rises to 70% after the second episode, and to 90% after the third. Between 5% and 10% of people with Major Depressive Disorder eventually develop Manic Episodes and are diagnosed with Bipolar Disorder (American Psychiatric Association, 2000).

Questions for Reflection and Discussion

1. What kinds of events or circumstances have seemed to trigger depression in your own life or the lives of others you have known?

2. What conclusions would you draw from the data on remission and recurrence?

When Depression Proves Fatal

Now it is time to address the most highly stigmatized aspect of depression, the taking of one's own life. Suicide is still considered a crime. Until recently, few people thought twice about saying that someone had "committed" suicide. Many people who have survived attempts at suicide have been punished by the law; discriminated against (Bazelon Center for Mental Health Law, 1999, 2006a-c); and/or targeted with the anger and mistrust of family, friends, and colleagues.

Many people who have succeeded in suicide have been judged and criticized posthumously for "giving up" or deserting their loved ones—with most of that criticism coming from people who have never experienced anything close to the psychological anguish that led to their decisions.

"The common purpose of suicide is to seek a solution. The common stimulus in suicide is intolerable psychological pain. The common emotion in suicide is hopelessness. The common cognitive state in suicide is constriction" (Schneidman, 1970, quoted in Klott, 2005, p. 5). Clinicians sometimes speak of the "Amazing Reversal," an abrupt, rapid transformation that may take place about four to six days before suicide. In that period people often experience senses of calm, peace, and tranquility (Klott, 2005). They have found what they believe is the best or the only solution.

Suicide ranks 11th among causes of death in the United States, ending 30,000 lives each year (Solomon, 2006). In 2002 there were 31,655 suicide deaths in the United States, 11 for every 100,000 people (CDC, 2004). In 1998, suicide was the eighth leading cause of death in the United States (1.3%) and the third leading cause of death among 15-24 year olds (13.3%). At that point suicide had risen more than 300% since the late 1960s.

In the National Epidemiologic Survey (NESARC), "Of all persons who experienced MDD, nearly one-half wanted to die, one-third considered suicide, and 8.8 percent reported a suicide attempt" (NIAAA, 2005, p. 1). Between 10% and 15% of people with Bipolar II disorder complete suicide, usually during Major Depressive Episodes (American Psychiatric Association, 2000).

Populations at particularly high risk for suicide include older adults, college students, incarcerated men, law enforcement officers, military personnel, physicians, and people with Substance Use Disorders (Klott, 2005).

Suicide presents perhaps the greatest challenge for those who would heal the stigma of depression and its symptoms. How do we effectively discourage and even prevent suicide without contributing to the stigma, the discrimination against those who have attempted it, or the cloud that often hangs over the loved ones of those who have succeeded? How do we honor the pain, loss, and sense of betrayal of those left behind, without diminishing the agony of those who chose to leave or denying the fact that they believed their choices were necessary? Perhaps the answer to each of these questions is a personal one, and our first task is simply to ask and be open to the answers. (Note: The list of "Resources for Advocacy and Support," Page 165, lists organizations and web sites that can provide full information on warning signs, recommended courses of actions, prevention programs, hotlines, and support groups for survivors.)

Questions for Reflection and Discussion

1. What are your personal thoughts, feelings, and/or beliefs about suicide?

2. How would you begin to balance the desire to discourage suicide with the desire not to contribute to stigma?

Next Steps

So far this manual's journey has remained on the surface, studying the signs, symptoms, and incidence of these troubling disorders. The next chapter will dip below the surface, with a look at:

- Some of the chemicals and brain structures that are involved in the regulation of mood
- Some of the ways in which these elements sometimes change in the presence of depressive disorders
- A few implications for stigma-reduction efforts

Jennifer's Story

When Jennifer was a child, the world was a dangerous place. People were wolves in disguise, and objects were spiders in hiding. Her parents were Holocaust survivors, haunted by their own memories. They taught her not to trust anyone and told her they had survived the war so that their children could make a difference in the world. She felt the pressure intensely.

Jennifer's first depressive episode descended when she was five years old, triggered by a humiliating visit to her mother by her kindergarten teacher.

Her second episode took place at age six or seven, following an emotionally charged family conflict. She remembers crawling into a hole in the house and staying there for a long time, wishing herself dead. Finally, her father—a psychoanalyst—found her and shouted, “If you don't snap out of it, I'm going to put you in the hospital! You're acting crazy!”

After that, Jennifer learned the secret: Act normal. Act normal, so no one would know she was depressed long after these incidents. Stop crying, snap out of it—whatever it took to appease her family.

No one outside her home knew about the illness that Jennifer and her family considered her shameful secret. She spoke to no one about it. At age 20 she married a man who was in many ways like her parents, in a desperate attempt to escape her home. It soon became apparent that the marriage was a disaster, but she believed in marriage “‘til death do us part.”

“Okay,” she said to herself. “Then it's death.”

At age 20 Jennifer made her first unsuccessful attempt at suicide. But she fell asleep, and her husband caught on to her plan and intervened. He threatened to hospitalize her, but at the last minute, her best friend took her in for the weekend. Something about the way her friend supported her that weekend—and the fact that someone outside her family could learn that she had a serious problem and still remain her friend—brought Jennifer out of her crisis. Even so, she remained depressed for the five years of her marriage.

In graduate school for social work, Jennifer had a serious depressive episode that kept her from concentrating on her work, so she decided to drop out. She despaired of ever being able to help people with mental illnesses, given the severity of her own illness. She made an appointment with her Dean to discuss her decision, but his response surprised her. The Dean said he had checked with her professors, who had said she was doing well, and so he refused to accept her resignation. That was the first time she realized she might not be perceiving herself or her worth accurately. The Dean's affirmation kept her from diving farther down into the depression.

In the years that followed, Jennifer continued to keep her depression a secret from her friends, colleagues, and community members, afraid of risking the stigma and shame. During the years in which she worked as a psychotherapist, she perceived that her experience with depression enhanced her ability to connect with the people she served, particularly those with suicidal tendencies. Still, she made no attempts to disclose her history to anyone.

Over the years, Jennifer has found moderate success with antidepressant medication. From time to time her medication stops working, and her doctor has to raise her medication levels or prescribe a new medication. However, she fears that the day might come when neither of these measures works.

Now in her 50s, Jennifer has been growing increasingly aware of negative patterns of perception, thought, and emotional reaction that might be mixing with her depression to make her life more difficult. Looking back on a recent business venture, she has identified ways in which she was defensive, hypervigilant, and far too ready to perceive the negative—whether or not it was there. At the time she feared, not that her colleagues would see her behavior as negative or inappropriate, but that they would realize she had a depressive disorder.

Recently Jennifer has been catching up on her reading about the neurology of depression. She has found her negative imagination drawn to dire predictions that fail to mention the role that successful treatment can play in halting or reversing the neurological damage in depression. For Jennifer, the world is still in some ways a dangerous place.

But she has come to see her depression as a thought disorder that can be corrected only by controlling her negative thinking—one minute at a time. Her recent reading of Martin Seligman's *Learned Optimism* has given her hope that she can influence and modify her thinking patterns. She also recently discovered new evidence of hope in other areas of biology—evidence that human cells can change their DNA based on their environment, and that people can change their lives by changing their belief systems. Jennifer and her sister have made a pact with one another to explore this concept and its implications for their own lives.

Jennifer is preparing to enter the next phase of her treatment and recovery, one in which she has a choice in her beliefs, her reactions, and her experience. She is beginning to believe that she might be able to choose hope, and that hope might turn out to be real.

Responses to Jennifer's story

1. What were some thoughts that went through your mind when you were reading Jennifer's story?

2. What were some feelings you had when you were reading Jennifer's story?

3. What could her parents or her husband have done that might have been more helpful than the responses they chose?

4. If you were Jennifer, how much would you have disclosed of your history of depression, and why?

5. How much have negative patterns of perception, thought, or emotional reaction played a part in your own responses to life situations? What have been some of the consequences?

6. To what degree do you believe we can change our lives by changing our belief systems? How do you think that happens?

7. If you could ask Jennifer anything right now, what would it be?

8. If you could tell Jennifer anything right now, what would it be?

Chapter Three: The Brain

In a strange way, though, after reading through a long series of studies, I ended up more reassured and less frightened. The very fact that science was moving so quickly had a way of generating hope, and, if the changes in the brain structure did turn out to be meaningful, I was glad that first-class researchers were studying them. Without science, there would be no such hope. No hope at all.

Kay Redfield Jamison, from *An Unquiet Mind: A Memoir of Moods and Madness*

Many people who do not have depressive disorders learn to cope with unpleasant moods through knowledge, insight, self-awareness, and humor. But people with great knowledge, deep insight, rigorous self-awareness, and wonderful senses of humor have succumbed to—and even died of—depressive disorders. So at what point does the neurology overwhelm these capacities?

Affective neuroscience is helping us understand the brain circuitry behind depressive disorders, look at these disorders more objectively, and see more clearly the relationship between ordinary moods and disorders of mood. It is clear, though, that some of us suffer from impairment in the way our brains regulate emotion or recover from stress and negative feelings, and some have a hard time responding to positive experiences (Davidson, Pizzagalli, Nitschke, & Putnam, 2002). It is the task of researchers to find out why, and the task of advocates and helping professionals to fit these findings into the larger context of the human life.

Several factors, including the following, make the study of neurology particularly challenging:

- A number of structures and processes in the brain seem to be involved in different mood disorders. Two people with very similar sets of symptoms may have very different things going on under the surface.
- Researchers often do not know whether the conditions they observe in the brain are causes or effects of the human experiences that people describe or display.
- The results cited in research studies represent percentages of their sample groups' experience, rather than absolute knowledge about what happens in the brain. For every 60% that responds in one way, there is always the remaining 40% that responds differently.
- Some research data come from the study of animal brains, which share a number of features with human brains but (obviously) lack some of our sophistication and our ability to articulate what we think and feel.

The study of the brain in depression is a region in which we must tread softly. Here is the power to heal or to hurt, to unravel the myths behind stigma or to create new and more rigid myths. A true understanding of the neurology behind depression can generate wonder, compassion, fascination, and still more questions. But a little knowledge in this area can look like evidence that people with these disorders are “defective” in the brain, or provide an excuse to give up on human lives and relationships. So how do we go straight to understanding without stopping at informed ignorance?

The truth is, of course, that all human brains are defective, and each one is extraordinary. The fact that anything works at all is a miracle, and the consequences of even a small imbalance can be agonizing. In many ways the brain is outdated, antiquated—for example, still signaling powerful, primitive “fight-or-flight” responses when we are upset with our loved ones’ behavior or caught in traffic on our way to an important meeting.

Some researchers have suggested that negative moods and depression might have been meant for a number of practical, adaptive purposes, such as “communicating a need for help, signaling yielding in a hierarchy conflict, fostering disengagement from commitment to unreachable goals, and regulating patterns of investment” (Nesse, 2000, p. 14), or reducing women’s levels of activity at key times to protect their offspring (Niculescu, 2001). Unfortunately, we have not found a way to tell our brain circuitry that we now have other means of reaching those goals.

So we begin with the understanding that our collective knowledge of the neurology of depression is incomplete, and that the brains we use to process that knowledge are fallible.

That said, the following is a general and much-simplified description of some of the major chemicals and brain structures thought to be involved in depression and the relief of its symptoms. As you read this information, please be assured that you will not be asked to remember any of it at the end of the chapter. This is also by no means an exhaustive list or a complete explanation of any of its components. The subject is far too complex to be captured within the scope of this manual. But the following may provide some evidence against the claim that people with depressive disorders can simply “snap out of it” or “pull themselves up by their bootstraps.”

Questions for Reflection and Discussion

1. What is usually your reaction when you read about brain chemistry? Are you:

- ☐ Interested?
- ☐ Skeptical?
- ☐ Confused?
- ☐ Apprehensive?
- ☐ Sleepy?

Why? _____

Chemical Messengers

Mayberg (2006) described depression as “a systems-level disorder affecting select cortical, subcortical, and limbic regions and their related neurotransmitter and molecule mediators” (Mayberg, 2006, p. 261). In other words, depression involves many structures, chemicals, and processes in the **cerebral cortex** (the “higher-order thinking” part of the brain), the diverse **subcortical** area beneath the cortex, and the more primitive emotion-processing **limbic system**.

Neurotransmitters and other chemicals travel through the brain by being passed from cell to cell, each time released by one cell and eventually pulled into the next cell by **receptors** that are matched to specific chemicals. Much of the work that these chemicals do takes place during the time between their release from one cell and their **reuptake** by the next (or their breakdown by other chemicals designed to eliminate them). Generally, the more time a chemical spends in the **synapse**, the space between brain cells, the greater its effect.

Since the neurotransmitters play an important role in discussion of the brain structures at work, it is helpful to look at these chemicals first. Scientists are still uncertain about the links between specific chemicals and specific symptoms of depression. However, they have identified several key chemicals called **monoamine neurotransmitters** that are involved in regulating mood, including the following

- **Serotonin** (often called 5-hydroxytryptamine, or 5-HT), travels throughout the central nervous system, playing an essential role in regulating moods and a number of other bodily functions (e.g., body temperature, sleep, sexuality, appetite). Many people with depression have fewer 5-HT transporters or receptor sites, or have problems with existing sites that may reduce their ability to release serotonin (Neumeister, Young, & Stastny, 2004).
- **Dopamine** (DA) is a key neurotransmitter in the brain’s reward system. It is activated by rewarding experiences (e.g., food, water, sex, certain drugs, rewarding activities)—and by the anticipation of these experiences—and it generates feelings of pleasure. People with depression have lower levels of some of the chemical building blocks or “precursors” of dopamine (e.g., tyrosine), possibly decreasing their levels of dopamine and increasing their feelings of helplessness (Shumake & Gonzalez-Lima). People with Bipolar Disorder may have higher levels of dopamine during manic phases. Dopamine is also a “precursor” to norepinephrine (a participant in the chemical process that creates it).
- **Norepinephrine** (also called “noradrenaline”) is both a neurotransmitter and a stress hormone. It activates the brain’s “fight or flight” functions while adrenaline activates similar functions throughout the body. Since norepinephrine levels are below normal in some depressed people, medications that boost the amount of this chemical may act as mood elevators.

Both serotonin and norepinephrine/dopamine appear to play a role in relieving the symptoms of mood disorders, but it is not clear if there are actually two separate types of depression that spring from problems in the production or use of these distinct chemicals, or if these chemicals simply tend to relieve symptoms of the same disorders (Bremner et al., 2003). In fact, science has found that changing the level of one neurotransmitter tends to change the amounts of other, seemingly unrelated brain chemicals. So depression may be related to irregularities in the levels of multiple neurotransmitters. For example, problems with the regulation of two more

neurotransmitters (acetylcholine and gamma-aminobutyric acid or GABA) are also associated with depression (American Psychiatric Association, 2000).

Corticosteroids are hormones that play a large part in our responses to stress. One of these, **cortisol**, is mentioned often in discussions of depression. Cortisol (the same composition as the medicine Hydrocortisone) lowers immune functioning, raises blood pressure and blood sugar levels, and promotes weight gain. Some studies have associated higher levels of cortisol with depression. Higher levels of serotonin tend to reduce the amount of cortisol in the brain, and dopamine and norepinephrine tend to increase it. Dysregulation in corticotropin-releasing hormone (CRH), a stress hormone and neurotransmitter involved in the release of cortisol in response to stress, has also been associated with depression (American Psychiatric Association, 2000).

Cytokines are messenger molecules produced in immune cells, and some researchers believe that they may play a role in various processes involved in depression. Some of these chemicals (called “proinflammatory cytokines”) stimulate immune responses (inflammation), and others (anti-inflammatory cytokines) dampen immune responses. Some of the chemical changes that take place in depression seem to trigger the release of more proinflammatory cytokines. In turn, cytokines can affect the transmission of serotonin, norepinephrine, and dopamine in different regions of the brain. Higher levels of proinflammatory cytokines may in some cases lead to excessive levels of cortisol and chronic reductions in serotonin transmission (Schiepers, Wichers, & Maes, 2004). This might contribute to depressed mood, and to the aches and pains sometimes associated with depression.

Questions for Reflection and Discussion

1. When you read about the chemicals described above, and the effects of their release and processing in the brain, what connections did you begin to make with the moods, emotions, thought patterns, and actions of the people you serve?

2. If you had to guess which chemicals play the biggest part in the challenges and well being of the people you serve, which ones would you guess, and why?

3. If you had to guess which chemicals play the biggest part in your own challenges and well being, which ones would you guess, and why?

Brain Structures

Several key regions of the brain also seem to provide clues to the mechanisms at work in regulating mood. Four brain structures in particular (the **prefrontal cortex** and the **anterior cingulate cortex** in the cerebral cortex, and the **hippocampus** and the **amygdala** in the limbic system) and one communication system (the **hypothalamic pituitary-adrenocortical axis**) are mentioned often in the literature on depression. There are a number of relationships among these structures and communication pathways.

There is also something of a central theme: In general, increased left-sided activity is associated with positive mood, and increased right-sided activity is associated with negative mood. This theme is interesting, given the tendency of some linear reasoning functions to center in the left hemisphere of the brain and the tendency of some more holistic and aesthetic functions to center in the right hemisphere—tendencies that are nowhere near as simple, pronounced, or universal as “pop psychology” would have us believe.

The following is a very basic introduction to some of the major structures and their possible association with depression. Because their locations in the brain may have implications for treatment, the locations of these structures (in the cerebral cortex, in the limbic system, or in the subcortical area) are also mentioned below.

The Prefrontal Cortex (PFC)

The prefrontal cortex (PFC) is the part of the cerebral cortex responsible for our goals and the ways in which we choose to pursue them. The PFC has several key areas, with differences between the left and right sides of these areas. In general, the left side of the PFC is designed to help us pursue our goals. Increased activity there is associated with positive moods, response to rewards, and more rapid recovery from negative or stressful experiences. The right side is designed to help us regulate our behavior. Increased activity there is associated with negative moods, response to punishment, and longer processing of negative or stressful experiences (Davidson, 2001; Davidson, Pizzagalli, Nitschke, & Putnam, 2002).

According to Davidson, Pizzagalli, Nitschke, & Putnam (2002), researchers have found that:

- Different people have different resting levels of activation in the left and right PFC, and these seem to be associated with differences in emotional reactions and general sense of well being.
- People with some forms of depression may have greater activity in the area of the prefrontal cortex that responds to punishment (the **right lateral orbitofrontal cortex**), and less activity in the area that responds to the possibility of reward (the **left medial orbitofrontal cortex**).
- Some people with Major Depressive Disorder (MDD) show lower levels of activity in several areas of the PFC, and activation in at least one of these areas (the **dorsolateral PFC**) increases during successful treatment with antidepressants.
- In some people with MDD who also have a family history of this disorder, some areas of the **frontal lobe** (the larger area that includes the PFC) are a little smaller than the same areas in people (including people with depression) who have no family history of MDD.

- In one study, people (particularly women) who showed higher levels of activity in regions on the right side of the prefrontal cortex also showed less positive responses to treatment with selective serotonin reuptake inhibitor (SSRI) antidepressant medication.
- People with lower levels of left prefrontal activity also showed lower levels of activity in a lymphocyte involved in immune responses (NK, or **natural killer cells**), even under stress, and produced fewer antibodies when they were given a vaccine (Davidson, 2004).
- Animals with greater right-sided prefrontal activity had higher levels of the stress chemical cortisol—a chemical sometimes associated with depressive symptoms—than did their counterparts with greater left-sided prefrontal activity.

Older adults who have developed depressive disorders late in life often have **white matter hyperintensities**, lesions (often associated with cerebrovascular disease and stroke) in some of the nerve cells that carry messages from one part of the brain to another. Although older adults without depression sometimes have these neurological changes too, people with depression are more likely to have them in the prefrontal cortex. People who have this “vascular depression” are also more likely to suffer higher levels of impairment from depression (American Psychiatric Association, 2000; Thomas et al., 2002).

Questions for Reflection and Discussion

1. What do you think of the fact that the left side of the PFC is supposed to be involved in pursuing our goals, and that activity there is associated with positive moods? Does that connection make sense to you, and why or why not?

2. What do you think of the fact that the right side of the PFC is supposed to be involved with regulating behavior, and that activity there is associated with negative moods? Does that connection make sense to you, and why or why not?

The Anterior Cingulate Cortex (ACC)

The Anterior Cingulate Cortex (ACC) is a part of the cerebral cortex that is involved in monitoring and evaluating performance, internal states, and the presence of reward and punishment. It may act as a bridge between attention and emotion, playing critical roles in reacting to stress, processing and expressing feelings, prioritizing incoming information, and interacting with people. The ACC monitors conflicts in the brain and asks the prefrontal cortex to help sort through all of this information and guide our behavior (Davidson, Pizzagalli, Nitschke, & Putnam, 2002).

The areas of the ACC that process emotions (the **rostral** and **ventral** areas) have many connections with the **orbitofrontal cortex** (the area of the prefrontal cortex involved in processing reward and punishment) and with many areas of the limbic system, including the **amygdala** (the “fear center” described on the following page) and the **nucleus accumbens** (the brain’s pleasure center or reward system). Higher levels of activity in the ACC areas that process emotions may be associated with more effective regulation of emotions (Davidson, Pizzagalli, Nitschke, & Putnam, 2002).

According to Davidson, Pizzagalli, Nitschke, & Putnam (2002), researchers have found that:

- When the ACC is operating at a deficit, it may not be able to call on the other regions of the brain for help with the internal conflicts it perceives.
- Some people with Major Depressive Disorders, including some receiving medication for these disorders, have shown decreased activity in the ACC.
- Activity in the cognitive ACC regions tends to increase when the depression goes into remission.
- People with Melancholic Depression tend to show lower levels of activation in **Brodman’s Area 25** (the **subgenual cingulate**), the area of the frontal cortex considered most important in regulating autonomic functions such as breathing, digestion, and cardiovascular functions.
- People who eventually respond well to treatment for depression tend to have higher baseline levels of activity in the ACC areas that process emotions (the rostral and ventral areas), although sleep deprivation can lower those levels of activity.

Questions for Reflection and Discussion

1. The ACC seems to play a sort of “diplomatic” role in the brain’s emotional functions, monitoring our thought and feeling processes, helping with communication and problem solving, and calling on other areas of the brain for help and guidance. What is one type of experience (in your life or the lives of the people you serve) when the work of this “diplomat” might be important, and why?

2. In your own mind, how does your ability to regulate your emotions help you deal with fear, and with your experience of reward and punishment in everyday life?

The Amygdala

The amygdala is the limbic structure involved in perceiving, processing, and responding to fear, anxiety, and difficult or unpleasant experiences (e.g., sights, sounds, smells, tastes). It also plays a prominent role in associating memories with emotional responses, both positive and negative. Researchers have seen the left side of the amygdala activated when people win money, and the right side activated when they lose. And increased activity in the amygdala may give people greater access to pleasant and unpleasant memories, possibly because of the way this structure interacts with the two structures described above (the prefrontal cortex and the anterior cingulate cortex) (Davidson, Pizzagalli, Nitschke, & Putnam, 2002). The amygdala may also be involved in perceiving ambiguity and signaling the other areas of the brain to resolve it (Davidson, 2004).

According to Davidson, Pizzagalli, Nitschke, & Putnam (2002), researchers have found that:

- In some studies, people with depression have had higher levels of activity in the amygdala. This has been particularly the case with people who have more severe depression, people whose depression has melancholic features, people with a family history of depression, and people who have suicided.
- Some studies have reported that, in many people with Major Depressive Disorder, certain areas of the amygdala are significantly larger on the left side than on the right.
- People with bipolar depression have been reported to have larger overall volume in the amygdala.
- People with depression have shown lower levels of dopamine stimulation in the amygdala, probably contributing to their sense of helplessness and loss of energy (Shumake & Gonzalez-Lima, 2003)
- People who respond well to medication for depression tend to show a return to normal activity in the amygdala, although people with a family history of unipolar depression often continue to show higher levels of activity on the left side of the amygdala even after remission.

Questions for Reflection and Discussion

1. What kinds of roles does fear tend to play in the lives of the people you serve?

2. What is your “gut” reaction to a description of fear as a function of a particular brain structure?

The Hippocampus

The hippocampus is the limbic structure involved in learning and memory. It plays a role in learning to associate positive and negative experiences with the contexts in which those experiences take place (Davidson, 2004). The hippocampus is involved in fear conditioning, and in regulating hormones in response to stress. It also has been linked with perception and memory of both positive and negative experiences (Davidson, Pizzagalli, Nitschke, & Putnam, 2002).

Cortisol and other stress hormones have powerful effects on the hippocampus, which has a high density of receptors for these chemicals and plays an important role in transmission of their messages. In moderate amounts, cortisol may facilitate memory, but at higher levels it may impair memory (Davidson, 2004).

The hippocampus is also one of two structures in the human brain where scientists have observed a process called **neurogenesis** (the growth of new neurons, or brain cells). Research indicates that stress, particularly chronic stress, can lower the speed of neurogenesis, and environments rich in learning can increase it (Rosenbaum & Covino, 2006).

According to Davidson, Pizzagalli, Nitschke, & Putnam (2002):

- Some studies associate Posttraumatic Stress Disorder (PTSD) and depression with lowered levels of activity (including neurogenesis) in the hippocampus. They speculate that the chronic high levels of cortisol associated with PTSD and other stress reactions may result in a loss of cells in the hippocampus.
- Other studies indicate that the loss of cells in the hippocampus may be a symptom, rather than a cause, of depression.
- Both depression and trauma may impair the functioning of the hippocampus, resulting in behaviors that seem extreme to the outside world but are appropriate to the inner experience.

Questions for Reflection and Discussion

1. If the hippocampus is involved in our perception of positive and negative experiences, and mobilizes hormones in response to stress, what role might it play in the lives and well being of the people you serve?

2. If environments rich in learning can increase neurogenesis (nerve growth) in the hippocampus, what implications might that have for your work?

The Hypothalamic Pituitary-Adrenocortical (HPA) Axis

The term “hypothalamic pituitary-adrenocortical axis” (HPA axis) refers to the interactions among the **hypothalamus** (in the limbic system), **pituitary gland** (in the subcortical area of the brain) and the **adrenal glands** (located above the kidneys). The HPA axis is an important part of the processes that respond to stress in the **neuroendocrine** system (involving both neurological functions and hormone secretion in the endocrine system), the immune system, and a number of other systems and functions in the body. Cortisol (which is produced in the adrenal gland) plays a key role in these processes, raising blood pressure and blood sugar levels and suppressing the immune system. The HPA axis is activated by stress and regulated by several monoamine neurotransmitters (e.g., serotonin, dopamine, and norepinephrine).

Some researchers believe that:

- Early life stress may cause long-term changes in the HPA axis, increasing levels of corticosteroids (Weiss, Longhurst, & Mazure, 1999) and raising children’s risk of a number of mental disorders (Heim & Nemeroff, 2001).
- Chronic stress may lead to a breakdown of some functions in the HPA axis.
- In some people, activity in the HPA axis may “go into overdrive.” Many people with depression or increased genetic risk of depression may have increased activity in this area, contributing to mood and anxiety disorders (Vythilingham et al., 2000).
- People with depression may have higher levels of cortisol and may not be able to suppress cortisol production. In people with Atypical Depression, the higher cortisol levels may contribute to symptoms such as weight gain, prolonged sleep, and **emotional lability** (excessive laughter, crying, or smiling); but in people with Melancholic Depression, higher levels of cortisol may in part compensate for their symptoms (Shumake & Gonzalez-Lima, 2003).
- In new mothers, high levels of cortisol have been associated with “the blues” and low levels with “highs” (Taylor et al., 1994).
- Women may be more vulnerable to stress-induced problems in the HPA axis, because of the effects of estrogen on cortisol production and regulation (Weiss, Longhurst, & Mazure, 1999).

Questions for Reflection and Discussion

1. What signs of HPA “overdrive” have you seen in some of the people you serve?

2. What signs or evidence have you seen of connections between early life stress or chronic stress and malfunctions in the HPA Axis functioning?

Other Structures Involved in Depression

The brain structures and pathways described above also have many relationships with a number of other structures and pathways. According to Mayberg (2006), some other structures that seem to be involved in depression and/or its treatment include:

- The **parietal lobe**, a structure in the cerebral cortex that integrates sensory information from a number of parts of the body
- The **insula** (or insular cortex), a structure in the cerebral cortex that has strong relationships with the limbic system, helping us translate our sensory experience into emotions and thoughts about those emotions
- The **hypothalamus**, a complex structure in the limbic system that links the endocrine system and many structures in the brain, by receiving and transmitting a number of chemicals and hormones (including dopamine and cortisol) and is involved in a number of behaviors and rhythms of sleep and wakefulness (called **circadian rhythms**)
- The **cingulate gyrus**, an integral part of the limbic system
- The **raphe nuclei**, a cluster of small-but-powerful structures in the brain stem (part of the subcortical area of the brain) that transmit serotonin throughout the brain and the remainder of the central nervous system
- The **basal ganglia** (or basal nuclei), a group of structures in the subcortical area that produce various neurotransmitters
 - The **striatum**, a dopamine-producing structure in the basal ganglia involved in movement and executive function, and stimulated by reward and punishment (includes the **putamen**, the **caudate nucleus**, and the **nucleus accumbens**)
- The **thalamus**, a subcortical structure that relays messages to the cerebral cortex and plays a role in sleep and wakefulness, but may also play more complex roles in brain functioning

Some of these brain structures will be revisited in the chapter on Treatment for Depression.

In Summary

It would take a very large manual dedicated to the neuroscience of depression to begin to do this subject justice. However, if this chapter has provided a glimpse of the scope and complexity of the brain's involvement in depressive disorders, it has done its work. To sum it up briefly, many researchers believe depression may be associated with:

- Difficulty regulating moods, often due to lower levels of serotonin
- Difficulty experiencing pleasure, often due to lower levels of dopamine
- In some women and some people with Atypical Depression, more extreme responses to stress (e.g., weight gain, prolonged sleep, emotional lability), possibly due to higher levels of cortisol
- Longer processing of negative and stressful experiences in the prefrontal cortex
- In some older adults, neurological changes in white matter in the prefrontal cortex associated with stroke, changes that are also associated with greater impairment

- Reduction in immune functioning, often including the reductions in immune activity caused by higher levels of cortisol and reduced levels of “natural killer” immune cells
- A failure of the anterior cingulate cortex to call on the prefrontal cortex and other regions for help in resolving the conflicts it perceives in the brain
- Heightened perception of danger and unpleasant experiences, and greater access to unpleasant memories, in the amygdala
- Levels of emotion that are out of context with the outside world, often due to problems with perception and memory of positive and negative experiences in the hippocampus—possibly in some cases because stress reactions have lowered the level of new cell growth and so reduced cell volume in the hippocampus

They also believe that:

- Some people with Melancholic Depression may have a harder time regulating some autonomic functions because of lower levels of activation in Brodman’s Area 25, but higher cortisol levels may help mitigate some of their symptoms
- People with bipolar depression may have higher levels of dopamine during manic phases and larger overall volume in the amygdala

Questions for Reflection and Discussion

1. On a scale of 1 to 10 (1=“not at all” and 10=“completely”), how overwhelming is all this information on the brain’s potential role in depression?

1 2 3 4 5 6 7 8 9 10

2. What are some ways in which some of this information might help people gain more understanding of depression and its effects on human lives, and why?

3. What are some ways in which some of this information might actually increase the stigma directed at depression, and why?

4. What are some ways in which some of this information might make it harder for people to feel hopeful about recovery from depression?

Implications for Stigma Reduction

The major implication of all this for stigma reduction is a simple one: These are not horrible defects that by any stretch of the imagination might legitimately set people apart from their fellow human beings. These are increases and reductions in activity, cell growth, cell volume, and communication in various areas of the brain. They are not indications of lower levels of intelligence, creativity, morality, or love of one's fellow human beings. People without any mental disorders also have their share of increases and reductions in activity, cell growth, cell volume, and communication in other areas—and some even in the same areas. These are normal human conditions.

Given that the brain itself is an unfathomably complex collection of interdependent and delicately balanced systems, it sometimes takes only a subtle difference to have a profound effect on a human life. Fortunately, there are many ways of addressing, compensating for, and even transcending many of these neurological factors. Unfortunately, it sometimes takes time and experimentation to find the right remedy—time that may seem like forever in the depth of pain that depression can produce.

It is the job of the community, the helping professional, the family, and the friend to send a consistent message:

- This is a common human illness.
- It is not something that people with this illness are supposed to be able to “will” away.
- There are many possible solutions.
- There are many sources of hope and help.
- Successful treatment makes a significant difference.
- Recovery has become a reality for many, many people whose pain was once just as deep, just as wide, and just as impenetrable.

Questions for Reflection and Discussion

1. On a scale of 1 to 10 (1=“not at all” and 10=“completely”), how important is it for the people you serve (and their families and communities) to hear the messages listed directly above this box?

1 2 3 4 5 6 7 8 9 10

2. Why?

Chapter Four: Treatment for Depression

A lively understandable spirit
Once entertained you.
It will come again.
Be still.
Wait.

From "The Lost Son," by Theodore Roethke

Illness and treatment should be simple. If something hurts, we should be able to take it to a doctor, have a blood test, pick up a prescription, swallow a few pills, and recover. Diagnosis should be unambiguous; treatment should be targeted precisely at the mechanisms that are impaired; and healing should be swift, complete, and permanent. Our faith in the precision of medical science often seems essential to our overall reassurance that life makes sense.

Depression provides a good example of the opposite:

- Depressive disorders exist on a continuum with ordinary moods and mood swings and share many symptoms with natural grieving processes, post-trauma effects, medication side effects, neurological disorders, and many other acute and chronic illnesses.
- These disorders sometimes coexist with a variety of other physical and mental disorders, often masking or exacerbating one another's symptoms.
- Depressive disorders combine patterns of impairment in neurological, cognitive, and emotional processes—patterns that wind around one another, often making it difficult to find causes, effects, and the hope of recovery.
- Differences in individual skill levels and personality traits from person to person can complicate the diagnostic process, when clinicians lack the time to learn enough about the individual to distinguish symptoms from characteristics.
- Cultural factors can further complicate the diagnostic process, when cultural traits are mistaken for symptoms, symptoms are mistaken for cultural traits, or the consumer describes real symptoms in terms that the healer steeped in another culture does not recognize.
- Diagnosis must often depend on observation, narrative descriptions of symptoms, tests to rule out other conditions, clinical questionnaires, intuition, experience, and luck.
- A dazzling array of brain structures and processes seem to be involved in depressive disorders and symptoms, and there is no physical test that can guide the prescription of medical treatment and other forms of therapy precisely toward the injured areas.

- Medication and other treatments that have worked well with one person may work not at all with another who has similar symptoms. Medication may take several months to show even whether or not it will work. Switching to a new medication often requires a gradual weaning from the old medication before the new can be introduced. And medication that has been working well may suddenly stop working for no apparent reason.
- A depressive disorder that has gone into remission may arise again at some unforeseen time. However welcome recovery may be, it is always haunted by that possibility, and the very possibility contributes to stigma.

These flaws in the healing process may draw sympathy for people with depression, but they often draw more than a little suspicion and cynicism as well. As a society, we are not comfortable with “maybe this, maybe that,” or “wait and see.” And when we are not comfortable, one of our first instincts is to pass judgment—“He can't really be trying,” or “Those doctors don't really know what they're doing!”

Stigma-reduction efforts will be lacking if they do not help us make peace with the ambiguities of diagnosis and the uncertainties of treatment, and provide some hope for greater precision and relief in the future.

Questions for Reflection and Discussion

1. Of the complexities described above, name one that might particularly contribute to the stigma directed at depression, and tell why.

Stigma and the History of Treatment

Before the search for hope begins, though, it is important to acknowledge another topic, one that is far beyond the scope of this manual: the tragic, sometimes heroic, but often horrific history of human attempts to understand, diagnose, and treat mental illnesses, including depressive disorders. Although the magnitude of suffering brought on by our more primitive attempts to heal, contain, and control mental disorders has diminished greatly over the years with the introduction of more effective medications, that history leaves behind three questions that should never be left out of our inquiries:

1. To what extent do the remnants of early (and sometimes not-so-early) attempts to explain mental illness—as anything from “bad blood” to demonic possession—still influence current attitudes toward people with these disorders and fuel the stigma, stereotypes, and discrimination?

2. To what extent do some of the practices that came out of those eras still exist, in other countries and even in the United States, and how does stigma contribute to their longevity?
3. What might we someday learn about our currently accepted practices in understanding, diagnosing, and treating mental illness that might make future generations look with criticism, or even with shame, on this era in psychiatric history?

The answers to these questions are certainly far beyond the scope of this manual, though the questions themselves must be raised. One important point, though: Human cultures develop in many ways like human beings, beginning with the most primitive attempts at understanding and gradually building reason, sophistication, and depth. Like stigma itself, counterproductive and even highly destructive treatment methods often begin as unwise but well intentioned attempts to help. The advocate would do well to look, not for villains, but for unquestioning acceptance of primitive beliefs—conscious or unconscious—and at the cascade of cause and effect that often follows.

Questions for Reflection and Discussion

1. If you had to guess at the answer to the first question (bottom of the previous page), what would your answer be?

2. If you had to guess at the answer to the second question (top of this page), what would your answer be?

3. If you had to guess at the answer to the third question (the second on this page), what would your answer be?

Diagnosis

In the realm of diagnosis of depressive disorders, three issues seem to have particular interest for a discussion of stigma reduction:

- The rise in diagnosis of depression beginning in the late 20th century
- Individual considerations in diagnosis
- Cultural considerations in diagnosis.

The Rise in Diagnosis of Depression

“We do know that the number of consumers diagnosed with depression has doubled over the last 30 years, without any great change in diagnostic criteria,” wrote Dworkin (2001). “But this simply raises another question: Are doctors more aggressive in diagnosing depression, or are they simply diagnosing ‘everyday unhappiness’ as a variant of depression and reporting it as such?” (Dworkin, 2001, pp. 85-86).

The implications of this question for stigma reduction are clear: If doctors are becoming more aggressive in diagnosing depression, this indicates some progress in combating stigma, at least within the medical community.

But if the category “depression” is being expanded to include “everyday unhappiness,” then not only are people being treated inappropriately, but the category of depression as a whole is being devalued. As this category weakens, the main line of defense against stigma is jeopardized. It is precisely a recognition of the distinct experience of people with depressive disorders that has won some respect for their needs and some access to care. We cannot destigmatize an experience by denying or minimizing it, or by confusing it with other, less stigmatized, conditions.

People are often diagnosed with and treated for depressive disorders by their family physicians, rather than by psychiatrists. If diagnosis is sometimes inaccurate, it may be that some doctors who are involved in this process lack the education or training to support these diagnostic roles. “In one study, over 30 percent of the family practitioners interviewed confessed to needing further training to treat emotional disorders, even though it was part of their routine practice to do so” (Dworkin, 2001, p. 90).

In his interview for this manual, Joshua Mark noted that mood disorders in children tend to be either underdiagnosed or overdiagnosed, depending on the knowledge and beliefs of the diagnostician. According to Mark, the automatic use or the overuse of antidepressant medicine in children can also be stigmatizing in its own way, in its failure to give children's spirits a chance to address the illness with the help of appropriate therapy.

It is also uncertain the extent to which the increase in diagnosis of depression might reflect an actual increase in the incidence of depression, or an increasing co-occurrence of depression with a variety of other disorders. As explored in the previous chapter, there is considerable overlap between depressive disorders and a large number of other physical and mental disorders. Illness brings physical vulnerability to the human brain and emotional vulnerability to

the human spirit. Depressive disorders can also raise the risk of a number of other disorders, most notably Substance Use Disorders.

Individual Considerations in Diagnosis

An encounter between psychiatrist and consumer brings together two vast worlds full of knowledge and experience. The psychiatrist brings many years' worth of medical education and practice, and a mind full of knowledge about the connections among symptoms, cognitive processes, emotional processes, neurology, medication, and outcomes. The consumer brings a lifetime's worth of knowledge and experience of his or her own values, traits, resources, abilities, experiences, needs, desires, priorities, and symptoms. Often they have only seven minutes to put their worlds together and make decisions that will have profound effects on the consumer's well being, and possibly on his or her survival. How can the psychiatrist know if—**for this particular person**—a particular action (e.g., quitting a job) or attitude (e.g., defiance) is a symptom or a sign of recovery?

When a consumer works with a therapist, there is a little more time. But each of us really is an entire culture, an entire universe. How much time is sufficient to learn this culture, map this universe with enough accuracy to lead us through it? Perhaps only a lifetime. Instead, it is better to work collaboratively, providing information and support for the consumer's priorities and decisions.

Many human service fields are beginning to give at least lip-service to the idea that the service consumer is the expert on his or her own life. However, the practice of this philosophy is far more difficult. It can require that the provider give up the illusion of control and learn many more consumer-centered approaches. It is important not to minimize the amount of courage, patience, and dedication required for a shift toward these approaches.

Cultural Considerations in Diagnosis

Culture brings another layer of complexity to the diagnosis of depression, and to the discussion of stigma:

- How often are depressive symptoms missed, or normal cultural expressions mistaken for symptoms, when there are cultural differences between the consumer and the diagnostician?
- How often do factors such as age or gender affect the experience and symptoms of depression, and lead diagnosticians to overlook important signs?
- How many people mask their symptoms because depressive disorders are foreign to their world view or considered particularly shameful in their cultures of origin?
- How often do families, communities, or the public as a whole discount or further stigmatize depressive disorders in members of groups who are already stigmatized for their socioeconomic or cultural circumstances?

To become truly competent about depression and other mental disorders, we must also become culturally competent. This must include a respect for the amount that we do not know about other cultures, and for the degree to which our own cultural background and biases influence

our perceptions. It can be a highly damaging or even fatal mistake either to identify as a symptom something that is really a cultural trait, or to dismiss a symptom because it has been identified as normal for the consumer's culture.

To think clearly about depression among non-dominant cultures, one must first learn the "language" in which depression is experienced and expressed in these cultures. It is not only the words used to describe the disorder or its symptoms, but also the feeling states that each culture recognizes and embraces within its understanding of human nature, that may have profound influence on the individual's experience of depression, descriptions of symptoms, and successful approaches toward treatment.

For example, in many Asian cultures, people who suffer from depression are more likely to experience and describe their maladies in terms of physical rather than emotional symptoms (Chen, 2005; Tran, Ngo, & Conway, 2003). According to Bradford (2003), African-American men with depressive disorders also tend to report more somatic symptoms, including headaches, backaches, stiff neck, achy shoulders, and gastrointestinal disturbances, rather than affective symptoms. Other examples of somatic descriptions of depression include "complaints of 'nerves' and headaches (in Latino and Mediterranean cultures); of weakness, tiredness, or 'imbalance' (in Chinese and Asian cultures); of problems of the 'heart' (in Middle Eastern cultures); or of being 'heartbroken' (among Hopi)" (American Psychiatric Association, 2000).

According to Baker (2001), many African Americans who meet the DSM IV criteria for mood disorders do not spontaneously report "depressed mood," but rather show clusters of symptoms that present more in terms of social roles or personality types. Based on his study of 58 African-American elders who met the DSM criteria, Baker identified three such roles: 1) "The Stoic Believer," whose depressive symptoms hide under a tenacious hold on religious faith; 2) "The Angry, 'Evil' One with a Personality Change," who often was pleasant and friendly in the past but has grown angry, irritable, and abrupt; and 3) "The John Henry Doer," who tends to take on more and more responsibilities and tasks, even when it compromises health, as a way to mask the pain.

Language may also be an important factor in diagnosing depression among men in general, who often feel less comfortable than women thinking or speaking about the "softer" emotions (e.g., sadness, feelings of worthlessness), and who may experience depression more in terms of their reactions to it (e.g., drinking more alcohol, acting "grumpy," lashing out at others, engaging in conflict) (Brownhill, Wilhelm, Barclay, & Parker, 2002). Men with depressive disorders also tend to experience greater conflict between their accomplishments and their expectations of themselves, to experience work-related conflict, and to perceive threats to their self-esteem and self-respect (Cochran & Rabinowitz, 2003).

In the many cultures that have tended to associate emotion with femininity, it is not surprising that men would be stigmatized more heavily for experiencing depression, or that men's experiences and descriptions of depression would take on more typically "masculine" patterns, and so be missed far more frequently in the diagnostic process. According to Murray (2005), "Statistically it takes 10 years and three health professionals to properly diagnose depression in men. Often depression is not recognized until men are in their 60s or even 70s" (p. 1).

Age can also complicate the diagnostic process. Older adults and their caregivers often mistake the symptoms of depression for the conditions of physical illness or normal aging (Barber, 1996), and the tendency of older generations to stigmatize depression may also add to

their reluctance to recognize or articulate their symptoms. Depression can also be triggered by some illnesses common in aging (e.g., strokes, diabetes, Parkinson's disease, some types of cancer) and by some medications often prescribed to older adults (e.g., some blood pressure and arthritis medications) (Barber, 1996).

Symptoms in children who suffer from depression may be different from those seen in adults, and may sometimes be confused with “symptoms” of childhood itself. Children with depression may appear more irritable, grouchy, manipulative, or compulsive, rather than depressed. They may also have more physical symptoms, rather than emotional ones (American Psychiatric Association, 2000).

It is not clear the extent to which stigma contributes to difficulties in diagnosing mood disorders in these and other groups. But in all these cases, one common theme may be the masking—conscious or unconscious—of the softer and more “typical” emotional components of depression. The question arises: Would people need to mask these symptoms if the society that nurtured them were more accepting of people with mood disorders?

And to what extent are people misdiagnosed because diagnosticians do not understand their cultural experience, or because of stigma and stereotypes already directed at their cultural groups? For example, psychiatry has a history of misdiagnosing bipolar illness in African Americans, most often mistaking it for schizophrenia (Baker, 2001).

It becomes clear that any serious discussion of stigma for one condition becomes a discussion of stigma in general, and of our human failure to accept our fellow human beings—and, in some cases, to accept our own human and professional limitations.

Questions for Reflection and Discussion

1. To what would you most attribute the rise in diagnosis of depression, and why?

2. What are your major challenges in learning about the people you serve and the complexities of their lives?

3. What examples have you seen where cultural (e.g., ethnicity, gender, age, sexual orientation) characteristics have been misinterpreted in the diagnostic process?

Treatment

When a condition is commonly stigmatized, it is not uncommon for the treatment of that condition to draw a certain amount of stigma as well. Erving Goffman's (1963) concept of "courtesy stigma" provides a little help in understanding this phenomenon: The people who treat "those people" and the methods they use are somehow suspect by their association with a stigmatized group.

But when the condition is complex and there is no sure way of predicting the effectiveness of any chosen treatment, the treatment process can also become a magnet for all the stigma born of:

- Frustration with the slow pace of progress
- Fear that the symptoms will never abate
- Guilt at not being able to contribute more to the healing process

That stigma can be transferred in subtle ways back to the consumer, whose self-stigma is already joining all the pain and frustration of the search for relief in a single chorus: "*Why am I not getting well?*"

A simple slogan such as "treatment works" might seem transparent to a family or community that has seen treatment fail to work, and insulting to a consumer who is waiting in agony for that phrase to come true (White, 2004). So what can stigma-reduction efforts offer? Certainly nothing simple, though people often long for simplicity.

The best remedy for stigma and self-stigma may be evidence of the success of treatment and recovery, in the form of real people who have found relief (Corrigan, 2005)—often after failed attempts and struggles just as harrowing as those the consumer is engaged in now. Another useful tool is a better understanding of what makes treatment work when it works, and the hope that clinicians will soon be able to predict with greater certainty the remedies that will work for particular consumers. That tool is the subject of the next few pages.

Modes of Treatment

For the consumer receiving treatment for depression, for the concerned family, and for the helping professional who serves this consumer in one of many human service fields, the critical question is, "What kind of treatment will work?" But first, a brief exploration of the major types of treatment, with a few excursions into the stigma directed at them.

Antidepressant Medications

Most antidepressants increase the availability of critical monoamine neurotransmitters to the brain by slowing the chemical process that breaks them down or the reuptake process that pulls them back into the nerve cell. The four classes of antidepressant medications are:

- The new generation of medications that work through the serotonin or norepinephrine systems (or both), including the selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine (Prozac) and sertraline (Zoloft), norepinephrine reuptake inhibitors such as

reboxetine (Edronax), and the new medication duloxetine (Cymbalta) that inhibits the reuptake of both serotonin and norepinephrine

- Antidepressants such as bupropion (Wellbutrin) that slow the reuptake of dopamine and norepinephrine
- The (older) tricyclic antidepressants such as desipramine (Norpramin) and nortriptyline (Pamelor) that slow the reuptake of serotonin, dopamine, and norepinephrine
- The Monoamine oxidase inhibitors (MAOIs) such as phenelzine (Nardil) and tranylcypromine (Parnate) that slow the breakdown of monoamines (e.g., serotonin, dopamine, and norepinephrine) (Diamond, 2002)

Antidepressant medications are often the treatment strategies of choice, but they sometimes fail, take months to relieve symptoms, or require experimentation to find the right medication or the right levels of medication (Keller, 2003; Mayberg, 2006, Stewart et al., 2003). Even if one does not choose to delve into some of the often-stigmatizing popular controversies that have attached themselves to antidepressant medication as a whole—from the books criticizing this genre of medicine (e.g., Breggin, 1995; Glenmullen, 2001; Scott, 2006) to movie star Tom Cruise's wholesale public denunciation of psychiatry and psychotropic medications—antidepressant medications have their limitations.

For example, any psychotropic medication is bound to have side effects, with different people experiencing more troubling or dangerous effects from different classes of medications (Diamond, 2002). And in October, 2004, the federal Food and Drug Administration strengthened its warnings about the use of antidepressant medications for children and adolescents, citing a danger that these medications might increase children's suicidal thoughts and actions. However, a 2006 study in Finland indicated that, while the SSRIs may increase the number of attempted suicides, they may actually decrease the number of *completed* suicides, and decrease the number of deaths from other causes as well (HealthDay, 2006).

New animal studies are also indicating that antidepressant medications may restore or stimulate neurogenesis (the growth of new neurons) in the all-important hippocampus (Rosenbaum & Covino, 2006). As you may recall from Chapter Three, the hippocampus is the structure involved in fear conditioning, regulation of stress reactions, and perception and memory of positive and negative experiences. Some people with PTSD or depressive disorders tend to show lower levels of neurogenesis in the hippocampus, possibly contributing to reduced cell volume. If successful antidepressant treatment can "jump-start" neurogenesis, then people in recovery from depression may have less reason to fear ongoing reduction in cell growth and greater hope of long-term relief.

It is worth noting that the herbal remedy St. John's Wort has also been tried and studied as an alternative therapy for mild and moderate depression. Studies have generally shown it to be more effective than placebo (Kim, Streltzer, & Goebert, 1999; Gaster & Holroyd, 2000) and either somewhat less effective than (Gaster & Holroyd, 2000) or as effective as (Kim, Streltzer, & Goebert, 1999) tricyclic antidepressants, but with fewer side effects. However, like most antidepressant medications, St. John's Wort affects the action of a number of liver enzymes, so it can have significant effects on the metabolism of other medications. People who are thinking of using St. John's Wort are strongly cautioned to coordinate these decisions with their physicians, to avoid dangerous drug interactions (Orbach, 2000; Bilia, Gallori, & Vincieri, 2002; Ernst, 2002).

While it is essential for prescribing physicians to have full knowledge of potential side effects, to prescribe for the least troublesome effects, and to heed any warnings of danger, it is also important not to dismiss the success that antidepressant medications have shown in saving lives and restoring quality of life. In his interview, Terrence Koller remarked that the side effects of many other types of medications have received nowhere near the amount of publicity directed at those of antidepressants. He speculated that the public's eagerness to dismiss these medications may spring from stigma and a general belief that the medications are not really necessary—a "crutch" used by "weak" people.

Psychotherapy

Even when it works well, medication does not address many cognitive, psychological, social, and lifestyle patterns that can have profound effects on depression and recovery. Although they lack the medications' powerful and direct impact on neurological functioning, psychotherapeutic interventions have been highly successful in some cases, either alone or in combination with medication.

In particular, cognitive therapies (including cognitive-behavioral therapy, or CBT) have shown promise in the treatment of some people with mood disorders, helping them recognize the counterproductive thought processes that contribute to depression and learn more realistic and constructive ways of thinking and responding to life.

As our approach toward the treatment of depression has become more and more associated with its medical aspects, an opposite trend has begun to balance the field. Practices such as mindfulness meditation, a non-judgmental practice of awareness and "unattachment" with roots in Buddhism, have become a staple of some therapeutic processes (e.g., Mindfulness-Based Cognitive Therapy, Dialectical Behavioral Therapy) and have begun to appear in the literature on treatment of depression.

Teasdale and colleagues write of the benefits of meditation in cognitive treatment for mood disorders. "Meditation leads to enhanced 'metacognitive awareness,' that is, an ability to experience thoughts as transient mental events, rather than as aspects of the self or reflections of objective truth" (Teasdale et al., 2002). Fennell also stresses the importance of metacognition: "...rather than seeking to alter the content of cognitions...we should seek to reduce their unhelpful impact by changing the nature of the patient's relationship to them" (Fennell, 2004, p. 1055). According to Shoeneman, Schoeneman, and Stallings (2004), clinicians might also do a better job of helping people explore the metaphors they use to describe their experience of depression, and might help them find metaphors to describe the experience of recovery.

Kissman and Maurer (2002) suggest a number of ways in which spirituality and spiritual practices might be used to enhance recovery from depression:

- By providing a "moral framework for giving meaning to life" and promoting "feelings of being cared for, valued, safe, hopeful, lovable and loved" (p. 35)
- By reducing anxiety and improving functioning and coping abilities
- By producing a "placebo effect" that increases faith in the healing process (p. 38)
- By helping people "let go" and transcend the hopelessness associated with the stress of illness (p. 38)

- By helping people heal self-stigma by accepting the duality of life and their illness (e.g., in mindfulness practices), to minimize the dualistic thinking that leads people to criticize themselves for having symptoms or to think of being symptom-free as “good” and having symptoms as “terrible” (p. 41)

And Nuckols (2005) reminds us not to dismiss the importance of that old mainstay of psychotherapy, the telling of the story. “For more than 4,000 years stories have been the favored format for passing on multi-level information. A story has the elements of the intellect, as well as emotions and body sensations. Neural growth and integration is enhanced by the integration of conceptual knowledge with emotional and body experiences using a narrative format that is co-created with a therapist” (Nuckols, 2005, p. 29).

“The process of listening to and telling stories brings together behavior, affect, sensation, and conscious awareness in a way that maximizes the integration of a wide variety of neural networks. Through stories we connect with others; share the words, thoughts, and feelings of the characters; and provide the opportunity for moral lessons, catharsis, and self reflection” (Cozolino, 2002, cited in Nuckols, 2006, p. 4).

Somatic Treatment for Depression

Some consumers do not respond to medication or psychotherapy, or cannot tolerate medications or the time spent waiting for them to bring relief. In these cases, people are sometimes forced to choose between more controversial and potentially harmful treatments such as electroconvulsive therapy (ECT) and the pain and danger associated with their unabated symptoms.

ECT is performed with lower electrical charges than in the past, and precautions such as general anesthesia, muscle relaxants, and oxygen can diminish some of the risks and trauma involved in the experience. However, general anesthesia presents risks in and of itself, and the literature is divided on the type, amount, and longevity of memory loss. Benefits of ECT are also temporary, so multiple treatments are necessary, and other forms of treatment are necessary for lasting relief. The confusion and disorientation that follow ECT—and the resulting (often temporary) changes in behavior and functioning—can also draw a great deal of stigma in families, communities, and workplaces where people do not understand depression or the side effects of ECT. A depressive disorder that was once barely noticeable to the outside world can receive the added burden of highly noticeable post-ECT effects.

In its 1985 position statement on ECT, the National Institutes of Health affirmed the effectiveness of this treatment “for a narrow range of severe psychiatric disorders in a limited number of diagnostic categories: delusional and severe endogenous depression and manic and certain schizophrenic syndromes. There are, however, significant side effects, especially acute confusional states and persistent memory deficits for events during the months surrounding the ECT treatment. Proper administration of ECT can reduce potential side effects while still providing for adequate therapeutic effects” (NIH, 1985, p. 20).

Scientists are also testing a number of new somatic strategies for treatment of depression (Mayberg, 2006), including:

- Transcranial magnetic stimulation, the use of powerful, rapidly changing magnetic fields, which may prove to be a less invasive way of providing relief without surgery or the attachment of electrodes
- Electromagnetic stimulation of the vagus nerve (a long nerve that runs from the brain stem to the abdomen, controlling many vital functions and releasing the chemical acetylcholine) through a pacemaker-like device implanted in the chest
- Deep brain stimulation, in which an implanted “brain pacemaker” sends electrical impulses to specific parts of the brain

Time will tell more about the safety, effectiveness, and affordability of these new strategies and the extent to which they can help people whose symptoms do not respond to medication or psychotherapy. Time will also tell whether these and other experimental treatments can help reduce the burden of stigma on those who use them, or whether the treatments themselves will become targets of stigma.

Questions for Reflection and Discussion

1. What has been your perception of the effectiveness of antidepressant medications in your life, or in the lives of people you have known or served in your work?

2. What has been your perception of the effectiveness of psychotherapy in your life, or in the lives of people you have known or served in your work?

3. What has been your perception of the effectiveness of somatic treatments for depression, in your life or in the lives of people you have known or served in your work?

Predicting Responses to Treatment

Given the amount of pain and danger that attend unrelieved depression, the prospect of predicting who will respond to what type of treatment has strong implications for our collective level of hope. Researchers are working hard to find evidence that can help clinicians predict the success of specific treatments for specific people, to eliminate some of the frustration and

suffering that come while people are waiting for relief—and to reduce the mortality rates among people who are unable to endure that suffering. For the most part, research is gaining ground in small increments.

Scientists have identified a number of symptoms and characteristics that might indicate that an individual may respond to antidepressants (summarized in Diamond, 2000):

- weight loss
- waking in the early morning
- feeling worse in the morning
- being depressed for no obvious reason
- anhedonia (not having fun doing things that used to be fun)
- feelings of hopelessness
- having a family member who is depressed or alcoholic, or who has made suicide attempts

Or take, for example, the following findings from a handful of studies:

- Approximately one in four people who had not found relief from one antidepressant had a remission of symptoms after switching to another antidepressant (Rush et al., 2006).
- People (particularly women) with higher levels of right-sided activity in the prefrontal cortex tended to respond less well to SSRI medication, and people who had higher baseline levels of activity in the anterior cingulate cortex tended to respond more positively to treatment (Davidson, Pizzagalli, Nitschke, & Putnam, 2002).
- People who had “polymorphisms” (common differences in DNA sequences) in certain genes (including genes that regulate serotonin, a protein involved in neurogenesis, and a receptor for the brain chemical glutamate) were more likely to respond well to treatment with an antidepressant (Celexa was used), and those who had polymorphisms in all three genes were most likely to respond well (Preidt, 2006).
- Monoamine oxidase inhibitors seem particularly effective with people who have Atypical Depression (Diamond, 2002).
- All of the antidepressants tested in recent animal studies in Finland (including SSRIs, tricyclics, norepinephrine reuptake inhibitors, and medications that work on the Natural Killer Cells) have been shown to re-start or stimulate neurogenesis (nerve growth) in the hippocampus (Rosenbaum & Covino, 2006).
- People who do not respond to one medication often respond well to a higher dose of that medication, to another medication, or to a combination of medication and CBT or ECT.
- Adolescents who received fluoxetine (Prozac) combined with cognitive-behavioral therapy (CBT) fared better than adolescents receiving either Prozac or CBT alone (Leon, 2005).
- People who experienced sudden gains early in cognitive-behavioral therapy were more likely than others to maintain these gains and to achieve better improvement and more solid recovery (Kelly, Roberts, & Ciesla, 2005).
- Compared to a control group, people who were trained in and practiced mindfulness meditation showed significant gains in activity in the left-sided brain areas associated with lower levels of depression, and produced far more antibodies in response to an influenza vaccine—with the people who showed the highest levels of gains in brain functioning also showing the highest increases in antibody production (Davidson, 2004).
- People who had experienced trauma early in their lives tended to respond more favorably to psychotherapy (Mayberg, 2006).

- People who experienced depressed mood and increased appetite in the first episode of depression were significantly more likely to experience recurrence of depression, and women were more likely than men to experience recurrence (Pettit, Lewinsohn, & Joiner, 2004).
- Older adults with late-onset depression and white matter hyperintensities (neurological changes associated with cerebrovascular disease and stroke) in the prefrontal cortex tend to respond less well to standard therapies (American Psychiatric Association, 2000)
- People with treatment-resistant depression experienced rapid and long-lasting (one week) relief of symptoms after a single dose of ketamine (an anesthetic and “club drug” that affects two receptors that regulate the flow of electricity in the brain), a finding that is not likely to lead to the widespread use of the often-abused ketamine for depression, but might provide clues toward the development of a new class of more rapid and longer-lasting medications (NIH, 2006).

The functional neuroimaging techniques mentioned in the chapter on the brain (Positron Emission Tomography, Functional Magnetic Resonance Imaging, and Near Infrared Spectroscopic Imaging) have made it easier for researchers to match specific forms of treatment to specific areas of distress in the brain. Mayberg (2006) found it helpful to look at these areas of distress and the changes brought about in treatment (measured in terms of changes in glucose metabolism or blood flow in a particular area) in three categories:

- Those centered in the cerebral cortex (e.g., the prefrontal and parietal areas)
- Those centered in the limbic or paralimbic systems (e.g., the cingulate, amygdala, insula)
- Those centered in the subcortical structures (e.g., thalamus, brainstem)

Based on his research, Mayberg (2006) suggested that:

- Patterns centered in the cortex may respond best to cognitive-behavioral therapy.
- Patterns that involve both the cortex and the limbic system may respond most strongly to medications.
- Patterns that involve both the limbic and subcortical areas may tend to resist both types of treatment.

It is unclear how important these findings might someday be, and how feasible it might be to use them to shorten an individual's period of suffering. However, understanding, hope, and progress at any level are important elements in the healing of stigma.

One Vision for Treatment and Stigma Reduction

Given the obvious need for much more research and much greater acceptance and understanding of treatment for depression, some advocates have looked to the progress made with other diseases such as cancer, once stigmatized far more heavily than it is today.

In 2006, the University of Michigan opened the country's first National Depression Center, an interdisciplinary treatment and research center where more than 135 experts on depression and Bipolar Disorder will collaborate on finding and providing the highest quality treatment (Solomon, 2006).

In an article on depression, stigma, and treatment, Andrew Solomon (author of *The Noonday Demon: An Atlas of Depression*) recommended that the National Institute of Mental Health coordinate and subsidize a network of these types of centers, similar to the network of cancer centers established by the National Cancer Institute in the 1970s. Like the cancer centers, depression centers might make effective treatment more accessible and more affordable. They might also reduce stigma by helping the public understand that depression is a common medical condition with legitimate treatments (Solomon, 2006).

Questions for Reflection and Discussion

1. Of the research findings listed on the previous two pages, which ones seem most relevant to or important for the people you serve, or others you know, and why?

2. What kinds of effects do you think higher levels of hope might have on the well being of the people you serve who have depressive disorders?

3. What kinds of effects do you think higher level of realistic hope might have on the stigma directed toward depressive disorders?

So far this manual has focused heavily on depression—the disorders themselves, the role of the brain, and modes of treatment. Before shifting to a focus on stigma, the document takes a small step back from depression with a look at some of the co-occurring conditions that often accompany it, and a few implications for stigma reduction.

Chapter Five: When Depression is Not Alone

As a clinician in the field told me honestly and, I think, with a striking deftness of analogy: “If you compare our knowledge with Columbus’s discovery of America, America is yet unknown; we are still down on that little island in the Bahamas.”

William Styron, from *Darkness Visible: A Memoir of Madness*

Just as we no longer believe the earth is flat, we no longer believe the body, mind, and spirit are separate. Yet we walk on the earth as if it were flat, and sometimes we treat the body, mind, and spirit as if they were separate. It is simply easier: Divide and conquer. But it is our arrogance that makes us think we can conquer this territory, solve this puzzle called the human being. And it is our fear that makes us think we have to conquer it. Often the best course is simply to respect it, in all its complexity.

Human lives seem to be growing more complex, though those who study them may also be growing more sophisticated. When depression appears in a human life, it often does so in the context of multiple life challenges, multiple stress factors, multiple diagnoses. In the replication of the National Comorbidity Survey (the NCS-R), Major Depressive Disorders rarely occurred alone. Seventy-two percent of respondents who reported these disorders also reported having had other mental disorders at some point in their lives, and 78.5% reported co-occurring disorders within the past year (Kessler et al., 2003). The forces that leave people more vulnerable to depression may also increase vulnerability in a number of other areas.

This chapter provides a brief survey of some of the medical and developmental disorders that often occur more frequently in people with depressive disorders, followed by a closer look at the co-occurrence of depression with three conditions: HIV and AIDS, Substance Use Disorders, and post-trauma responses.

General Medical and Developmental Disorders and Depression

“Among individuals seen in general medical settings, those with Major Depressive Disorder have more pain and physical illness and decreased physical, social, and role functioning” (American Psychiatric Association, 2000, p. 371). According to Treisman and Angelino, “Depressive symptoms are “the most common psychiatric complication of chronic medical

illness. Studies have shown that depression has a negative effect on patients' adherence, quality of life, and treatment outcome. Despite this important evidence, depressive conditions remain underrecognized, underdiagnosed, and undertreated in medical clinics" (Treisman & Angelino, 2004, p. 33).

According to the American Psychiatric Association, people with chronic and severe general medical conditions have increased risk of developing MDD. Between 20% and 25% of people with diabetes, myocardial infarctions, and cancer develop depression during the course of their disease. In these cases, the presence of depression often complicates management of the other illnesses, and it is associated with longer recovery times and poorer response to treatment. And 20% to 40% of people with neurological conditions such as Parkinson's disease, Huntington's disease, multiple sclerosis, stroke, and Alzheimer's disease develop "marked depressive disturbance" during the course of their general medical illness (p. 371). The presence of these and other serious general medical conditions also tends to complicate management of and recovery from depression (American Psychiatric Association, 2000).

A review of the literature provides many examples of chronic and acute conditions that have been associated with higher rates of depression, including:

- People in primary care for physical illness in general, whose depression may express itself in physical symptoms, which are often more difficult to detect and treat than the psychological symptoms of depression (Aragones, Labad, Pinol, Lucena, & Alonso, 2005)
- The 20-40% of primary care outpatients and 40-60% of specialty clinic patients with unexplained physical symptoms who are estimated to have psychiatric disorders (Estrand et al., 2004)
- Mothers of children with Attention-Deficit/Hyperactivity Disorder (West, Houghton, Douglas, Wall, & Whiting (1999)
- Women with intellectual disabilities (Lunsky, 2003)
- People with Down syndrome (Hurley, 1996)
- People with autism and Asperger syndrome, in whom diagnosis and assessment of depression are particularly difficult because of the overlapping nature of symptoms of these diseases (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006)
- People with sickle cell disease (Comer, 2004), who sometimes choose not to seek treatment for their depression because of the stigma associated with sickle cell disease (Jenerette, Funk, & Murdaugh, 2005)
- People with coronary heart disease and a history of heart attack, whose rate of depression may be as high as 65% (American Psychiatric Association, 2004), and who often experience high levels of depression following open-heart surgery
- Women with allergies, who show significantly higher rates of depression regardless of demographic factors or levels of neuroticism (Goodwin, Castro, & Kovacs, 2006)
- Adults with diabetes, who may be twice as likely to develop depression (Anderson et al., 2000), due both to stress and to the metabolic effects of diabetes on the brain (National Institute of Mental Health, 2002)
- People with diseases of the immune and central nervous systems such as fibromyalgia and chronic fatigue syndrome, two conditions that are still widely misunderstood; underdiagnosed; in some cases stigmatized by the medical community; and sometimes

mistaken for depressive disorders, even if depressive symptoms develop later in the course of these conditions (Hudson et al., 1992; Jason & Perdoux, 2004; Stein).

- People with cancer, approximately 15% to 25% of whom experience depression that extends beyond the normal grieving and adjustment processes (National Cancer Institute) and can be triggered (in both patients and their caregivers) by the symptoms of cancer and by the resulting immobility (Kurtz, Kurtz, Given, & Given, 1995).
- People with a history of migraine, who are believed to have a three to six times greater risk of major depression and other disorders (Estrand et al., 2004)
- People with neurological disorders (including stroke, multiple sclerosis, epilepsy, Parkinson's disease, and dementia), whose depression is an indicator of poor quality of life and has a negative impact on response to treatment of the neurological disorders, and whose overlapping symptoms may present problems in differential diagnosis (Kanner, 2005)
- People with Alzheimer's disease, whose rate of depression is estimated at 20% to 40% (Alzheimer's Association, 2005), and for some of whom unchecked Major Depressive Disorder may have contributed to the risk of developing Alzheimer's (Kennard, 2006)

The possible link between depression and immune functioning mentioned on Page 36 may play a role in the co-occurrence of depression with some of these disorders. Many illnesses (e.g., gastroenteritis, cytomegalovirus, influenza, rheumatoid arthritis, cancer, Alzheimer's Disease, Multiple Sclerosis, and other neurodegenerative disorders) are accompanied by depressive symptoms. In some cases these symptoms may be a result of immune activation and the secretion of cytokines sometimes linked to depression. Studies have shown that, in these cases, challenges in immune system regulation tend to precede the onset of depression. Also, medications and processes that lower the level of cytokines or cytokine activity (e.g., cytokine synthesis inhibitors, cytokine antagonists, and cytokine gene manipulation) can also lower the levels of depression triggered by these immune responses (Schiepers, Wichers, & Maes, 2004).

Questions for Reflection and Discussion

1. What signs or evidence have you seen of depressive disorders in people with some of the medical conditions named above?

2. What signs or evidence have you seen of people with these conditions being stigmatized for depression, or of medical practitioners failing to diagnose the depression?

HIV and Depression

Readers of this manual are no doubt far beyond the common simplistic response, “Of course people with HIV get depressed. Wouldn’t you?” However, it is worth taking a closer look at:

- The prevalence of co-occurrence
- The role of HIV stigma in contributing to depression
- Implications for service providers in general
- Implications for management of HIV and psychotropic medications.

Co-Occurrence of HIV and Depression

As always, the studies on prevalence cannot paint the whole picture, but they do give us a good place to start. Among the 3,000 people with HIV surveyed in the HIV Cost and Services Utilization Study, 36% were found to have major depression and 26.5% to have dysthymia (MATEC/GLATTC, 2002).

According to Treisman and Angelino, “Depression is a significant problem in HIV, as it serves both as a risk for perpetuating the epidemic and a complication preventing the effective treatment of infected individuals. Persons with depression care less about their own safety, are hopeless, and are more impulsive. Moreover, HIV infection worsens depressive symptoms by creating an atmosphere of helplessness and stress. In an advanced infection, HIV creates direct injuries to subcortical regions of the brain” (Triesman & Angelino, 2004, p. 33).

Although depression can be an early symptom of AIDS-related dementia, it can also be a function of, or triggered by, the psychological stress of HIV infection (Gabuzda, 1996). “Increasing symptoms, progressive disability, and decline in function may bring sadness, anxiety, fear, insomnia, and a feeling of being overwhelmed...Grief over the loss of loved ones (who may also have had AIDS) can be severe” (SAMHSA, 2000). “The diagnosis of major depression in an HIV clinic is complicated by the high frequency of depressive symptoms that are associated with chronic illness, significant losses and isolation, and complex medical treatments” (Treisman & Angelino, 2004, p. 35).

Economic and cultural factors may play a role in increasing the risk of co-occurring disorders. For example, some inner-city HIV ambulatory clinics have also reported rates of mental disorders as high as 50% (MATEC/GLATTC, 2002). And Simoni and Mayra (2003) found that 66% of their cohort of HIV-positive Puerto Rican women experienced symptoms above the threshold for a diagnosis of clinical depression.

Depression can also be part of the person’s life or history before HIV infection. Some symptoms of depressive disorders (e.g., confusion, affective instability, delusions, deficits in cognition and problem-solving skills) can even make people more likely to engage in behaviors that might raise the risk of contracting HIV (MATEC/GLATTC, 2002).

The Role of HIV/AIDS Stigma

If depression-related stigma can add to the burden of depressive symptoms, how much greater might be the effects of the stigma of HIV—stigma that is often so much stronger? “Stigma related to HIV/AIDS appears to be more severe than that associated with other life-threatening conditions,” wrote Brimlow, Cook, and Seaton (2003). “It also extends beyond the disease itself to providers and even volunteers involved with the care of people living with HIV disease. Often, HIV/AIDS-related stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, and injection drug use” (p. 1)

According to Brimlow and colleagues, “HIV-related stigma manifests itself in various ways. HIV-positive individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault. For these reasons, HIV-related stigma must be recognized and addressed as a life-altering phenomenon” (Brimlow, Cook, and Seaton, 2003, p. 3).

Along with these psychological burdens, the stigma of HIV might also contribute to delayed testing and treatment. “In a study of gay and bisexual men who were unaware of their HIV status, two thirds of the participants expressed the fear of discrimination against people with HIV and said it was a reason for not getting tested” (Brimlow, Cook, & Seaton, 2003, p. 6).

Comer, Henker, Kemeny, and Wyatt (2000) looked at the interaction of cultural factors, stigma, and co-occurring HIV status and mental disorders among women. They found that Latina women who disclosed their HIV status had higher levels of depression, psychological distress, and pain, although those findings were not replicated among women of other cultures. The authors speculated that the relative absence of HIV-positive people within these women's social networks—and the increased likelihood that disclosure will lead to greater isolation—may contribute to the association between disclosure and distress.

Implications for Service Providers

When an HIV-positive person suffers from depression as well, how much does the origin of the depressive disorder change the service provider's response? Although the diagnosis and the experience of HIV and AIDS can trigger depressive episodes, it is essential to:

- Remember that people with HIV who are depressed have both diagnoses, regardless of the order in which these disorders have appeared
- Treat both disorders (MATEC/GLATTC, 2002).

It is important to dispel the myth that HIV causes depression, or that it is natural for people with HIV infection to be depressed. A person with the HIV virus who is depressed has two diagnoses. Like any other population, the HIV-positive population has its share of people with concurrent depression, anxiety, and other mental disorders. These disorders are also more likely to become symptomatic when people are under stress. And the experience of pain, stress, and grief associated with HIV and AIDS—and with the illness and death of loved ones—can raise people's vulnerability to a variety of disorders (MATEC/GLATTC, 2002).

In an interview for this manual, Carol Goldbaum cautioned that it is also important to look beyond the stress associated with HIV infection. “Particularly in dealing with HIV, the assumption is often that a recent depression is only related to this diagnosis, but that’s usually not the case,” said Goldbaum. “There are often other familial or environmental triggers that need to be looked for.”

“The presence of depression in an HIV-positive patient warrants screening, diagnosis, and consideration of treatment...Depression and anxiety can affect immune functioning...The best practice in the treatment of these co-occurring disorders is integrated service delivery. Partnerships and mutual referral/communication networks among HIV doctors, psychiatrists, and addictions professionals are essential to patients’ well being” (MATEC/GLATTC, 2002, p. 16).

Implications for HIV Medication Management

In an ideal world, all physicians who prescribed for a particular patient would have knowledge of all of that patient’s diagnoses, prescribing physicians, medications, and doses. But in the world in which we really live:

- Patients are often overwhelmed and confused
- Clinical visits are breathtakingly brief
- Time for the necessary communication and networking may be scarce
- Case managers and other helping professionals may have even less information about these matters that can be so critical to people’s safety and well being

For these reasons, we are including some very basic information about potential drug interactions here, as a caution and an invitation to further study. Far more information is available at http://www.aidsetc.org/pdf/workgroups/pcare/pcwg_depression.pdf, in a set of clinical tools published by the AIDS Education and Training Centers (AETC). These tools include:

- Diagnostic and Treatment Algorithms
- Guidelines for selecting and prescribing medications and managing co-occurrence
- Reference tools
- Patient health questionnaires
- Medication interaction charts

Clinicians who prescribe psychotropic medications for people who have both HIV and depression have a number of important considerations to weigh in the prescription process. Many psychotropic medications have a higher potential for interactions with protease inhibitors (particularly Kaletra and Norvir) and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs). Like many anti-retroviral (ARV) medications, many psychotropic drugs may be susceptible to clinically significant interactions involving the Cytochrome P450 system (one of the many engines in the liver that help filter medications):

- **P450 enhancers**, medications that make the P450 system run more quickly, result in more rapid metabolism of other medications that use this system. So the enhancers can leave people with too little of other medications that they need.
- **P450 inhibitors**, medications that make the P450 system run more slowly, result in slower metabolism of other medications that use this system. So the inhibitors can lead to toxic levels of those other medications.

Enhancing or inhibiting effects of either the ARV or the psychotropic medications can lead to dangerous interactions. Until they know more about specific drug interactions, clinicians must remain aware of the potential for interactions (MATEC/GLATTC, 2002). Here are a few examples, but by no means do they represent a complete or exhaustive list:

- Psychotropic medications use one of the enzymes in the cytochrome P450 system that is also involved in metabolizing Ritonavir (which is included in Kaletra and Norvir). Ritonavir inhibits the enzyme in the P450 system that metabolizes the following medications:
 - Fluoxetine (Prozac)
 - Fluvoxamine (Luvox)
 - Venlafaxine (Effexor)
 - Tricyclic antidepressants such as amitriptyline (Elavil), nortriptyline (Pamelor), desipramine (Norpamin), and doxepin (Sinequan) (Diamond, 2002).

So people who take any of those antidepressants with Ritonavir can have toxic levels of their antidepressants.

- Patients can tolerate low to moderate, or even high, levels of some of the newer selective serotonin reuptake inhibitor (SSRI) antidepressants without dangerous interactions with the ARVs. Of the SSRIs, Celexa has the lowest level of Cytochrome P450 interactions, and therefore may be the safest for people taking ARVs (MATEC/GLATTC, 2002).
- People undergoing HIV treatment should avoid taking Tegretol (carbamazepine, temazepam, a mood stabilizer and anticonvulsant) or Trileptil (oxycarbazepine, a Tegretol derivative), for two reasons:
 - There are potential interactions with ARVs in the cytochrome P450 system
 - These two medications can also lead to thrombocytopenia (low platelet counts) (MATEC/GLATTC, 2002).
- Psychotic disorders and mania are challenging to treat, and unless people with these conditions are very stable, they should be under specialty care. A few cautions (MATEC/GLATTC, 2002):
 - If a patient needs mood stabilizers or antipsychotics, it is best to refer him or her to a psychiatrist.
 - If a patient is receiving lithium, he or she should be under a psychiatrist's care.
 - The older antipsychotics are no longer first-line choices for a number of reasons. They have increased risk of side effects, particularly irreversible movement disorders (e.g., tardive dyskinesia). The risk of irreversible movement disorders is higher among people with HIV, because of both the effects of HIV virus and the effects of these drugs on the basal ganglia.
 - The newer antipsychotics have fewer side effects and treat more symptoms. These antipsychotics include Zyprexa, Risperdal, Seroquel, and Geodon.

Questions for Reflection and Discussion

2. What signs or evidence have you seen of depressive disorders in people with HIV?

3. What signs or evidence have you seen of people with HIV and depression being doubly stigmatized?

4. What have been some of the consequences of that dual stigmatization?

5. What signs or evidence have you seen of medical practitioners failing to diagnose depression in people with HIV?

6. What have been some of the consequences?

Substance Use Disorders and Depression

Another common and often-tragic combination is the co-occurrence of depression with Substance Use Disorders (SUDs). First, a brief overview of these disorders for those who are not familiar with their diagnostic criteria. In the Diagnostic and Statistical Manual of Mental Disorders (DSM), the category of Substance Dependence Disorders has a number of sub-types, including two separate types of disorders, “Substance Dependence Disorders” and Substance Abuse Disorders.” They are distinguished as follows:

“The essential feature of **Substance Dependence** is a cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues use of the substance despite significant substance-related problems. There is a pattern of repeated self-administration that usually results in tolerance (the need for greatly increased amounts of the substance), withdrawal, and compulsive drug-taking behavior” (American Psychiatric Association, 2000, p. 192).

“The essential feature of **Substance Abuse** is a maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of substances...There may be repeated failure to fulfill major role obligations, repeated use in situations in which it is physically hazardous, multiple legal problems, and recurrent social and interpersonal problems...Unlike the criteria for Substance Dependence, the criteria for Substance Abuse do not include tolerance, withdrawal, or a pattern of compulsive use and instead include only the harmful consequences of repeated use” (American Psychiatric Association, 2000, p. 197).

There is also within the Depressive Disorders a diagnosis called “Substance-Induced Mood Disorder,” “a prominent and persistent disturbance in mood...that is judged to be due to the direct physiological effects of a substance (i.e., a drug of abuse) and medication, other somatic treatment for depression, or toxin exposure” (American Psychiatric Association, 2000, p. 405).

Co-Occurrence of SUDs and Depression

The 1991 National Comorbidity Survey (NCS) found people with Depressive Disorders twice as likely—and people with Bipolar Disorders seven times as likely—to have co-occurring Substance Use Disorders (Kessler et al., 1997). Estimates of co-occurring depression (allowing for the difficulty of diagnosis during withdrawal) range from 20% to 67% among people seeking treatment for alcohol dependence (Brady, Myrick, & Sonne, 1998), and from 30% to 40% among people with cocaine dependence (Quello, Brady, & Sonne, 2005).

A few more points from the literature:

- Mood Disorders are the most common disorders co-occurring with Substance Use Disorders (Quello, Brady, & Sonne, 2005).
- People (particularly women) who use illicit drugs are more likely to show higher levels of serum cortisol and more depressive symptoms than others with depressive disorders (Wisniewski et al., 2005).
- In their study of male and female street drug users, Johnson, Yep, Brems, Theno, and Fisher (2002) found that women reported higher levels of depression than men, and that people who shared needles reported higher levels of depression than those who did not.
- People in recovery from substance dependence disorders are also at greater risk of developing depressive disorders than the general population (O'Connor, Berry, Inaba, Weiss, & Morrison, 1994).

When depression and Substance Use Disorders join forces, the whole is often greater than the sum of its parts. “Mood and SUD comorbidity downgrades the clinical course, treatment outcome, and prognosis for each problem” (Quello, Brady, & Sonne, 2005, p. 13). “Studies indicate that individuals with SUD and a mood disorder have a more severe clinical course and

worse outcomes than individuals who have only one or the other” (Quello, Brady, & Sonne, 2005, p. 17).

Co-occurring Substance Use Disorders can also raise the risk of mortality from depression. “A tragic association between SUDs, mood disorders, and suicide has long been recognized. The disinhibition and despair often associated with intoxication likely set the stage for impulsive and self-destructive acts” (Quello, Brady, & Sonne, 2005, p. 17).

Quello, Brady, and Sonne (2005) review the three categories of theories that attempt to explain the high co-occurrence of mood and Substance Use Disorders:

- **“Disorder Fostering Disorder,”** that the symptoms of one disorder might increase the risk of developing the other (e.g., self-medication for depressive symptoms with alcohol or other drugs)
- **“Overlapping Neurobiological Pathways,”** the tendency of each disorder to grow more intense by sensitizing neurons through a process called “kindling”
- **“Underlying Genetic Factors,”** emphasizing the likelihood that the families of people with one type of disorder might also have a history of the other, and that people who inherit a vulnerability to one might also inherit vulnerability to the other.

The Role of Stigma

Like the symptoms of co-occurring depression and Substance Use Disorders, the combined stigma associated with these two types of disorders can also have synergistic effects. White (1998) tells a chilling tale of the signs and symptoms of the stigma of addiction throughout American history, including:

- The contempt for alcoholics shown in early temperance movements
- Sensationalized media coverage of people with substance dependence disorders
- Sterilization of alcoholics and addicts, as an attempt to contain their disorders
- The use of electroconvulsive therapy to try to cure alcoholism
- The use of lobotomies on alcoholics in 1940s and 1950s
- The harsh, punitive techniques used in the early therapeutic communities
- The increasing criminalization of substance use and its consequences in contemporary society
- The pop culture denial that addiction exists, and the assertion that it is simply a failure of will power

Like the stigma of depression, the stigma of Substance Use Disorders also rests on a number of central myths, including:

- A tendency to consider Substance Abuse and Substance Dependence the same disorder, to refer to them both with the stigmatizing term, “substance abuse,” and to call people with these disorders “substance abusers”
- The belief that Substance Dependence Disorder does not really exist, that it is rather a moral weakness or a failure of will power
- The belief that all people with Substance Dependence Disorder should be able to achieve permanent abstinence from alcohol and other drugs as soon as they begin treatment or recovery

- The tendency to characterize a return to substance use as a “relapse,” whether or not the person has actually achieved recovery
- The tendency to blame people for relapse or return to use, regardless of the many factors (including inappropriate treatment) that may be propelling them toward return to use
- The belief that dependence on certain substances (e.g., illegal drugs and substances associated with low-income groups or people of color) is somehow “worse” or less of a legitimate disorder than dependence on alcohol or prescription medication
- The belief that people who achieve recovery through methadone treatment are not really in recovery, in spite of ample evidence of the effectiveness of this form of treatment

As self-stigma keeps people from seeking help for depression, it has an equal if not greater effect on people’s ability to accept the fact that they have a problem, and to seek and receive treatment for SUDs. In a 2001 survey of 250 people in recovery from substance dependence disorder, 40 percent of the survey respondents identified shame as a significant obstacle to recovery. Nineteen percent cited the fear of discrimination, and 60% cited denial (Hart, 2001). Of the survey respondents:

- 63% said the public needs to know that shame and discrimination hinder recovery
- 39% had experienced shame or embarrassment about being in recovery
- 37% were concerned about others knowing when they first sought help
- 12% had been denied a job because of recovery status
- 12% had been denied insurance or had paid higher premiums³

Just as there is no clear evidence of the extent to which stigma is keeping people from seeking help for Substance Use Disorders, we have no idea how many are also delaying the quest for help for their co-occurring depressive disorders out of shame at having one or both disorders. In each case, the delay allows both diseases to progress, to inflict more damage, and to complicate the course of future treatment.

Implications for Treatment

The task of untangling these two complex disorders is a challenging one, given the number of symptoms and circumstances they share:

- When people enter treatment for depression, they may report high levels of substance use. These levels of use might be signs of Substance Use Disorders that existed before their depressive disorders began, Substance Use Disorders that are secondary to the depressive disorders, or attempts to self-medicate the painful symptoms of depression that have not progressed to Substance Use Disorders.
- When people enter treatment for Substance Use Disorders, they may show or report depressive symptoms. These symptoms might be signs of depressive disorders that existed before the Substance Use Disorders began, symptoms of depressive disorders that are secondary to the Substance Use Disorders, or symptoms of something called “Post-Acute Withdrawal Syndrome.”

Post-Acute Withdrawal Syndrome (PAWS) is a set of neurological, emotional, and motor

³ Regarding the last two percentages cited, it is not clear what percentage of respondents actually disclosed their recovery status to potential employers or insurance carriers.

symptoms that many people with substance dependence disorders experience during the first six to 18 months after they stop using alcohol/addictive drugs. These symptoms are natural outgrowths of the body's attempt to return to normal after being poisoned with these substances. Many of the PAWS symptoms resemble symptoms of depression, including:

- Cognitive deficits:
 - Difficulty with problem solving and decision making
 - Difficulty understanding the meaning of other people's communication
 - Memory deficits, both long and short term
- Emotional lability:
 - Mood swings
 - An inability to understand their own feelings
- Sleep disturbances:
 - Insomnia
 - Falling asleep at inconvenient times
 - Vivid dreams and nightmares
- Difficulty recognizing and managing stress:
 - Partly an effect of difficulty understanding one's own feelings
- Endocrine system disruption:
 - Changes in the levels of testosterone and estrogen (Rosenfeld, 2002)

These similarities yield two dangers:

- That PAWS symptoms or natural grieving processes will be mistaken for clinical depression and treated inappropriately with antidepressant medication
- That depression will be mistaken for PAWS, for “resistance to treatment,” or for “being on the pity-pot,” and so will not receive appropriate treatment

Unfortunately, many people who show signs of depression in early treatment or recovery do indeed have serious depressive disorders. For people who have been “self-medicating” symptoms of depression with alcohol or other drugs—and for people for whom the ravages of these substances and attendant lifestyles have brought about neurological changes that have induced depressive disorders—the ascent into sobriety can also be a descent into full-blown depression.

The effects of stigma have significant impact far beyond the individual's willingness to seek help. Stigma also guides many decision-making processes among policy-makers and those who determine third-party payment for treatment services. Stigma can also impair collaboration among allied helping fields, including the SUD treatment field and the mental health field. There is a critical need for greater cross-education and cross-training, stronger collaboration, and more effective communication on the needs of individual consumers.

The SUD treatment system has many “revolving doors.” One of these metaphorical doors leads back and forth between mental health treatment and SUD treatment. The all-too-common patterns include a number of sequences such as this:

1. Initial abstinence in SUD treatment, with depressive symptoms unrecognized or untreated by clinicians
2. Successful discharge from SUD treatment
3. The emergence of depressive symptoms after treatment has ended

4. Return to substance use to ease the symptoms of depression
5. Further progression of the symptoms of both disorders
6. Attempts to seek treatment for depression, with access to treatment denied because of the active substance use

Many mutual help recovery groups and paraprofessionals who run recovery homes for people with SUDs have gained increasing knowledge and acceptance of co-occurring mental disorders and their treatment. However, some people in recovery still encounter misunderstanding, rejection, and inappropriate advice from members of their recovery support systems. When lack of knowledge is combined with an authoritarian leadership style, people who need psychiatric treatment and psychotropic medication can be shamed and even discouraged from seeking or remaining in mental health treatment, leading to recurrence of symptoms of one or both disorders.

With two types of disorders that so often seem to contribute to one another's course—and can so easily prove fatal on their own—each of these complications represents a significant danger. Clinicians in both fields would do well to:

- Learn as much as possible about all co-occurring disorders
- Assess for co-occurring disorders at the outset, regardless of the fact that assessment might be more productive after the symptoms of one disorder began to diminish
- Weigh all factors carefully in the assessment process, maintaining a careful balance between the desire not to over-treat and the desire not to under-treat
- Educate people who have these disorders in the implications of each disorder, including the stigma, misunderstanding, and counterproductive advice they might receive in the outside world

Questions for Reflection and Discussion

1. What signs have you seen of depressive disorders in people with SUDs?

2. What signs have you seen of people with SUDs and depression being doubly stigmatized, and what have been some of the consequences?

3. What signs or evidence have you seen of medical practitioners failing to diagnose depression in people with SUDs, and what have been some of the consequences?

Trauma and Depression

The experience of stress and trauma may be the most central, most pivotal contributor to vulnerability to depression, other mental disorders, and other physical disorders that we will ever encounter. Resilience—“the capacity to recover following a stress” (Rosenbaum & Covino, 2005)—is the mind’s, the body’s, and the spirit’s answer to stress and trauma. But in depression, resilience is often compromised. It is worth a little further exploration of human responses to trauma both as co-occurring conditions and as contributors to depression.

First it is important to note that many experiences that are not traumatic are still highly stressful, and that a single stressful episode, or the cumulative effects of multiple episodes or life patterns, can have significant effects on people’s vulnerability to depression or other disorders. One does not have to survive a hurricane or a tornado in order to experience a sudden or gradual wearing down of one’s natural resilience. And in many ways, it is not only the stressful events, but also the degree to which the neurology is allowed to recover after or between stressful situations, that determines the degree of stress they place on the individual’s reserves of resiliency.

It is also important to remember that not all post-trauma reactions constitute the diagnosis, Posttraumatic Stress Disorder (PTSD). In the Diagnostic and Statistical Manual of Mental Disorders, this is the description of PTSD:

“The essential feature of Posttraumatic Stress Disorder is the development of characteristic symptoms following exposure to an extreme traumatic stress or involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one’s physical integrity; witnessing an event that involves death, injury, or threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate... The person’s response to the event must involve intense fear, helplessness, or horror (or in children, the response must involve disorganized or agitated behavior)” (American Psychiatric Association, 2000, p. 463).

PTSD Symptoms include a re-experiencing of the event (through intrusive memories, dreams, or psychological reliving of the event), continuing avoidance of stimuli associated with the trauma, numbing of general responsiveness, and continuing symptoms of increased arousal (e.g., insomnia, anger, problems with concentration, hypervigilance, and exaggerated startle response) (American Psychiatric Association, 2000).

Symptoms that occur within the first month after trauma are diagnosed as Acute Stress Disorder. Posttraumatic Stress Disorder can be diagnosed after one month, with one of these specifiers: “Acute” (lasting less than three months), “Chronic” (lasting three months or longer), or “With Delayed Onset” (beginning at least six months after the traumatic event).

However, most people respond to trauma with a variety of physical and psychological effects. These are normal, natural reactions to the extraordinary amount of effort that the body and mind must put forth to survive and function in the face of intense pain, fear, and/or grief (Woll, 2006). These effects are in no way pathological, although they can “use up” some of our natural stores of resilience and leave us more vulnerable to conditions such as depression.

Co-Occurrence of PTSD and Depression

Of the people treated for Posttraumatic Stress Disorder (PTSD), 48% receive a co-occurring diagnosis of depression. (Shumake & Gonzalez-Lima, 2003). But according to DeMarco (2000), traumatic stress may be more a predictor of an initial episode of depression than a predictor of recurrence. Social support and self-esteem can also limit the effects of stress on the likelihood of depression (DeMarco, 2000).

Age and gender can contribute to vulnerability to post-trauma effects. For example, some studies indicate that women are more likely than men to show more severe post-disaster symptoms, and school-aged children show greater post-disaster impairment than adults, but younger and middle-aged adults show higher levels of distress than older adults (Norris, 2002).

The Substance Abuse and Mental Health Services Administration estimates that as many as half a million survivors of Hurricane Katrina may need psychological help for depression, anxiety, and Posttraumatic Stress Disorder (Barrett, 2006).

Shared Neurobiological Roots

There seems to be an interactive network of neurochemicals that respond to acute stress and regulate one another. We have yet to map that network and its effects, but we do know enough to respect its power and complexity.

According to Rosenbaum & Covino (2005), “The vulnerability to stress and an individual's capacity for resilience and/or recovery are complex, reflecting the biological state and genetic and environmental risk or resilience factors. The contribution of stress to the onset and course of depression and anxiety requires more study. New tools, such as neuroimaging and genetics, may clarify our understanding of the role that stressors may play in either the new onset of illness or the exacerbation of symptoms associated with depression and anxiety” (Rosenbaum & Covino, 2005).

The results of multiple studies have suggested that a greater vulnerability to depression in response to stressful events—including maltreatment in childhood—may be linked to characteristics of the gene that rules the transport of serotonin, the 5-HTT gene (Rosenbaum & Covino, 2005). As you will recall from Chapter Three, serotonin plays a key role in the regulation of moods. And as you may recall from Chapter Four, the 5-HTT gene is also one of the genes whose characteristics may affect the potential effectiveness of treatment with antidepressant medication.

As mentioned in those chapters, norepinephrine and cortisol are also important players in the neurological processes that affect moods. Studies using military trainees have indicated that people whose bodies respond to stress more effectively with certain chemicals tend to perform better under psychological and physical stress. These chemicals include the peptide neurotransmitter **neuropeptide Y**, which tends to counteract the effects of norepinephrine; and **DHEA** (dehydroepiandrosterone), an adrenal steroid that may counteract the effects of cortisol (Rosenbaum & Covino, 2005).

Stigma and Post-Trauma Responses

One very common myth that underlies much of our stigma is the belief that human beings should always be “tough.” “Hard” emotions such as anger and aggression are considered strong, and “soft” emotions such as sadness, empathy, and fear are considered weak. Many people consider post-trauma responses signs of weakness or an inability to survive—when they really are signs of the body’s amazing ability to survive and adjust to the effects of trauma (Woll, 2006).

Although PTSD has been a well known condition since it was first identified in Vietnam War veterans (and before that, when it was known as “shell shock” or “battle fatigue”), it is still misunderstood and stigmatized among many people—including many people who suffer from it.

Like the stigma directed toward depression, the stigma directed toward post-trauma responses also tends to create that which it condemns. It does this by discouraging people from seeking help before their problems have escalated to crises, for fear that others will know how “weak” they are. Stigma also complicates the course of post-trauma reactions by encouraging people to numb or “control” their feelings and reactions. Feeney and colleagues (2000) found that people who experienced more emotional numbing after trauma were more likely to develop Posttraumatic Stress Disorder, regardless of their other depressive or dissociative symptoms.

Initial reactions to trauma often include denial or discounting of the event or its consequences, anxiety, intense emotions (e.g., sadness, anger, fear, guilt), personal disorganization (“falling apart”), and physical symptoms (e.g., headaches, migraine, dizziness, fainting, increased heart rate, changes in blood pressure, shortness of breath, lethargy, fatigue, digestive system dysfunction) (Brenson-Lazan & Sarmiento, 2001).

As it is, the experience of these normal post-trauma reactions can be painful and frightening, and the idea of avoiding them can seem attractive. But people who also consider these initial reactions pathological may be even more tempted to “stuff,” cover up, or delay their feelings and reactions, with or without the help of sedatives or antidepressant medications. Even people who do not have depressive disorders may assume that they do have depressive or post-trauma disorders, when their reactions—although quite uncomfortable—may be quite normal and healthy. And people who do have depressive disorders or PTSD might simply try harder to hide their symptoms, by “numbing them off,” “toughing them out,” or drowning them in alcohol or drugs.

It is ironic that the steps people often take to dampen emotion and ward off what they think of as unhealthy responses may in some cases raise their risk of developing unhealthy responses later. Brenson-Lazan & Sarmiento (2001) cite four “dysfunctional strategies” that people sometimes use to cope with their initial reactions to trauma:

- **Agitate:** Avoid awareness of the current reality
- **Abdicate:** Become passive and dependent
- **Automate:** Become stuck in unproductive behavior with the hope that it might become productive
- **Alienate:** Try to gain control through hostile and/or aggressive behavior, power struggles, etc.

According to Brenson-Lazan & Sarmiento (2001), the frequent or dominant use of these counterproductive strategies can lead to a secondary crisis, marked by more rigid behaviors or

disorders (e.g., hyperactivity, apathy, excessive identification, chronic psychosomatic disorders, relational crises, drug/alcohol dependence, aggression, suicide attempts, or depressive disorders with psychotic features), leading to a need for more professional help. They cite several factors that tend to increase the risk of a secondary crisis, including a history of depression and a delay in the grieving process following a traumatic incident.

As to the role of stigma in complicating the effects of trauma, it may differ greatly from person to person. In general, the more an individual, family, or culture stigmatizes emotion, the more that stigma is likely to keep people from working through their normal post-trauma reactions and seeking help when they need it.

Questions for Reflection and Discussion

1. On a scale of 1 to 10 (1="not at all" and 10="completely"), how high is the level of stress in the lives of many of the people you serve?

1 2 3 4 5 6 7 8 9 10

2. What are some of the major stress factors they face?

3. On a scale of 1 to 10 (1="not at all" and 10="completely"), how significant is the experience of trauma in the history of many of the people you serve?

1 2 3 4 5 6 7 8 9 10

4. What correlation (if any) do you see between the experience of trauma and the development of depression?

5. What evidence of depression have you seen in people with no history of trauma?

With this last look at the tangle of symptoms, syndromes, and disorders, we leave our examination of depressive disorders and move to a more concentrated focus on stigma itself. The next two chapters look at stigma and its effects, and the final two chapters look at hope and healing.

Louise's Story

Louise lay in the grass in the park across from her home, looking up at the sky and telling God she wanted to die. She was three or four years old.

In her family, Louise was her alcoholic father's favorite child, and the only one he did not mistreat. She thought this might be because she had dark skin like his mother, but she never really knew. In school as a small child, she was painfully shy and withdrawn, and spoke only when questioned. Her teachers recommended that she visit the school social worker.

In middle school and high school, Louise sought refuge from her emotional pain in alcohol, marijuana, pills, and cocaine. After high school, though, she switched to beer, tired of hangovers and attempted rapes.

In her mid-twenties, now an accountant, Louise moved out of state to take a new job. She was no longer drinking or using any drugs. A few months later, she began to believe some of her co-workers were taunting her because they interpreted her shyness as snobbery. She immediately began to have daily crying spells, with intense, constant feelings of sadness and despair. It took every ounce of energy to leave her couch, dress, and go to work each day. At the end of the day she would sink into the couch and remain there until the following day. Many days she called in sick.

Louise called her family, seeking support. Their responses, though well intentioned, were confusing and not helpful. One day, on an expressway, Louise made her first attempt at suicide. She closed her eyes and drove around a curve at high speed, crying, "I want to die, God!" Soon after that, she packed up and moved back to her mother's house.

For the next eight months, Louise was bedridden with depression, sleeping all day and wanting to die. She would not consider the possibility that she might have a mental illness, thinking it horribly shameful. But one day her sister gave her a self-help book by John Bradshaw, in which he recounted his story and advised people with suicidal feelings to contact the nearest hospital. She followed that advice, despite her mother's warning that "All those white people are going to do is write a book about you!" She started receiving medication and therapy. In her words, "My healing began."

For the next few years Louise had spotty success. Her psychiatric medication helped, but the pain was still intense, and she once again began self-medication with alcohol and other drugs. After her eldest sister died of AIDS-related illness, Louise tried suicide a second time, and then started smoking crack cocaine for relief.

She also started attending 12-Step recovery meetings and made some healthy connections there, but her intense shame and shyness often made the meetings more painful than her addiction. She desperately did not want the people in the meetings to know she had a mental illness.

Louise spent the next several years traveling in and out of treatment programs for her addiction to crack. At age 40, she entered a highly recommended privately owned recovery home, where she thought she would be able to heal without the temptation to drink or use. But the recovery home staff and the 12-Step sponsor they had found for her talked her into discontinuing all of her psychotropic medications, including one antipsychotic.

Soon Louise's paranoia returned full-force. She cut off all connections with the 12-Step community—healthy and unhealthy—and suffered an emotional breakdown. Back in her room at her mother's house, she slept, prayed, and listened to Gospel music. After a while, she started to take all her medications again.

As functioning returned, Louise began to read voraciously—The Bible, Mother Theresa, St. Francis of Assisi, Gandhi, Maya Angelou, Iyania Vanzant, M. Scott Peck, Marianne Williamson, A Course in Miracles, Wayne Dyer, and others. These were her mentors and her guides. Before that year was over, Louise was able to return to work in a temporary position. She spent her first paycheck on crack cocaine, which kept her high all night. The next day she felt like crying all day, but she made it through work, then sobbed all the way home, praying. She felt as if she were in a state of complete surrender. She stopped using completely.

Three years ago, Louise accepted a permanent job and began therapy once more. She was able to take in her high school-aged nephew, who needed a home, and began to instill in him her love of learning. Last year she stopped smoking cigarettes, and this year she is beginning a regular exercise program. She recently had the courage to re-connect with healthy friends from her past, with whom she had burned all bridges after she had stopped taking her antipsychotic medication. Not knowing how her friends would react after all the things she had said and done in her paranoia, Louise nevertheless took the plunge.

Louise is still quite shy, and still learning how to navigate the complex social situations in her workplace, her family, and her life. The symptoms of her depressive disorder also rise and fall, sometimes triggered by these social situations. But she seeks guidance from her therapist and her mentors when the shame and self-stigma begin to distort her thinking. Through an active prayer life and an active sense of humor, adherence to her treatment and therapy, healthy friendships, and guidance from her many spiritual teachers, Louise is building her own kind of recovery.

It is not a life without pain, shame, or depression. But it is a life lived with love, friendship, and joy.

Responses to Louise's story

1. What were some thoughts that went through your mind when you read Louise's story?

2. What were some feelings you had when you were reading Louise's story?

3. What could her family or pastor have done that might have been more helpful than the responses they chose?

4. What would you tell the recovery home staff and volunteers who persuaded her to stop taking her medication?

5. If you or someone you knew needed emotional healing, and you were to recommend some books that might help, what would be your first few choices?

6. How would you have felt, and how would you have reacted, if a friend or client who had broken off your relationship in a psychotic state several years ago contacted you and told you about his or her recovery?

7. If you could ask Louise anything right now, what would it be?

8. If you could tell Louise anything right now, what would it be?

Chapter Six: Stigma and Depression

Much of the stigma of mental illness is ingrained in deep and ancient attitudes held by virtually every society on earth. These attitudes govern the decisions societies make and the behaviors they tolerate. Newspapers and television stations can print or broadcast statements about those with mental illness that simply would not be tolerated if they were said about any other minority group. Stigma also insinuates itself into policy decisions, access to care, health insurance, employment discrimination, and in research allocations and priorities. Unfortunately, people who have mental illness also stigmatize themselves. They make few demands and their expectations are frighteningly low—with grave consequences. Stigma can kill.

Kay Redfield Jamison, from “The Many Stigmas of Mental Illness”

If stigma were a diagnostic category in the *Diagnostic and Statistical Manual of Mental Disorders*:

- It would probably contain several distinct disorders, including things like “Stigmatizing Episode,” “Primary Stigmatization Disorder,” “Self-Stigmatization Disorder,” “Courtesy Stigmatization Disorder,” and (of course) “Stigmatization Disorder Not Otherwise Specified.”
- Symptoms of Primary Stigmatization Disorder might include “persistent and delusional belief in the worthlessness or inferiority of the target group,” “distorted perception of the assets and liabilities of target group members,” and “acts of subtle or flagrant discrimination.”
- Symptoms of Self-Stigmatization Disorder might include “persistent and delusional belief in one’s own worthlessness or inferiority” and “fear of seeking help for legitimate human concerns.”

Stigma certainly deserves a diagnostic category. In 1999, United States Surgeon General David Satcher declared stigma the most important problem facing the mental health field (US Department of Health and Human Services, 1999). In a survey of mental health service consumers, “...fully 78% reported overhearing hurtful or offensive comments about mental illness, and more than a third reported being treated as less competent by others” (Teachman, Wilson, & Komarovskaya, 2006, p. 77).

“If all stigmatized conditions were considered together and all outcomes examined, we believe that stigma would be shown to have an enormous impact on people’s lives,” wrote Link & Phelan (2006). “To exemplify one part of this point we analyzed nationally representative data from the USA, in which multiple stigmatized conditions were taken into consideration in relation to self-esteem, and found that stigma could explain a full 20% of the variance beyond the effects of age, sex, and years of education” (Link & Phelan, 2006, p. 528).

Depression is not stigmatized as heavily as many other serious mental illnesses, such as schizophrenia (Gaebel, Zaské, & Baumann, 2006), perhaps because so many of its symptoms are easier to hide than those of other disorders. However, its burden of stigma, stereotypes, and discrimination is still sufficient to deprive people of hope, opportunities, well-being, and help that might save their lives.

A number of factors can contribute to the stigma directed toward depression, and to its complexity:

- Because depression exists on the same continuum as healthy moods and personality traits, it may seem like a tangible possibility for individuals who are not afflicted with it, and therefore more of a threat than many other stigmatized conditions. In some people, this can lead to a stronger desire to isolate depression and gain distance from the people who suffer from it.
- Many elements of our society's cultural and political heritage predispose us to have difficulty reconciling our concepts of strength and health with an illness like depression and the need to take medication to manage it.
- The most extreme symptom of depression (suicide) is illegal, is highly stigmatized, and is even considered by some religions an "unforgivable sin." This adds elements of moralism and legalism to the already complex mixture of thoughts and feelings that fuel this stigma.
- In many cases self-stigma, and the resulting sense of secrecy, may be mixed with a legitimate desire for privacy in this very personal area of human experience. Loyal and protective friends and families may have strong motivation to respect that desire for privacy, and a fear of alienating their loved ones by intervening or discussing this condition with helping professionals.

The next chapter will consider some effects of stigma, including discrimination and self-stigma. But first, this chapter will look at the initial stigmatizing attitudes, including:

- Why people stigmatize
- Attitudes toward depression and toward its treatment
- Cultural influences on stigma
- Stigma among, and toward, helping professionals

Questions for Reflection and Discussion

1. Of the factors listed above (contributing to stigma and its complexity), choose one and explain why you believe it is significant.

Why People Stigmatize

Very few people stigmatize others out of a malevolent desire to hurt them, or even to insult them. Stigma and discrimination are seldom primary goals. More often they are by-products of cognitive or emotional processes we believe are essential to our own well-being. If we have strong feelings about our need for these processes, we may tend to stigmatize more strongly, overlook things we know to be true, and tolerate our behaviors that violate some of our basic values.

It is helpful to think about motivation toward stigma in two ways:

- In terms of our **thinking**—our process of reconciling what we see and hear with our beliefs, so we can feel comfortable and certain
- In terms of our **feelings**—our process of using our beliefs, thoughts, feelings, and attitudes to defend ourselves against emotional discomfort

Thinking: The “Rational Actor”

According to Corrigan (2004), “Psychologists have argued for more than a century that humans are fundamentally rational actors; that they behave in specific ways based on their ‘logical’ understanding of the circumstances. Psychologists describe the notion of humans as rational actors with a simple formula: Attitudes → Behaviors” (Corrigan, 2004, p. 13). In other words, people stigmatize largely because of what they believe. Most people’s beliefs about the nature and course of mental illness and its treatment come from media reports, from personal contact with people who have these illnesses, and from knowledge about the mental health care system (Gaebel, Zaské, & Baumann, 2006).

Attribution theory takes it a step farther by describing the emotional component. This theory “holds that behavior is determined by a cognitive-emotional process: persons make attributions about the *cause* and *controllability* of a person’s illness that lead to inferences about *responsibility*. These inferences lead to *emotional reactions* such as anger or pity that affect the likelihood of *helping or punishing* behaviors” (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003, p. 165).

Many authors (e.g., DHHS, 1998; Link, Phelan, et al., 1999; Hinshaw, 2005) have noted the common fear that people with mental illnesses are “dangerous.” Hinshaw (2005) describes four dimensions of stigmatization that can increase its strength or its effects. These include:

- **Concealability**, often a factor when symptoms of depression are not apparent on the surface, leading to anxiety about whether or not to reveal the condition
- The **Chronicity** of the condition, leading to a far greater likelihood that it will be stigmatized
- Perceived **Dangerousness**, associated with depression primarily through the risk of suicide
- **Controllability**, the belief that people can control their symptoms, a belief that often diminishes compassion and leads to blame and anger (Hinshaw, 2005).

Teachman and colleagues wrote that “These blaming views are presumably associated with the numerous negative consequences that follow perceiving an illness as controllable...such as

reduced pity or desire to help and increased anger toward the marked person” (Teachman, Wilson, & Komarovskaya, 2006, p. 91). The fact that many people have implicit or unconscious biases indicates that “...even wishing to be tolerant or feeling conscious positive evaluations may not be sufficient to override the enormous number of negative social messages about mental illness encountered every day” (Teachman, Wilson, & Komarovskaya, 2006, p. 92).

Another common belief is that people with mental illnesses cannot take care of themselves or make decisions for themselves (Corrigan & Lundin, 2001). This view exists, not only in the general public, but also among some mental health providers, often leading to a reduction in the self-direction that is so essential to effective treatment and recovery. Hinshaw (2005) described an ambivalence that is common to stigmatizing responses, combining sympathy and concern for symptoms with distancing and discrimination based on over-learned, biased associations.

A 2003 study by Corrigan and colleagues (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003) suggested that familiarity with mental illness often reduces people’s discriminatory responses. According to that study, those who believe that people with mental illnesses have somehow caused their illnesses are more likely to avoid, coerce, or segregate people with those illnesses, or to withhold help. However, they also found that people did not need to believe that those who suffer from mental illness caused their illness in order to believe that they are dangerous.

In an interview for this manual, Amy Watson noted that the stigma attached to depression is different from that directed at many other forms of mental illness, in that it does not carry with it the strong sense of “dangerousness” that people often associate with other disorders. However, she said, a great deal of blame and frustration is often directed at people with depression who are not “getting better” as quickly as they or others believe they should.

Stigma as an Antidote to Emotion

Sometimes our responses to illness grow more complicated. We may have learned multiple and sometimes opposing views of the illness, or our beliefs might lurk beneath conscious awareness. In many situations, we might have trouble tolerating our emotional reactions to the symptoms of people with the illness. In these cases, our emotions might tip the scales, propelling us toward the attitudes and actions that bring us relief from our discomfort.

Ernest Kurtz once pointed out that most of us fear the limitations that we all have as human beings. When we see someone who seems to have an extra layer of limitation—perhaps an inability to feel good, to complete a task, or to get out of bed—it might remind us of our own limitations, whether or not our limitations are the same. This creates discomfort. However, if we can make this person a symbol of limitation itself, thereby creating some distance between us, we might be able to forget for a time that we, too, are limited human beings (Kurtz, cited in Woll, 2005).

Some of the emotions we experience in the face of illness might also have strong influences on our beliefs. For example:

- A man might have heard since childhood that people with depression are lazy and weak.
- He might have read several pamphlets that explain the illness and its symptoms, and these explanations might make sense to him.

- His wife might be unable to get out of bed because of a depressive disorder
- He might have compassion for her pain, but he may also feel helpless and frightened.
- Feeling angry and judgmental toward his wife might be more comfortable to him than feeling compassionate, helpless, and frightened.
- He might unconsciously “choose” the less tolerant beliefs that are more congruent with the more comfortable, less compassionate emotions. But he might not be conscious of having chosen those beliefs. Instead, the beliefs might seem to be driving the emotions.

Hinshaw (2005) describes three factors that can have a negative effects on families’ attitudes toward family members with mental illness:

- The pain associated with experiencing and responding to the illness
- The tendency to blame the parents for the existence of mental disorders, which may make parents reluctant to seek help for their children
- Families’ tendency to respond with shame and secrecy, increasing isolation and reducing social support

Evolutionary psychologists speculate that stigma might have deep roots in survival-level fears, including a fear of contagion and “low social viability.” If that is true, a characterization of moods as “contagious” might trigger stigmatizing reactions toward depression, and the toll of depression on social functioning might influence social attitudes toward people with depression (Hinshaw, 2005).

But according to Jamison (2006), moods really are contagious. “Hypomania and depression can spread across members of a group like wildfire. That is, in part, what moods are for—to affect others in a group. So we have to acknowledge that mental illness can have a powerful effect on those close to it” (p. 534).

In some ways, stigma might be thought of as an elaborate defense structure against uncomfortable emotions such as pain, ambivalence, and fear.

- Depression is not as painful for the people who surround it as it is for the person who experiences it first hand, but there is pain in watching people suffer, losing valued activities and routines, compensating when people are debilitated and cannot fulfill responsibilities, losing loved ones to suicide, etc.
- Onlookers often have a hard time understanding why people who are depressed believe some of the things they believe, feel the way they do, and act (or fail to act) as they do. Those watching the process of depression may simultaneously feel:
 - Loving
 - Concerned
 - Sympathetic
 - Mistrustful
 - Frustrated
 - Fearful for their loved ones
 - Fearful of their own losses
 - Helpless in the face of something they can neither control nor understand
 - Sad, grieving the relationship they could have had
 - Angry at the person with the depressive disorder

- Angry with themselves for being angry
- Angry with themselves for not being able to make things better
- Ambivalence can be difficult to tolerate. Concerned onlookers may fear the jumble of emotions that they feel, and associate that fear with the people and experiences that inspired them. They might feel a need to create distance, to construct psychological defenses that will protect them from pain and ambivalence. Stigmatizing beliefs can be important parts of those defense systems. Judgmental attitudes can even seem like important ways of helping—as if understanding someone else's behavior somehow perpetuates it, and judging or criticizing the behavior somehow discourages it.

If these experiences take place when people are more impressionable—childhood, for example—it is possible that the belief systems they construct will tend to be more rigid. Of course, both children and adults have the option to respond to their discomfort in many other ways. They can seek help, they can seek information, and they can choose to tolerate the uncomfortable emotions without retreating into judgmental attitudes and stigmatizing beliefs. However, these options often require levels of emotional strength and courage that may not be available under conditions of extreme stress.

Questions for Reflection and Discussion

2. Of the two factors influencing stigma described above (thinking and feeling), which seems most important or powerful to you, and why?

3. What were some of the beliefs about people with depression that you grew up with, and how might they have influenced your attitudes toward the people you serve who have depressive disorders?

4. What are some uncomfortable emotions that other people's depression seems to raise in you, and how might these emotions have influenced your attitudes toward the people you serve who have depressive disorders?

Next comes a look at some of the beliefs and attitudes that come out of these processes.

Attitudes

Attitudes toward people with depression have been studied less frequently than attitudes toward mental illness in general. Regarding the latter, there is good news and bad news: "... although public understanding of the nature of mental illness has improved since the 1950s, there is still a strong tendency towards avoidance" (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003, p. 163). According to the results of one survey, 85% of Americans believe people with mental disorders are not to blame for their conditions, but only 26% believe people are caring and sympathetic toward people with mental illness, and only a quarter of young adults believe that people with mental illness can eventually recover (Ad Council, 2006).

In a study of people with and without psychiatric diagnoses, Teachman and colleagues studied explicit bias (bias that people consciously choose to hold) and implicit bias (bias that is unintentional, often lying outside conscious control and awareness) toward mental illness, and compared it with attitudes toward people with physical illnesses (Teachman, Wilson, & Komarovskaya, 2006). They found that people both with and without psychiatric diagnoses:

- Held high levels of implicit bias in the areas of negative attitude, blaming, and belief in the helplessness of people with mental illnesses
- Held explicit bias in the areas of negative attitude and belief in the helplessness of people with mental illnesses

Implicit biases can be particularly powerful, precisely because people are not fully aware that they hold them and therefore do not tend to question these biases or try to control the actions that spring from them.

In a survey of attitudes toward people with mental illness in general, findings from the MacArthur Mental Health Module, 1996 General Social Survey (Pescosolido et al., 2000) showed that Americans are hesitant to interact with people who have mental illnesses:

- 38% are unwilling to be friends with a person having mental health difficulties.
- 64% are unwilling to have a person with schizophrenia as a close co-worker.
- More than 68% are unwilling to have a person with depression marry into their families.

In Switzerland, Lauber and colleagues (2003) found that members of the general public contacted in telephone surveys identified the following as the most likely causes of depression:

- Difficulties within the family or the partnership (56.6%)
- Occupational stress (32.7%)
- Unspecified further stress (19.9%)
- Traumatic events (17.9%)
- Depressive disorder (14.1%)
- Further unspecified illnesses (11.6%) (Lauber, C., Falcato, L., Nordt, C., & Rössler, W., 2003)

In an Australian study, Jorm and colleagues learned that respondents often saw environmental factors as likely causes of depression, and half of the people interviewed identified weakness of character as a likely cause of depression (Jorm, Korten, Rodgers, Pollitt, Jacomb, Christensen, & Jiao, 1997).

Although there is some evidence that an understanding of the genetic and biological aspects of depression can reduce stigma, some researchers are finding that this kind of information may not have the desired effect, may lead to stigmatization of relatives, and in some cases may increase the desire for social distance (Hinshaw, 2005). According to Corrigan and colleagues, “educational programs that focus on biological causes may increase pity, or sympathy, for people with mental illness...But pity yields both positive and negative results.... In trying to elicit sympathy, there is an overreliance on or dramatization of what people with mental illness cannot do” (Corrigan, Watson, Byrne, & Davis, 2005, p. 365).

But stigmatizing attitudes are certainly not limited to people’s beliefs about the nature of the stigmatized condition. A stigmatizing attitude might be any stereotypical view, any attempt to reduce the whole human being to a narrow and negative set of real or assumed characteristics. According to advocate M. Fred Friedman, people who know of a consumer’s mental health diagnosis will sometimes attribute to that diagnosis emotions or attitudes that are simply part of being a human being. For example, if someone with depression becomes angry or frustrated, a friend might interpret that anger or frustration as a symptom of the depression—particularly if the friend is uncomfortable with those emotions.

Stigma Toward Treatment

Another clear target of stigma is the field of mental health treatment. “In my own experience as a mental health professional, it’s difficult to go very long without experiencing the reality of stigma around mental illness, people saying ‘I don’t believe in mental health treatment,’ as if it’s a belief system,” said Terrence Koller in an interview for this manual. “I’ve seen plenty of hesitation to seek treatment because of stigma, where the family or the spouse might want to refer the consumer to treatment, but the consumer reacts by recoiling, feeling stigmatized even more. They believe that, if you need help, you must be out of control, completely nonfunctional, the subject of ridicule.”

In one study, Lauber and colleagues found that general opinion survey participants believed the most helpful interventions for mental disorders were “psychologist,” “general practitioner,” “fresh air,” and “psychiatrist.” The form of psychiatric treatment most often identified as helpful was “psychotherapy,” and medication and electroconvulsive therapy were identified as helpful by less than a quarter of the interviewees (Lauber, C., Falcato, L., Nordt, C., & Rössler, W., 2003). A similar study in Australia revealed that interviewees regarded medication for depression in a particularly negative light, and instead recommended “lifestyle treatments” for people with depression (Jorm et al., 1997).

Antidepressant medication has certainly been a subject of controversy. Myths about antidepressants seem to fall into three main categories: Either it will “fix people completely,” “make people all zoned out,” or “hurt people or make them hurt themselves or others.”

Some studies indicate that the last of these beliefs is quite prevalent. In a study of 89 outpatients attending a neurology clinic, 74% reported a belief that antidepressants were addictive, and 47% reported a belief that these medications could cause physical harm (Stone et al., 2003). And in one German survey, 80% of interviewees said they believed antidepressants were addictive, and 69% said these medications changed people's character (Gaebel, Zanke, & Baumann, 2006).

Like many human service providers who work with stigmatized groups, mental health providers are often the targets of courtesy stigma. Many experts believe that students are discouraged from pursuing training in mental health disciplines, residents and trainees experience professional stigma and demoralization, practitioners feel underappreciated by consumers and society, and mental health services receive fewer resources because of stigma (Corrigan & Kleinlein, 2005).

Stigma and Culture

How does membership in a cultural minority group tend to affect people's attitudes toward mental illness, or others' attitudes toward them? The culture's, the community's, the family's, and the individual's tendency to stigmatize or not stigmatize depression will often reflect cultural beliefs. Most people combine beliefs handed down through their cultures of origin with beliefs they have gathered from the cultures around them, to different degrees depending on their levels of acculturation.

While the evidence shows that people in minority cultures use mental health services at lower rates than those in the dominant culture, the research has not revealed the extent to which this is due to lower levels of need for these services, socioeconomic factors, educational factors, access to insurance, cultural appropriateness of treatment approaches, cultural attitudes toward mental illness, self-stigma, or other factors. However, Chen asserted that "Social stigma associated with mental illness among different ethnic minority groups is one of the major factors that leads to healthcare disparity in our society" (Chen, 2005, p. 1062).

People from ethnic minority groups who suffer from depression often bear a triple burden of stigma, stereotype, prejudice, and discrimination:

1. The stigma that their cultures of origin may attach to depression, seeking help for depression, the use of medication for depression, etc., and the contribution of that stigma toward their own self-stigmatization
2. The stigma and stereotypes that the dominant culture attaches to depression and its treatments, and the many forms of self-stigma and discrimination that follow
3. Stereotypes, prejudice, and discrimination directed at people because of their cultures of origin, and the degree to which the effects of these factors have been internalized

"The combination of stigma and membership in an ethnic minority group can impede treatment and well being, creating preventable and treatable mortalities and morbidities" (Gary, 2005, p. 979).

In some cases, culture of origin can provide some protection against self-stigma—and identification with the dominant culture can increase the level of self-stigma. According to Grandbois (2005), American Indians and Alaska Natives tend to stigmatize mental disorders to the extent that they have been “deculturated” from traditional belief systems and “reculturated” within the dominant culture. Attitudes and practices vary widely between Tribes, but in general, the more an individual or Tribe has taken on Western ways, the greater the acceptance of Western medical treatments for mental illness—and the stronger the tendency to stigmatize.

Questions for Reflection and Discussion

1. What are some of the stigmatizing attitudes toward people with depression that have been directed toward people you know or the people you serve? What has been the evidence of those attitudes?

2. If you live with depression or have lived with it in the past, what stigmatizing attitudes have most often been directed toward you by the people you know? What has been some evidence of those attitudes?

3. What evidence of the stigma directed toward treatment for depression have you seen in the media or in the lives of people you know or work with?

5. What evidence have you seen of the ways in which stigma toward depression can interact with cultural attitudes or prejudices?

Stigma and Helping Professionals

The attitudes of family, friends, and even strangers can play important roles in shaping the experience of people suffering from depression. However, the attitudes of the professionals whose work it is to provide help, support, and medical care can be even more critical to people's well being.

Stigma Toward Consumers

It is probably safe to say that no helping professional wants or chooses to stigmatize his or her clients or patients. Although we often unconsciously choose stigmatizing beliefs, very few people consciously choose to hold beliefs or attitudes toward others that we know are false and damaging. And those who seek work in the helping professions most often do it out of love and a desire to make things better, regardless of any internal conflicts they might have. However, the experts interviewed for this manual and the articles that addressed the subject confirmed that there is some implicit bias among helping professionals.

“Many well trained professionals from most mental health disciplines also subscribe to stigmas about mental illness,” wrote Corrigan and Lundin (2001). “Psychiatrists, psychologists, social workers, psychiatric nurses, among others, have all been known to paint a bleak picture of severe mental illness, silently inferring that ‘patients’ are unable to care for themselves and should learn to view most work and interpersonal goals as unattainable. Families and persons with mental illnesses themselves also fall victim to stigma, damning the potentials of future life” (Corrigan & Lundin, 2001, p. 15).

Although research shows that the best way to challenge stigma is through contact with real people in the stigmatized group, this may not hold true in therapeutic situations. According to Reinke and colleagues (2004), “Treatment providers, especially in-patient clinicians, largely interact with people with mental illness when they are acutely ill, a status that is likely to confirm the stereotype rather than challenge it. Most of these people are frequently discharged before recovery is evident so that the treatment provider does not have an experience that disconfirms the stereotype” (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004, p. 386). Mirabi and colleagues agreed: “Meeting the person with mental illness whose symptoms and other problems are highlighted is not likely to challenge one’s stereotypes. This may be one reason why mental health service providers are likely to endorse the stigma of mental illness so highly” (Mirabi, Weinman, Magnetti, & Keppler, 1985).

The respective positions of clinician and consumer may add to the stigma as well. “Although a great number of those in the mental health professions are genuinely committed to clinical care and the fostering of autonomy, the very models of training in psychology, psychiatry, and other helping professions often convey a superior attitude, promoting an ‘us versus them’ mentality” (Hinshaw, 2005, p. 721).

Supervision may also play a significant role. “The views that individuals have in practice seem to be related to their supervision and the experience they’ve had during that process,” said Randi Tolliver in an interview for this manual. “The degree to which helping professionals stigmatize depression may be related to the way they were trained, how they’re supervised, and the role models they’ve known. People are influenced by their personal and educational

experiences, but supervision is translation of that information in a different form—and sometimes stigma is transferred along with it.”

According to Tolliver, the discussion of stigma among helping professionals might suggest a number of changes in supervision practices. Too often, she said, supervision sessions are reserved for discussing charts, monitoring consumer progress, and making sure the unit is meeting its projected goals. An equally important aspect of the supervisor's job, particularly during training periods, is attention to the ways in which supervisees are addressing and resolving the concerns that arise for them in their contact with consumers' symptoms.

Terrence Koller agreed, and he cited the countertransference that can turn a helping professional's frustration or disappointment with a consumer's lack of progress into a judgment or stereotyping of that consumer. “Any good therapist is going to have feelings of frustration, anger, or disappointment when the consumer is not doing well,” said Koller. “It's important to know who we can consult in those cases.” In his interview for this manual, Patrick Corrigan said that the research also indicates that, among helping professionals, stigmatization of people with mental illness correlates highly with being “burned out.”

Along with supervision targeted at eliminating stigma, direct anti-stigma training is an important element in preparing helping professionals to work more respectfully and more collaboratively with consumers. Materials such as the videotape “Stigma in Our Work, in Our Lives,” developed by The Stigma Project (a joint venture of On Our Own of Maryland, Inc. and the Maryland Mental Hygiene Administration), with its interviews of people who have been affected by stigma, can be useful training tools (Contact information in “Resources for Advocacy and Support,” Page 165).

When people have co-occurring disorders, stigma across the helping fields that serve them can be another issue. For example, in spite of each field's more than passing understanding of the other, there is a fair amount of stigma toward depression in the addiction field, and toward addiction in the mental health field. For people with co-occurring depression and Substance Dependence Disorders, the coercive attitudes and practices still in place in some SUD treatment facilities and recovery groups may also be counterproductive, reinforcing feelings of shame, helplessness, and depression (O'Connor, Berry, Inaba, Weiss, & Morrison, 1994).

Stigma Toward Depression in Helping Professionals

When people in the helping professions suffer from depression, their experience may provide a benefit—a deeper understanding of the consumer's experience—but it may also subject them to higher levels of stigma and self-stigma. They may wrestle with some of these beliefs:

- “I should be an example—should be healthier than this.”
- “I should know enough to prevent this.”
- “I'll be discredited if I admit my condition or get treatment.”
- “This calls all my work and my competence into question.”
- “How can I help others if I can't even help myself?”
- “I should be the one giving help, not the one receiving it.”

Jamison (2006) wrote of some of the extra challenges that people in medical fields face if they have mental disorders. “Mental illness is at least as common in our colleagues as it is in the general public, which is to say it is common. Suicide occurs far too often. We need to reach out

to our colleagues. As mentors and educators we need to be proactive, we need to educate medical students, house staff, and graduate students about depression and other mental illnesses. We need to make it easy for them to get treatment. We need as well to educate them more effectively about how best to diagnose and treat mental illness in their patients. We as a profession also need to reach out to society to say that we will not tolerate the kind of pain and discrimination that has gone on for far too long” (Jamison, 2006, p. 534).

Although the depression rate among physicians is higher than that in the general population, and untreated depression has been identified as a major risk factor, “Barriers to physicians’ seeking help are often punitive, including discrimination in medical licensing, hospital privileges, and professional advancement...As barriers are removed and physicians confront depression and suicidality in their peers, they are more likely to recognize and treat these conditions in patients, including colleagues and medical students” (Center et al., 2003, p. 3161).

Depression may be common in many helping professions. In one study of 1,000 social workers in North Carolina, 19% of the sample measured positive for depressive symptoms, 16% had seriously considered suicide at some time in their lives, 20% were currently taking medication for depression, and 60% said they either were depressed or had been depressed at some time in the past (Siebert, 2004). A random-sample survey of 1,000 psychologists also showed depression (dysthymia) as the most frequently acknowledged diagnosis. Many respondents said that their own illness increased both their empathy for clients and their sense of isolation from their peers (Gilroy, Carroll, & Murra, 2002).

According to Amy Watson, the degree to which helping professionals stigmatize depression in their own lives may in some cases depend on how thoroughly they acknowledged and addressed depression before they took on their helping roles. The helping professional who enters the field with a history of depression and recovery may have included that history in the construction of his or her identity as a helper, whether or not he or she has disclosed the history. Even so, the recurrence of symptoms may still raise self-stigma, particularly if the symptoms draw questions or negative attention from colleagues. But the helping professional who enters the field without this history, or without having recognized the presence of a depressive disorder, may have a professional image with less room and less flexibility to accommodate the onset of depressive symptoms.

An important ethical question concerns the potential impact of a helper’s depressive disorder on the effectiveness of services. According to Jamison, though, this argues more for disclosing the illness than for hiding it. “The possibility always exists that my illness, or the illness of any clinician, for that matter, might interfere with clinical judgment,” wrote Jamison (1995, p. 207). “The privilege to practice is exactly that, a privilege; it is not a right. The real dangers, of course, come about from those physicians (or, indeed, from those politicians, pilots, businessmen, or other individuals responsible for the welfare and lives of others) who—because of the stigma or the fear of suspension of their privileges or expulsion from medical school, graduate school, or residency—are hesitant to seek out psychiatric treatment.”

Questions for Reflection and Discussion

1. What signs or evidence have you seen—however subtle—of helping professionals' stigma toward consumers who have depressive disorders?

2. What might be the role of stress and burnout in increasing stigma?

3. How might supervision and training help remedy the stigma?

4. What evidence have you seen of stigma toward helping professionals who have depressive disorders?

5. If you have a depressive disorder, what experience have you (as a helping professional) had of stigma from others, or self-stigma regarding your own disorder?

The next chapter explores the impact of stigma on the individuals who are its targets.

Chapter Seven: The Effects of Stigma

I wanted to tell her that if only something were wrong with my body it would be fine, I would rather have anything wrong with my body than something wrong with my head.

Sylvia Plath, from *The Bell Jar*

In the depths of depression, it can seem as if there is no way out. In the climb back to life, it can seem as if the work is far too hard and hope is only a tiny spot in the sky. For many people, the way out and the way back up require the help of other people. Ignorance, stigma, and discrimination can turn other people into part of the problem, thus robbing the solution of some of its most important resources. And self-stigma can convince us that we **are** the problem and do not deserve a solution.

“Someone with a broken arm or an illness will just suffer with that illness,” said Terrence Koller in an interview for this manual. “But someone with a mental illness suffers with the illness *and* with the stigma. They work together to make it even more difficult to get help, to be optimistic about the outcome, or to feel like they're making progress at all.”

Stigma often reduces life opportunities; limits social contacts; reduces self-esteem; and makes people more reluctant to seek help, leading to postponed treatment and more rapid progression of the disease. Taken together, these factors may lead to increased need for rehabilitation measures (Gaebel, Zaské, & Baumann, 2006).

Corrigan and Watson identified three common responses to stigmatizing attitudes and actions by others:

- Internalized self-stigma and loss of self-esteem
- Galvanizing righteous anger
- A lack of response or apparent effect (Corrigan & Watson, 2000).

One factor that may tip people away from self-stigma is what researchers often call a “protective in-group bias.” This bias springs from relationships with others in the stigmatized group who provide living evidence that the stigma is not founded in reality.

Courtesy stigma also ensures that people with mental illnesses are not the only ones who suffer at the hands of the stigma against these disorders. “... although consumers of mental health services most likely experience the most harsh consequences of stigma, it also harms their family members and friends, the other stakeholders involved in any aspect of services to this group, and the public as a whole” (Corrigan & Kleinlein, 2005, p. 11).

This chapter looks at the effects of stigma in four categories:

- Discrimination
- Effects on seeking help
- Self-stigma
- Exacerbation of depressive symptoms.

Discrimination

If we consider stigma and discrimination in the world as a whole, its impact is staggering. According to Link and Phelan (2001), “because there are so many stigmatized circumstances and because stigmatizing processes can affect multiple domains of people's lives, stigmatization probably has a dramatic bearing on the distribution of life chances in such areas as earnings, housing, criminal involvement, health, and life itself. It follows that social scientists who are interested in understanding the distribution of such life chances should also be interested in stigma” (Link & Phelan, 2001, p. 363).

Discrimination against people with mental illness forms a large portion of that effect. For example, in 1997, the second most common charge filed with the Equal Employment Opportunity Commission (EEOC) under the Americans With Disabilities Act (ADA) concerned discrimination against people with mental disabilities. According to Corrigan and colleagues (2005), these charges represented 9.9% of the total number of cases. The following year, discrimination against people with mental disabilities became the most common charge filed with the EEOC, and the majority of these cases involved depression. In spite of the evidence of discrimination, a number of researchers have found that people with mental disorders do not receive the degree of protection or priority that other disability groups receive under the law (Corrigan, Watson, Heyrman, Warpinski, Gracia, Slopen, & Hall, 2005).

Discrimination against people with depression is often more subtle than discrimination against people with more “obvious” disorders such as schizophrenia. Common forms of discrimination include withholding responsibility, assuming that people won't be able to handle stress, questioning their qualifications, considering their opinions less valid because of the depression, or terminating their employment.

Discrimination against the individual is just part of the picture. The concept of “structural discrimination” refers to institutional policies or practices that are by nature discriminatory. An overarching form of structural discrimination against people with mental disorders lies in the laws, financial systems, and reimbursement systems that fail to cover treatment for mental disorders on an equal basis with somatic disorders (Rüsch, Matthias, Angermeyer, & Corrigan, 2005). It is often more difficult to raise funding for mental health services than it is to raise money for other types of diseases or disabilities. The lack of parity for coverage of mental health care denies both the legitimacy of mental illness and the potential devastation it can bring about in people's lives. And the traditional lack of unity among allied health care systems threatens the quality and availability of care for those whose ailments have both physical and psychological roots and consequences. In the words of Link and Phelan (2006), “if a stigmatized illness has received less attention and fewer research and treatment dollars, the effectiveness of treatments may lag behind treatments for other less stigmatized diseases” (p. 529).

“Despite the evident mind-body connection, our mental and primary health care systems largely remain separate,” said SAMHSA Center for Mental Health Services Director A. Kathryn Power in a 2005 presentation. “This separation is the byproduct of stigma and ignorance related to mental illnesses. Our society has a long history of discrimination against those with mental illnesses, removing them from their communities and under-funding their care. We in the 21st century need to move forward with new understanding. We need to begin viewing, treating, and funding mental and physical illnesses the same.”

According to Burris (2006), “There are three broad areas where law affects the operation of stigma in society. Law can be a means of preventing or remedying the enactment of stigma as violence, discrimination, or other harm; it can be a medium through which stigma is created, enforced, or disputed; and it can play a role in structuring individual resistance to stigma” (p. 529).

Examining a 1999 survey of state laws for evidence of structural discrimination related to mental illness (Hemmens, Miller, Burton, et al., 2002), Corrigan and colleagues found that “about a third of the 50 states restrict the right of an individual with mental illness to hold elective office, participate on juries, and vote,” and “About 50% of states restrict the child custody rights of parents who have a mental illness” (Corrigan, Watson, Heyrman, Warpinski, Gracia, Slopen, & Hall, 2005, p. 557).

The Bazelon Center for Mental Health Law monitors examples of discrimination, including the following instances specifically related to depression:

- Three 1999 Supreme Court decisions (Sutton, Murphy, and Kirkingburg) that indicated that people who take measures to control the effects of a disability (e.g., people who take medication for depression) may be unable to claim the protection of the Americans with Disabilities Act, even if they are discriminated against because of their disabilities (Bazelon Center for Mental Health Law, 1999)
- The eviction of a woman suffering from depression by a public Housing Authority for repeated failure to comply with housekeeping and yard-maintenance standards (Bazelon Center for Mental Health Law, 2006a)
- A student at the City University of New York who was barred from her dormitory room at Hunter College because she was hospitalized after a suicide attempt (Bazelon Center for Mental Health Law, 2006b)
- A straight-A sophomore at George Washington University who, after seeking emergency psychiatric care for depression, was charged with violating the school code of conduct, suspended, evicted from his dorm, and threatened with arrest for trespassing if he set foot on university property (Bazelon Center for Mental Health Law, 2006c)

The loss of meaningful opportunities for education, employment, financial security, and housing can also exacerbate the feelings of hopelessness, helplessness, and worthlessness engendered by depression.

As discrimination affects life chances, awareness of discrimination affects people's belief in their opportunities and chances for success. In his study of individuals with mental disorders in self-help groups and outpatient treatment, Markowitz (1998) found that 72% of respondents agreed or strongly agreed that people with mental illness will be devalued and discriminated against, and half of the respondents said they had experienced discrimination during the past six months.

Although depression is thought to receive less discrimination than other mental disorders, a study of 1,187 depressed patients in primary care clinics found that 67% expected depression-related stigma to have negative effects on employment, 59% expected negative effects on health insurance, and 24% expected negative effects on friendships (Roeloffs, Sherbourne, Unutzer, Fink, Tang, & Wells, 2003).

Questions for Reflection and Discussion

1. What evidence have you seen of discrimination toward people you serve who have depressive disorders?

2. What have been some of the consequences of that discrimination in their lives?

Effects on Help Seeking

Although we lack the crystal ball that would show us the full impact of stigma on people's willingness and ability to receive professional help, Corrigan and colleagues estimate that more than half of the people who might benefit from mental health services may choose not to seek services for fear of being labeled (Corrigan, Watson, Byrne, & Davis, 2005).

The U.S. Department of Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that 13.5 million adults in the United States have serious mental illnesses but do not seek treatment. In SAMHSA's 2004 national survey, 26% of people who had not sought treatment for mental illness cited the stigma associated with these conditions as one of the main reasons for that decision (SAMHSA, 2005).

Of the National Comorbidity Survey respondents who reported having had Major Depressive Disorder (MDD) within the past year, only 51.6% had received health care treatment for this disorder, and only 41.9% of those who had received treatment (21.7% of the total with MDD) had received adequate treatment (Kessler et al., 2003).

One Australian study found that a general sample of adults in the community believed that they would feel embarrassed seeking help for a depressive disorder, that they would expect others (including professionals) to respond negatively if they did seek help, and that this might make them less likely to seek professional help (Barney, Griffiths, Jorm, & Christensen, 2005).

Stigma may affect, not only people's likelihood of seeking treatment, but also their likelihood of continuing and adhering to medical treatment. One study found that people with major depression were less likely to adhere to their medical treatment if their caregivers believed their depression had its roots in cognitive or attitudinal factors (Sher, McGinn, Sirey, & Meyers, 2005).

Self-Stigma

Along with the fear of being labeled, looked down on, or discriminated against by others, many people with depression and other mental disorders also learn to label, look down on, or discriminate against themselves. The term “self-stigma” refers to “the reactions of individuals who belong to a stigmatized group and turn the stigmatizing attitudes against themselves” (Rüsch, Matthias, Angermeyer, & Corrigan, 2005, p. 531).

Self-stigma is a common and understandable condition, a component of shame and hopelessness. Self-stigma magnifies every flaw and ignores every strength, leading to what seems like a natural conclusion: “I don’t deserve help or hope.”

People who live with depression are just as well aware of the stereotypes about this illness as anyone else. The degree to which their awareness leads to self-stigma often depends on the extent to which they believe the stereotypes. Higher levels of empowerment tend to mitigate self-stigma (Rüsch, Matthias, Angermeyer, & Corrigan, 2005), but empowerment is subjective and takes place in many domains. One might be highly empowered in some areas of life and hold significant self-doubt and self-stigma in other areas. For example, Abraham Lincoln, who lived with a depressive disorder, thought of himself as a “hick” and an inferior person and believed the Gettysburg Address was a failure (Gates, 2006).

People who suffer from long or repeated bouts of depression might come to see the depression as part of their true identity or self, rather than as a departure from that identity (Fennell, 2004, p. 1059). “A self-maintaining sequence is established: experience, interpreted as failure, leads to self-blame and so to a sense of global worthlessness, and self-condemnation. Since defects are viewed as an intrinsic part of the self, there is no possibility of change, and hopelessness sets in” (Fennell, 2004, p. 1058). The more constant, intense, pervasive, generalized, and chronic the consumer’s identification of him- or herself with problems and deficits, the harder it will be to form collaborative working relationships, and the longer and more difficult the course of treatment is likely to be (Fennell, 2004).

One study of 182 people with serious mental illnesses found that, among people with lower self-esteem, stigma had “significant and dominant” effects on their self-esteem—effects that were often not mitigated by their sense of mastery or their overall levels of functioning (Blankertz, 2001).

In another study, “...we found no evidence that members of the stigmatized group have more tolerant or forgiving attitudes about persons with mental illness than does the general public” (Teachman, Wilson, & Komarovskaya, 2006, p. 92). “The absence of a protective in-group bias was disappointing, because it suggests equal negativity from persons who have extensive experience with mental illness...and who will be hurt most by the stigma” (Teachman, Wilson, & Komarovskaya, 2006, p. 91).

As life circumstances sometimes leave us more or less vulnerable to depression, a number of factors might also leave us more susceptible to self-stigma. According to one Taiwanese study, people with more severe depression and lower levels of education had higher levels of self-stigma concerning their depressive disorders (Yen, Chen, Lee, Tang, Yen, & Ko, 2005).

For children and adolescents who develop depressive disorders, the effects of stigma can be particularly savage. Negative labels tend to have long-lasting effects on children's self-concept and opportunities. Their peer groups have very little understanding of depressive disorders and tend to refer to any mental illness in terms such as “psycho” and “crazy.” And for many adolescents, the desire to fit in and be like their peers sometimes seems stronger than the will to survive. The tendency of stigma and self-stigma to separate and to emphasize differences and impairment can have devastating effects (Hinshaw, 2005).

One mental health professional interviewed for this manual recalled the desperation and ultimate futility of his efforts, and those of a loving social network, to help a dear friend whose illness eventually took her life. “Stigma surrounds the whole issue,” he said. “It wasn't stigma around her so much as what was inside her. It was much more psychological than social. It took on very insidious and very troublesome features, despite our trying to be direct and honest and positive and self-esteem enhancing. And as she became more ill, everything became distorted in the negative. Society made the stigma, but she internalized that message: If you can't help yourself, you're weak and bad. Maybe if she'd heard a completely different message from girlhood on it might have helped, but what we had to offer was too little and too late.”

Major and O'Brien (2005) caution against making blanket assumptions about the effects of stigma on self-esteem, emphasizing the importance of a number of factors in the lives of stigmatized individuals and subgroups (e.g., exposure to stigma, social influences, personal characteristics) that might make reactions to stigma vary considerably from group to group and individual to individual, and at different times in the same person's experience.

And Rüsch and colleagues (2005) caution against confusing decreases in self-esteem prompted by stigma with the loss of self-esteem during depressive episodes (Rüsch, Matthias, Angermeyer, & Corrigan, 2005). The challenge of separating the symptoms of self-stigma from the symptoms of depression is the subject of the following and final section of this chapter.

Questions for Reflection and Discussion

1. What effects does stigma seem to have on help-seeking among people you know with depressive disorders?

2. If stigma has caused people to delay seeking help, or to neglect their treatment, what have been some of the consequences in their lives?

3. What evidence of self-stigma have you seen in people you serve who have depressive disorders?

Effects on Depression

You may recall from Chapter One the many symptoms that self-stigma and depression share:

- Low self-esteem
- Loss of hope
- Loss of confidence in one's ability to succeed
- Feelings of helplessness
- The "why try?" attitude
- Giving up on goals
- Denying credit for accomplishments
- Self-blame for failures (and perceived failures)
- Problems with sleep, fatigue, eating patterns
- Loss of interest in keeping on living (Corrigan & Lundin, 2001)

These similarities can make it particularly challenging to separate self-stigma from depression. They can also make it particularly difficult to heal from both conditions.

According to Blankertz (2001), for people with severe mental illness, self-esteem has an important impact on quality of life, affective states, and recovery. He cites Mead's (1934) "theory of reflected appraisals" and its assertion that self-esteem depends on people's perceptions of what others think of them (Blankertz, 2001). In one study, Kahng and Mowbray found that, among people with severe mental illness, positive affect was the characteristic most often associated with high self-worth, and negative affect most often associated with low self-worth (Kahng & Mowbray, 2004).

Stigmatizing actions and attitudes tend to make themselves painfully evident. It takes a remarkable amount of resilience to resist their effects, resilience that may not be available in times of emotional distress.

Both the erosion of opportunities caused by stigma and the constant threat of being stigmatized can also make stigma a significant source of stress in general, and so trigger depressive episodes and symptoms (Link & Phelan, 2006). And although the symptoms of mental illnesses may subside with successful treatment, many negative consequences of the illness that stigma and discrimination tend to promote (e.g., social isolation, unemployment, low income, and less desirable housing conditions) have often taken root in people's lives (Markowitz, 2001).

If one is tempted to wonder whether stigma's contribution to depression among people with mental disorders is simply part of the natural progression of mental illness, Markowitz's (1998) study would indicate otherwise. In a group of people with mixed psychiatric diagnoses, Markowitz found the impact of stigma to be more strongly linked with depressive symptoms than with psychotic symptoms, even though psychotic symptoms might be expected to elicit greater stigma than depressive symptoms (Markowitz, 1998). A reasonable inference might be that the experience of stigma somehow instilled or increased depressive symptoms.

Mickelson (2001) cited a number of studies (Crocker et al., 1998; Baxter, 1989; Coffey, Leitenberg, Henning, Turner, & Bennett, 1996; Devins et al., 1994; Hermann, Whitman, Wyler, Anton, & Vanderzwaag, 1990; Mansouri & Dowell, 1989; Rybarczyk et al., 1995; Crandall & Coleman, 1992; Demi, Bakeman, Moneyham, Sowell, & Seals, 1997; Baxter, 1989; Link et al., 1997) in which stigma contributed to depression or emotional distress among people in a variety of stigmatized groups. In Mickelson's own study, he found that perceived stigma did indeed increase depressive symptoms, particularly in situations in which the stigma had also eroded social support (Mickelson, 2001).

Self-stigma may even have some multi-generational effects. According to Hinshaw, stigma can interfere with a parent's ability to communicate effectively about his or her own depression, adding to children's confusion, shame, and self-blame. Along with other risk factors linked with a parent's depression (e.g., genetic transmission of vulnerability, difficulty caring for children during depressive episodes, and difficulty modeling emotional coping skills), this effect of stigma might make it more likely that children will also suffer from depression (Hinshaw, 2005).

Questions for Reflection and Discussion

1. Among the people you serve who have depressive disorders, what effects does stigma seem to have had on the course of their treatment and recovery from those disorders?

2. What connections or similarities have you seen between self-stigma and the symptoms of depression?

3. What evidence of self-stigma have you seen in people you serve who have depressive disorders?

The Remainder of This Manual

For the reader who has chosen to follow the course of the manual from start to finish, this must by now seem like a particularly bleak topic. Although it was necessary to examine the problem in detail, it is now very important to turn toward the solution. The final two chapters attempt to provide as much hope and help as possible. Chapter Eight focuses on ways of healing stigmatizing beliefs, attitudes, and actions in ourselves, our communities, and our society. Chapter Nine focuses on healing self-stigma through cognitive strategies, empowerment, resiliency, and recovery.

Chapter Eight: Healing The Stigma in Society

The goal is not to smite the unjust source of stigma. Rather, the goal is to correct the social and psychological forces that promote stigmatizing views in some people in positions of power. *Smiting* requires anger and force. *Correcting* similarly benefits from anger and force but also needs wisdom and strategy. Avoid the blame game.

Patrick Corrigan, from *Beat the Stigma and Discrimination: Four Lessons for Mental Health Advocates*

It is not by mere chance that this manual is called *Healing the Stigma* rather than *Smiting the Stigma*. When we try to cut off the heads of our monsters, we often find them attached to our own necks. Like depression, stigma is an illness whose vulnerability is passed from generation to generation and whose triggers include a multitude of stressors. The patient is ourselves—our society, our species—and the patient is in pain. The answer is not to punish, but to treat.

Many healing processes are best begun on the inside, so that is where this chapter starts: with the exploration and healing of our own stigmatizing beliefs, attitudes, words, and actions.

Starting With Ourselves

The first step might be to identify the sources of one's own beliefs about depression and people with depressive disorders, including:

- Attitudes learned in the family
- Early reactions to other people's depressive symptoms
- Images in the media
- Portrayals in literature
- Things people have said
- Myths and stereotypes
- Educational texts
- Scholarly articles
- Feelings about our work with people who have depressive disorders
- Professional training and education
- Attitudes within our helping professions

This kind of exploration is important whether or not we have depressive disorders. Self-stigma begins on the outside and works its way in. The following questions are designed to help you explore some of these sources.

Questions for Reflection and Discussion

On the lines that follow, write a few words that characterize the beliefs about people with depressive disorders that you have been exposed to in your life through each of these sources.

1. Things people said when you were young

2. Early perceptions of people with depression

3. Images in the media and characters in literature

4. Myths and stereotypes about people with depression

5. Professional training, educational texts, and scholarly articles

6. Feelings about your work with people who have depressive disorders

7. Attitudes within your profession

The next step is to identify any areas of your knowledge and understanding that may still need to be supplemented:

- ☐ Genetic factors in the etiology of depression
- ☐ Neurology of depression and pharmacological agents used to treat it
- ☐ Psychological factors and treatment approaches
- ☐ Common co-occurring disorders
- ☐ The nature and effects of stigma and discrimination
- ☐ Public education and advocacy for stigma reduction
- ☐ The concept of recovery from depression

Looking at Our Words

Human beings are impressionable. The words we use to describe someone or something often have profound effects on our images, attitudes, and beliefs. As we know from labeling theory—and from watching the world around us—words are very powerful. Gather enough of them together, and they can make the difference between hatred and forgiveness, between alienation and belonging, between giving up and trying again.

Words are also very absorbent. A word can begin innocently enough, as a matter-of-fact term for a person or condition, and then gain toxicity if the person or condition is the object of stigma, ridicule, or discrimination. From time to time, some words have to be replaced.

“The wrong words, by conveying that people are not worthy and capable of recovery, fuel self-destruction and prevent or postpone help-seeking,” wrote William L. White. “The right words catalyze personal transformation and offer invitations to citizenship and community service. The right words awaken processes of personal healing, family renewal and community and cultural revitalization. The wrong words stigmatize and disempower” (White, 2007, p. 1).

It is unlikely that anyone who would take the time to read this manual is going to blurt out any blatantly stigmatizing phrases in the company of vulnerable souls. This section is not about our reasons for avoiding language that is overtly stigmatizing. We already know those reasons. It is about the power of the subtle to create or destroy hope. Following are some stigmatizing options and some less stigmatizing or more empowering alternatives:

More Stigmatizing

Identifying people by their diagnoses, e.g., “depressives” or “the depressed” or (worse) “the afflicted”

Assuming or stating as fact a generalization about an individual's life or experience based on that individual's diagnosis

Making assumptions about the words an individual considers respectful or disrespectful

Focusing first and foremost on an individual's challenges, problems, symptoms, and diagnoses

Less Stigmatizing

Identifying people first, e.g., “people with depressive disorders”

Asking the person to describe his or her life or experience, and confirming any generalizations or conclusions

Asking the person which words he or she considers respectful or disrespectful, and using the respectful words

Bringing the focus back frequently to the individual's strengths and resources, and placing challenges in that context

Choice of language is not a simple thing. Wrote Kay Redfield Jamison, “One of my friends, prior to being discharged from a psychiatric hospital after an acute manic episode, was forced to attend a kind of group therapy session designed as a consciousness raising effort, one that encouraged the soon-to-be ex-patients not to use, or allow to be used in their presence, words such as ‘squirrel,’ ‘fruitcake,’ ‘nut,’ ‘wacko,’ ‘bat,’ or ‘loon.’ To say these words, it was felt, would ‘perpetuate a lack of self-esteem and self-stigmatization.’ My friend found the exercise patronizing and ridiculous. But was it? On the one hand, it was entirely laudable and

professional, if rather excessively earnest, advice: the pain of hearing these words, in the wrong context or the wrong tone, is sharp; the memory of insensitivity and prejudice lasts for a long time. No doubt, too, allowing such language to go unchecked or uncorrected leads not only to personal pain, but contributes both directly and indirectly to discrimination in jobs, insurance, and society at large.

“On the other hand, the assumption that rigidly rejecting words and phrases that have existed for centuries will have much impact on public attitudes is rather dubious. It gives an illusion of easy answers to impossibly difficult situations and ignores the powerful role of wit and irony as positive agents of self-notion and social change. Clearly there is a need for freedom, diversity, wit, and directness of language about abnormal mental states and behavior. Just as clearly, there is a profound need for a change in public perception about mental illness. The issue, of course, is one of context and emphasis. Science, for example, requires a highly precise language. Too frequently, the fears and misunderstandings of the public, the needs of science, the inanities of popularized psychology, and the goals of mental health advocacy get mixed together in a divisive confusion” (Jamison, 1995, pp. 180-181).

So it seems that language presents almost as many complexities as the conditions it seeks to describe. Particularly when different groups prefer different words for the same condition—each for legitimate reasons—the advocate’s task can be a challenging one. “There is no easy solution to the problem of how to identify a particular group,” wrote Corrigan (2004, p. 10). “Instead, advocates need to be aware of the tension among various labels and be prepared to deal with the anger or misunderstanding that may come from another group when such a label is used.”

Choosing a Stigma-Reduction Role

For some who pick up this manual, reading a 175-page book might seem like sufficient commitment to stigma reduction. But if we buy into the idea that the problem of stigma belongs to all of us, then it follows that each of us must play a role in the solution. One challenge in becoming motivated to effect social change is that we often tend to think of it as requiring talents we lack, tasks we would rather avoid, risks we cannot afford to take, and/or far more time than we have to commit. But what if that were not the case? What if it were possible to make a difference in ways that fit your life and responsibilities? For every skill or inclination that you lack, there is another skill that comes easily to you, another task that you enjoy that others find difficult. It is simply a question of matching your assets with the need. And in the area of stigma reduction, that becomes easy, because the need is so great.

The “Choosing a Role” box on the following page might help you explore some options that are well matched to your skills and inclinations. Many or most of the roles that you consider will involve collaborative efforts with other people. It is important to contact others who share your purpose early in your stigma-reduction efforts. Collaboration is often absolutely essential—not only to the success of our efforts, but also to our willingness and ability to begin those efforts. We need input from other people, shared enthusiasm, and the contagious energy that comes from collective effort. What we lose in control (or the illusion of control) we more than make up for in confidence and stamina.

Choosing a Role

1. Please check all the areas of stigma and stigma reduction that interest or attract you most strongly:
 - ☐ Stigma or self-stigma within your own life, family, and friendships
 - ☐ Self-stigma among the consumers you know or work with
 - ☐ Stigma within your organization or your field
 - ☐ Stigma within your faith community
 - ☐ Stigma within your community
 - ☐ Stigma within your culture
 - ☐ Stigma perpetuated by the media
 - ☐ Stigma reflected and perpetuated in policy and legislation
 - ☐ Stigmatizing language, stereotypes, or images
 - ☐ Discrimination toward _____
 - ☐ _____
2. Please check all of your skills or interests (future skills) that might be useful:
 - ☐ Clinical skills
 - ☐ Motivational skills
 - ☐ Helping people understand
 - ☐ Organizing people, efforts, and/or events
 - ☐ Public speaking
 - ☐ Writing
 - ☐ Analyzing policy and legislation
 - ☐ Fund raising
 - ☐ Providing moral, logistical, or administrative support to other advocates
 - ☐ Enlisting the help of influential people
 - ☐ _____
 - ☐ _____
3. Please check all the roles you might see yourself playing:
 - ☐ Quiet opinion leader within the field, community, faith community, or culture
 - ☐ Understanding, respectful, non-stigmatizing friend, family member, or helper
 - ☐ Agent in the healing of self-stigma in the lives of people you know or serve
 - ☐ Change agent within your organization and/or your field
 - ☐ Member or board member of advocacy organizations
 - ☐ Contributor to the advocacy efforts of professional organizations
 - ☐ Organizer of advocacy events
 - ☐ Organizer of anti-stigma campaigns
 - ☐ Public speaker
 - ☐ Writer of letters to the editor, blogger, caller-in to radio talk shows, etc.
 - ☐ Writer of brochures, articles, manuals, or books
 - ☐ Fundraiser or grant writer
 - ☐ _____
4. How much time could you devote to these efforts each week? _____
5. What might be your first step in starting one of these efforts? _____

Choices About Self-Disclosure

If we are also in recovery from depression and/or other mental disorders, the choice of stigma-reduction roles includes the choice to disclose or not disclose information about our own disorders. On one hand, disclosure of any stigmatized condition leaves us far more vulnerable to the effects of stigma. On the other hand, non-disclosure leaves us where we started:

1. People hold distorted stereotypes of people with mental illnesses
2. So mental illnesses are stigmatized
3. So people in successful recovery may hide their recovery status
4. So their lives are not used as examples to challenge the stereotypes
5. So mental illnesses are stigmatized, etc.

To what degree is it the individual's duty to challenge the stereotypes, at the risk of jeopardizing social acceptance, financial security, or professional success?

"There is a very large group that I think of as the silent successful—people who get well from psychiatric illness but who are afraid to speak out," wrote Kay Redfield Jamison (2006). "This reluctance is very understandable, very human, but it is unfortunate because it perpetuates the misperception that mental illness cannot be treated" (p. 533).

The decision is a personal one, based on the individual's own values, needs, circumstances, priorities, and levels of vulnerability. There are also many degrees of self-disclosure, with many different degrees of risk. There is a vast difference between being a member of the crowd at a recovery event and declaring one's diagnosis in the popular media—and many gradations in between. The following considerations can make a great deal of difference in the safety and appropriateness of an individual's choices about self disclosure:

- **Level of exposure on which the self-identification takes place:** The woman who casually mentions to a few friends that she is being treated for depression may be at low risk, compared to the woman who mentions her diagnosis and treatment at a town meeting or in an interview for a newspaper article.
- **Level of disclosure:** A man who tells his employer that he has Bipolar Disorder is at lower risk than a man who reveals intimate details of the personal, financial, marital, and legal problems that he experienced before he received treatment.
- **Level of financial vulnerability:** Someone who has a firmly established career and finances—or someone who feels he or she has nothing to lose—may be less vulnerable than someone who is struggling for job recognition and financial security.
- **Level of emotional vulnerability:** A woman with a strong network of true friends and supporters might have an easier time handling discrimination than a woman who is just starting to build her support network. A man with strong coping and disease-management skills would be less vulnerable to the effects of stigma than a man who is having a hard time learning to manage his symptoms.
- **The length and stability of recovery:** A man might make an informed decision to disclose even though it might put him at some risk of discrimination. If he is stable in his recovery and his support network, and the discrimination would not endanger his medical or psychological well being, then he is making a courageous decision. But if he is new or unstable in his recovery, and there is a danger that discrimination might increase his stress and raise his risk of recurrence, then he will need to take these factors into account in his

decision. His fellow advocates, his support network, and the helping professionals in his life have a responsibility to help him find safer ways of being involved.

- **Other Stigmatized Factors:** People with mental illnesses can also experience extra discrimination related to their ethnic or racial characteristics; socioeconomic status; history of Substance Use Disorders or physical illnesses; disabilities (including HIV status); religion; gender or sexual orientation; family circumstances; age; educational level; involvement with criminal justice, welfare, or child custody systems; experiences as victims of violence or abuse; or occupational status. For example, a Caucasian woman might suffer less discrimination as a result of her self-disclosure than would an African-American woman—even if their economic and educational circumstances were the same—simply because of the greater tendency toward discrimination against people of color. Potential change agents should be aware of how society might react to all their characteristics, and take that into account in their decisions about self-disclosure.

Helping professionals are in excellent positions to help consumers consider these distinctions, weigh the risks and benefits, and develop plans that are tailored to their own circumstances and convictions.

Questions for Reflection and Discussion

1. For the people you serve who have depressive disorders (or for yourself), what (if any) are some of the reasons for speaking openly about having these disorders?

2. What (if any) are some of the reasons for **not** speaking openly about having these disorders?

Choosing Strategies Based on Their Effectiveness

Once you have identified the stigma-reduction roles that fit your skills and aptitudes, and begun to contact people with whom you can share your efforts, it will be time to look at some stigma-reduction strategies or approaches, and their potential impact. The research on stigma reduction has focused on three types of anti-stigma efforts and measured their levels of effectiveness (Corrigan & Lundin, 2001; Rüsch, Matthias, Angermeyer, & Corrigan, 2005):

- **Contact:** This strategy includes first-hand contact with real people who are successfully managing depressive disorders. This can take place in a friendship or family situation, through a presentation by a consumer, in a team that includes consumers and non-consumers, etc. Interventions characterized by contact have been found the most effective in reducing stigmatizing attitudes. They provide direct, tangible evidence that the stereotypes are not true, that people are people.
- **Education:** This strategy includes information about depressive disorders, symptoms, neurology, treatment, recovery, etc. This information might come in the form of written materials, presentations, or information shared informally between friends or colleagues. Education is an important building block, and it can help spark dialogue and lay the groundwork for a change in attitudes, but it is less effective than contact.
- **Protest:** This strategy includes calling public attention to stigmatizing actions and attitudes, and to the inappropriateness and unfairness of these actions and attitudes. In studies, protest seems to be an effective tool for countering discrimination (e.g., by protesting a proposed piece of legislation) or combating stigmatizing public images (e.g., by protesting a stigmatizing movie or advertising slogan). However, protest has been found to be the least effective strategy in reducing stigmatizing attitudes.

Given these differences in impact, before choosing an action—or lack of action—it is important to understand your own goal. Once you know what that goal is, you can choose an action that has been shown to be effective in reaching that type of goal. For example, if you want to change a law or abolish a form of discrimination, protest may be your first choice. If you want to influence people to be more understanding and respectful toward people with depression, you may choose instead to introduce them to someone who is successfully managing a depressive disorder and back it up with some basic information about the illness. Here is a little more information about these three strategies and their relative effectiveness, and some notes about the role of rewards and “punishers” in changing stigmatizing behaviors.

Contact

One study indicated that, although only a quarter of young adults believe that people with mental illnesses can eventually recover, more than half of those who know someone with a mental illness believe that treatment can help people with these disorders lead normal lives (Ad Council, 2006). If that is true, contact can double the percentage of people who are willing to consider a less-stigmatizing point of view.

According to Patrick Corrigan, partnerships that include consumers, family members, and experts have shown the greatest success in combating stigma. Advocacy organizations such as the National Alliance on Mental Illness (NAMI) and a variety of local organizations might help catalyze these partnerships. Corrigan (2004) also characterized several factors that can enhance contact as a strategy for decreasing stigma and discrimination, including:

- Allowing people with mental illnesses to tell their stories, so that others do not dismiss them as not having had “real” mental illnesses
- Allowing interaction between people with mental illnesses and the people they are attempting to influence
- Making sure that people with mental illnesses are not presented as pitiful, but rather as peers worthy of respect and interaction

- Making sure that the information presented differs from the stereotypes for these illnesses
- Allowing for repeated contact and interaction, to promote significant and lasting change (Corrigan, 2004)

In a study by Reinke and colleagues (2004), investigators found that both videotapes and face-to-face contact with people who had mental illnesses could be effective in reducing stigma. Understandably, they found that videotapes that do not provide evidence against the stereotypes (e.g., a scene with someone having a psychotic episode) do not reduce stigma. However, they also found that videotapes that provide moderate evidence against the stereotypes (e.g., an “ordinary person” successfully managing his or her symptoms) are more effective at reducing stigma than videotapes that provide strong evidence against the stereotypes (e.g., a highly successful person who has no symptoms and seems “too good to be true”) (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004).

Education

Kay Redfield Jamison called research “the greatest destigmatizer.” “We need to get people interested in the brain, and in the fact that these are very interesting illnesses. We need to capture the imagination of the young and explain that understanding the brain is the last great frontier. To make an illness interesting is to some extent to help destigmatize it” (Jamison, 2006, p. 534). Of course, sparking interest in the study of mental illness is quite different from giving people simplistic information that might reinforce their stigma.

Jamison (2006) made the following suggestions for stigma reduction through education:

- Understand the origins of stigma
- Stimulate interest in the brain chemistry of mental illness
- Be more willing to talk about mental illness among clinical professionals
- Standardize the teaching of the clinical science
- Become better advocates

If you are working in a human service capacity, two excellent audiences for your informed educational efforts are the consumers of your services—who may have misleading “knowledge” about their own illness that may be adding to self-stigma—and your colleagues at work.

Here are a few steps you can take to extend your stigma-reduction efforts into your own organization:

- Examining your organizational culture for any signs and effects of stigma, and addressing these in organizational development processes
- Providing training and supervision to ensure that all approaches toward service provision are individualized, consumer centered, strength based, empowering, and respectful
- Identifying any hierarchies that exist in staff perceptions of consumers—or in consumers’ perceptions of one another—and helping to promote a greater sense of equality
- If you are a manager or an administrator, you might review the salary structures in your organization and their implications for staff morale and the value that staff members place upon their work

You can also enlist help in educating your colleagues. For example, NAMI has a 10-week “Provider Education Program” designed for line staff at public agencies who work directly with people who have severe and persistent mental illnesses. According to the NAMI course description, this program “presents a penetrating, subjective view of family and consumer experiences” and “helps providers realize the hardships that families and consumers face and appreciate the courage and persistence it takes to live with and recover from mental illness.”

Protest

When education and contact fail to reduce stigma—so that discrimination continues, or opinion leaders and the media continue to misrepresent people with mental illnesses—protest may become an effective option. Corrigan described protest as “a reactive approach that is meant to quickly and pointedly stop stigma by reacting to disrespectful images. It has two components. (1) A moral message that stigma is wrong. One way this is effectively done is through audiovisual presentations that highlight many of the disrespectful images about mental illness perpetuated by the media. (2) Directions that these kinds of thoughts and behaviors should be suppressed. ‘Stop thinking and acting that way!’” (Corrigan, 2004, p. 52).

According to Corrigan and Lundin, protest is unlike education and contact in that it tends to target public figures (e.g., media figures, companies that generate products or services that perpetuate myths about mental illness, and others who spread negative images of people with mental illnesses) rather than private individuals. Examples might include newsmedia outlets that focus on the violent acts of a few people with mental illnesses and virtually ignore the significant progress in treatment; movie studios that portray people with mental illnesses as serial killers; and greeting card companies that, in attempts at humor, spread absurd images of people with mental illnesses (Corrigan & Lundin, 2001).

Examples of protest strategies include letter-writing campaigns, boycotts of stigmatizing products or services, some op-ed pieces or letters to the editor, blogging, phone-call campaigns, public denunciation of stigmatizing actions by organizations or individuals, press releases, marches, and sit-ins.

Corrigan (2004) identified two advantages of protest: 1) its ability to raise consciousness of and discomfort with the problems associated with stigma and discrimination and 2) its potential impact on business decisions (particularly the decisions of media organizations). However, he also noted that the research has identified two factors that mitigate against the effectiveness of protest in changing attitudes for the better. According to Corrigan and Lundin, “there is some evidence to suggest people who are the object of protest may actually become more stubborn in their attitudes about mental illness. This effect is called ‘attitudinal rebound’ and may occur for two reasons” (Corrigan & Lundin, 2001). They identified the two reasons as:

1. “Suppression rebound,” the natural human tendency think **more**, rather than less, about the things people have told us **not** to think about (e.g., “stop thinking about people with mental illness as dangerous”)
2. “Social resistance,” the tendency to want to do what people have told us not to do (e.g., think of people with mental illnesses as dangerous), as a way of asserting our independence.

Rewards and “Punishers”

People in the behavioral sciences are no strangers to the concept of reward and punishment as “reinforcers” for (respectively) positive and negative behaviors. For example, protest strategies might be thought of as ways of “punishing” people for their stigmatizing practices and discriminating behaviors. An example of a reward might be a public service award presented to a television series that has taken steps to promote non-stigmatizing images of people with mental illness.

Corrigan (2004) cautioned that rewards and punishers are often more effective in changing behaviors than in changing attitudes. While people or organizations may change their behaviors to gain rewards and avoid punishment, the attitudes may remain unchanged, and simply “go underground.” When that happens, there may be significant limitations on the extent to which the discrimination will be halted.

“Consider the employer who publicly states that hiring people with mental illness is a priority, but privately believes they are incompetent as a group. She is likely to find other excuses that prevent the actual hiring of people with psychiatric disabilities. She may limit job opportunities to those at the low end of the pay scale. She is likely to undermine reasonable accommodations, small changes that make the work place more conducive to people with psychiatric disabilities. Advocates need to keep in mind that changing the behavior may not be enough” (Corrigan, 2004, p. 22).

Questions for Reflection and Discussion

1. Of the stigma-reduction strategies described on the past few pages (contact, education, and protest), which one are you most drawn to, and why?

2. Which strategy are you least drawn to, or least comfortable with, and why?

3. What is one circumstance in which you might choose to use the strategy you named in Question 2 (above) in spite of your discomfort, and why?

Becoming an Advocate

In his (2004) book, *Beat the Stigma and Discrimination! Four Lessons for Mental Health Advocates*, Patrick Corrigan provided a wealth of information and suggestions for advocates, based on many years' experience in the roles of advocate and researcher. He organized these resources under four lessons:

Lesson One, Understand the Problem: The problem might be local, statewide, or national. It might have to do with stigmatizing images, policies, or practices that are illegal.

Lesson Two, Identify the Targets: The targets of your advocacy efforts will depend, of course, on the problem you are trying to correct. Targets might include landlords, employers, health care providers, criminal justice professionals, public policy makers, the media, or educational institutions. They might include people with mental illnesses or their family members. The targets are people whose attitudes and actions can have a major impact on stigma and discrimination.

Lesson Three, Select Change Strategies: First it is essential to assess the target group. Focus groups and interviews with key members of the target group are good places to start. According to Corrigan (2004), "Perhaps the best advice for leaders conducting focus groups is 'Avoid being judgmental!'" (p. 41). He invited advocates to challenge the "rational actor," the function of the human being through which beliefs are translated into attitudes and actions.

Lesson Four, Measure the Impact: It is important to find out how successful your efforts have been, in terms of attitude change and behavior change. Corrigan suggested seeking help from local researchers, to ensure the accuracy of your evaluation efforts.

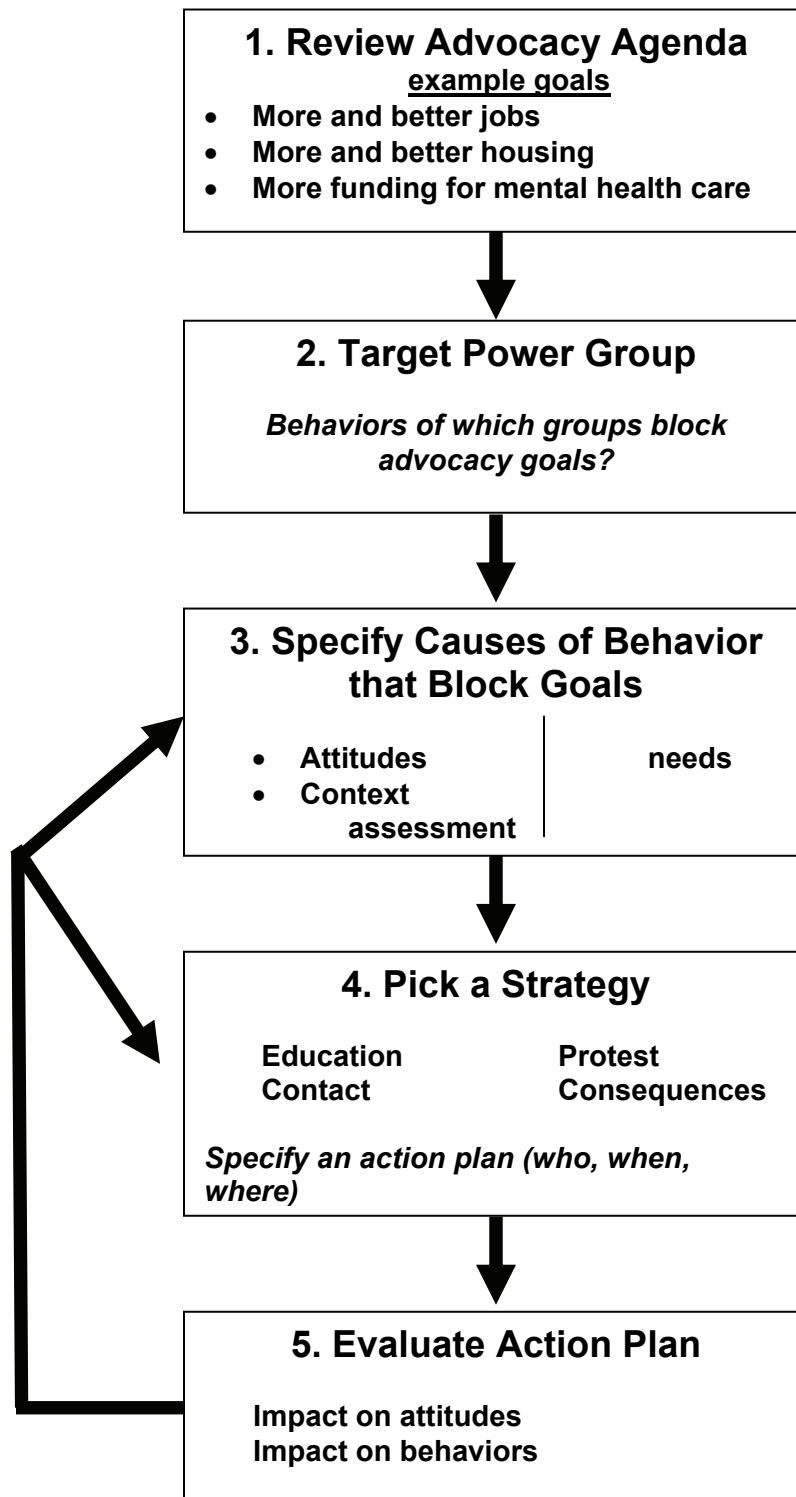
Questions for Reflection and Discussion

1. What is a problem that you might choose to address as an advocate?

2. Who might be the primary targets of your advocacy efforts?

3. What might be the best change strategies to use, and why?

Corrigan summarized his four-lesson plan in the following diagram:



(Reprinted with permission from Corrigan, 2004, p. 70.)

Effective Advocacy

In preparation for the self-study workbook, *Healing the Stigma of Addiction: A Guide for Treatment Professionals*, Woll (2005) interviewed several advocates in the field of Substance Use Disorder treatment. They provided a number of suggestions for people who want to become effective advocates, including the following:

- **Plan and carry out strategic moves:**
 - Start out small
 - Look for opportunities
 - Find and use mentors
 - Make a personal action plan
 - Make a long-term plan
 - Use social marketing techniques
- **Approach audiences effectively:**
 - Be aware of your own attitudes and biases
 - Understand the psychological roots of stigma
 - Know your audience as well as possible
 - Keep respect at the forefront
 - Listen and respond to what you hear
- **Use effective messages:**
 - Avoid blaming and shaming people who stigmatize
 - Use “people first” terminology (e.g., “people with depression” instead of “the depressed”)
 - Protect the privacy of individuals
 - Use medical terminology and approaches to counter moralistic attitudes
 - Avoid perpetuating stigmatizing images and stereotypes
- **Use research to heal stigma:** Back up your arguments with evidence
- **Define the issues carefully:** Work with the experts to define and refine your message

Is it worth all this effort? Are advocacy initiatives really making a difference? According to Jamison (1995), “Attitudes about mental illness are changing, however glacially, and it is in large measure due to a combination of these things—successful treatment, advocacy, and legislation” (p. 183).

Questions for Reflection and Discussion

1. What might be a simple way for you to get started in stigma-reduction efforts in the next few weeks?

Examples: Anti-Stigma Campaigns

For the fledgling advocate, the study of existing anti-stigma campaigns can be an interesting and illuminating way of bringing some of these ideas into concrete terms—and sparking more ideas. That study is, of course, ample subject for a manual in itself. But the remainder of this chapter provides brief overviews of a few large-scale campaigns and two local grassroots efforts, and the list of “Resources for Advocacy and Support” (Page 165) provides e-mail addresses and other contact information for some additional resources.

Large-Scale Campaigns

SAMHSA's National Anti-Stigma Campaign

After several years' preparation, the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS) in 2006 launched a \$1 million campaign to reduce the stigma associated with mental illness. Partners in this National Anti-Stigma Campaign (NASC) include the Centers for Disease Control and Prevention; the National Institutes of Health, National Institute of Mental Health; state mental health agencies; leading researchers on stigma; and a broad coalition of stakeholders. Target populations include young adults, older adults, and people in rural areas.

“We took a new approach to de-stigmatizing mental illness with this campaign,” said Assistant Surgeon General Eric B. Broderick, SAMHSA Acting Deputy Administrator. “Instead of telling people why they shouldn't discriminate against people with mental illnesses, we are showing how friends can be supportive of those who have disclosed they are having a mental health problem and the critical role that friendship plays in recovery” (Ad Council, 2006, p. 1). The “What a Difference a Friend Makes” campaign (www.whatadifference.org) targets people ages 18-25 with information and resources, encouraging and supporting them in their efforts to provide ongoing understanding, friendship, and support to friends who are living with mental illnesses.

In the words of CMHS Director A. Kathryn Power, “If you have early and consistent support from your peers and you get appropriate treatment, then you have a much better chance of managing the illness over time. It's important as a friend in a relationship with someone recovering from mental illness that you exhibit social acceptance” (Leinwand, 2007, p. 1).

The SAMHSA/CMHS project responsible for carrying out this campaign is the Resource Center to Address Discrimination and Stigma (the ADS Center). In its fifth year of operation, the SAMHSA ADS Center “helps people design, implement and operate programs that reduce discrimination and stigma associated with mental illnesses. With the most up-to-date research and information, the ADS Center helps individuals, organizations, and governments counter such discrimination and stigma in the community, in the workplace, and in the media” (ADS Center, 2007, p. 1). The ADS Center (<http://www.stopstigma.samhsa.gov/>) provides:

- Information about what works in reducing stigma and discrimination

- Training and technical assistance to help create anti-discrimination and anti-stigma initiatives
- Information about and how to connect with effective campaigns and programs that are already in place
- Information about available publications, events, research, and issues of relevance regarding discrimination and stigma
- A comprehensive bibliography of the literature addressing discrimination and stigma
- Resources and information about the unique needs of special populations such as children, older adults, and racial and gender minorities; as well as information for employers, realtors/landlords, medical providers, educators, faith groups, policy makers, and the media
- Information on the rights of people who have mental illnesses

NAMI's Stigma Busters

The “StigmaBusters” initiative of the National Alliance on Mental Illness (NAMI) “is a network of dedicated advocates across the country and around the world who seek to fight inaccurate and hurtful representations of mental illness. Whether these images are found in TV, film, print, or other media, StigmaBusters speak out to challenge stereotypes and to educate society about the reality of mental illness and the courageous struggles faced by consumers and families every day.

“StigmaBusters' goal is to break down the barriers of ignorance, prejudice, and unfair discrimination by promoting education, understanding, and respect. Each month, close to 20,000 advocates receive a NAMI StigmaBusters Alert, and it is read by countless others around the world online” (NAMI, 2007). The web site is www.nami.org/Template.cfm?Section=Fight_Stigma.

National Depression Screening Day

“National Depression Screening Day® (NDSD) began sixteen years ago as the first nationwide, community-based mental health screening program. Today it is the largest provider of mental health screening services in the country through its partnership with thousands of community-based, college, and primary care screening sites. NDSD has expanded in recent years to offer both in-person and online screening for four of the most common and frequently co-occurring mental disorders: Depressive Disorders, Bipolar Disorders, Generalized Anxiety Disorder, and Posttraumatic Stress Disorder.

“NDSD Mental Health Screening is designed to call attention to mood and anxiety disorders on a national level, to educate the public and clinicians about the symptoms and effective treatments, to offer individuals the opportunity to be screened for the disorders, and to connect those in need of treatment to the mental health care system. NDSD Finishes 2006 with nearly 450,000 Mental Health Screenings” (NDSD, 2006, p. 1).

NIMH's “Real Men, Real Depression”

A project of the National Institutes of Health, National Institute of Mental Health (NIMH), “NIMH's ‘Real Men, Real Depression’ is a large-scale public awareness initiative that uses brochures, videos, and audio media to address the fact that men are less likely than women to recognize,

acknowledge, and seek treatment for their depression. Web site is <http://www.nimh.nih.gov/health/publications/real-men-real-depression.shtml>. They feature male participants who are hyper masculine in their gender identities and career pursuits, acknowledge and respond to the dynamics of men's reluctance to seek help, and incorporate traditionally masculine norms and values into depictions of the help seeking process" (Rochlen, McKelley, & Pituch, 2006).

Australia's "beyondblue"

"beyondblue: the national depression initiative" is a not-for-profit organization funded by Australian national, state, and territorial governments since 2000 to improve responses to depression. This campaign focuses on community awareness and destigmatization, consumer and career support, prevention and early intervention, primary care training and support, and applied research. In a study of the impact of beyondblue, researchers found that the initiative raised awareness of depression within the community, and awareness of discrimination against people with depression. However, researchers found little change in people's beliefs about long-term outcomes, apart from a stronger belief that people with depression are more understanding of other people's feelings (Jorm, Christensen, & Griffiths, 2005).

One International Campaign

In its 1996 "Programme to Reduce Stigma and Discrimination Because of Schizophrenia," the World Psychiatric Association (WPA) established anti-stigma projects in 20 countries, using a variety of social marketing techniques, including:

- Establishing an action committee
- Conducting a local survey of perceived stigma
- Having the local action committee select target groups
- Crafting messages for the target groups and the media used to reach them
- Setting up a consumer speakers' bureau
- Establishing media watch organizations, to advocate with news and entertainment media
- Proposing changes in curricula for high school students or for police officers in training (Warner, 2005)

Again, a variety of other organizations and initiatives are listed in section on "Resources for Advocacy and Support," beginning on page 165.

Two Local Grassroots Efforts

In the interviews for this manual, two projects were offered as examples of local grassroots efforts to promote understanding and reduce stigma. Finding the local efforts in your community will require a bit of networking with local advocates, NAMI affiliates, and involved community members. However, once you begin to find appropriate targets for your inquiries, the enthusiasm of the partners involved will probably ensure that you have ample information.

Erica's Lighthouse

Erica's Lighthouse is an organization started in 2001 by the parents of a young student at Washburn Junior High in Winnetka, Illinois. Founded in her memory, Erica's Lighthouse is dedicated to teaching teens about depression and suicide. The organization seeks to help teens understand that depression is not a flaw or weakness, and to educate them in the warning signs of suicide, so they can help their friends. Students who are involved wear their Erica's Lighthouse T-shirts proudly and are willing to discuss the subject frankly and constructively.

The Reggi Marder Memorial Task Force

At the Jewish Reconstructionist Congregation in Evanston, Illinois, the Reggi Marder Memorial Task Force on Depression and Suicide has undertaken a number of initiatives to raise awareness of these issues, to "normalize" these issues within the Congregation, to help members find ways of addressing depression within their own lives and families, and to memorialize Reggi, a beloved member of the congregation. The Task Force's work includes discussion sessions and Congregational forums; articles in the Congregation's newsletter; and a new support group for people with depression, using Jewish text and discussion to explore the illness and its meaning in people's lives. The task force has also been connected with like-minded organizations in the area, and with congregations that have similar initiatives.

Questions for Reflection and Discussion

1. What individuals or organizations do you already know who would be good sources of information and collaboration for you in stigma-reduction activities?

2. What kinds of people, information, or resources do you need to locate to help you plan and carry out some of the activities you would like to try?

The Final Step

The last chapter of this manual links the subject back to its center, the experiences of people with depressive disorders. This time, the focus is on the healing of self-stigma and the rekindling of hope.

Fred's Story

When Fred was 13 years old, something unexpected happened. He tried to write a paper for school and found it impossible. He might as well have been paralyzed. For reasons that made perfect sense to him at the time, he decided that, if he was unable to write a paper, he would be better off dead. When the overdose of aspirin had failed to kill him and he had weathered his first depressive episode, he started over.

For Fred, starting over meant leaving behind everything he did and everything he was. It meant that he could not walk back into the same life—friends, sports, studies—that he had left in what seemed like utter disgrace. Being depressed, having a mental illness, having attempted suicide, these were not things he could even consider asking anyone to try to accept. They were shameful to him beyond his capacity to contemplate. He left them behind, along with his memories and the rest of his life.

Fred's next incarnation jumped into debate, politics, a whole new set of friends. He chose the university with the best political science department he could find, and enjoyed his studies until the next episode of depression, and the next attempt at suicide, in his freshman year. Once again, he started over. He took up economics and never returned to the political science department, to his friends, or to any vestige of the life he believed he had disgraced beyond redemption.

This was the pattern that became Fred's life for the next three decades: dedication, studies, stellar achievement, careers, friends, all left behind when six to nine months' worth of depression and immobility forced him to remember that he was—in his estimation—damaged beyond redemption. He would seek treatment and follow the advice of his doctors and therapists, but still the episodes would return, and still he would leave himself behind in shame.

Fred was married in his 20s and became an attorney, working in a small civil rights law firm in Chicago. After the next round of his illness, Fred's wife persuaded him to promise not to attempt suicide again, and he has kept his promise to this day. He did, however, once again leave his job and the rest of his life behind, starting a private consulting practice that took him around the country helping other firms with litigation. After the next episode, Fred closed out his practice, never went back, and never again spoke to the people he had known there. His next life was as a highly successful community organizer on Chicago's West side. He and his wife believed they had defeated the depression.

Then came the episode that convinced Fred's wife that she could no longer continue in the marriage. That episode left him lying on his living room couch for a year and a half, followed by another year and a half in a nursing home and 10 months in a homeless shelter.

Fred lost nearly everything important in his life—his marriage of 24 years, his 20 years as a practicing attorney, his home, and most of his physical possessions. But his deepest loss was of his ability to believe that, whatever happened, he would never wake up one day sleeping in a gutter and searching in a garbage can for something to eat.

When Fred entered the shelter, his wife suggested that he do it differently this time: Instead of leaving himself behind, blotting his old life out of his consciousness, and starting over, he needed to find out why the disability was returning and what he could do to prevent it. That understanding would not be possible until he stopped starting over. So he did.

For the past six years, Fred has built quite a different sort of life. Not only does he no longer leave himself behind, but he takes himself with him wherever he goes, depressive disorder and all. He has become a consumer advocate for people with mental illness and homelessness. Predictably, Fred has been a highly successful advocate, starting a new organization, working to change service systems, sitting on governing boards and boards of directors, and training consumers in concepts and skills of recovery. He still has periods of depression and immobility—more brief than those in the past—but is learning to manage them more effectively through medication, cognitive/behavioral therapy, mindfulness, using his strengths, knowing his limitations, and simply accepting himself and his illness.

Fred has found a home in the recovery model that places people with severe mental illness in charge of the decisions that shape their lives. For him the heart of the recovery message is that—regardless of how well treatment works—he can work to manage the illness and its symptoms, and to make his own life better. Far from hiding his illness or his history of homelessness, Fred has used these experiences to fuel his purpose in life.

Instead of bowing to stigma and shame, he defies and defeats them every day.

Responses to Fred's story

1. What are some thoughts that went through your mind when you were reading Fred's story?

2. What were some feelings you had when you were reading Fred's story?

3. How would you have felt if you worked with Fred and he simply disappeared and never contacted you again?

4. How would you have felt if you worked with Fred and he took a leave of absence because of a depressive episode, then returned to work?

5. Describe one instance when you took things that you once considered your mistakes, weaknesses, or failures and used them to make things better for yourself and/or others.

6. If you could ask Fred anything right now, what would that be?

7. If you could tell Fred anything right now, what would that be?

Chapter Nine: Healing Self-Stigma

People who are seriously mentally ill are taught not to hope. So the first thing we do is tell people, “Hope, dream, tell me what you want!” If you can’t dream, you can’t hope. If you can’t hope, for sure you’re not going to get it.

M. Fred Friedman, Interview

If the overwhelming message of stigma, self-stigma, and depression is hopelessness, then hope may be the principal instrument of healing. Along with their responsibility to help people solve problems—through medicine, psychotherapy, case management, outreach, organizing, and training—helping professionals have an equal responsibility to help people learn how to hope. For many people who have battled hopelessness for so long, this may be the most difficult skill to acquire.

This final chapter provides some information and ideas on five aspects of healing the effects of self-stigma:

- Countering self-stigma
- Resiliency
- Empowerment
- The Story
- Recovery

Countering Self-Stigma

Managing stigma and discrimination is a core component of the ongoing process of recovery from mental illness, along with controlling symptoms, regaining a positive sense of self, and working to lead a productive and satisfying life (Markowitz, 2001). However, managing the effects of stigma may prove more challenging than one might imagine. The skills required are not necessarily ones that come naturally to people raised in a stigma-driven society.

In one study of consumers of psychiatric services, Link and colleagues (1991) found that many “coping orientations” (combinations of attitudes and behaviors) commonly used to counter the negative effects of labeling actually tended to do more harm than good. They studied three of these orientations among the study group of consumers: keeping their treatment history a secret, educating others about their illness, and avoiding situations in which they might be rejected.

The researchers measured the effects of these orientations on two outcome variables, demoralization and unemployment. They found that, to varying degrees, all of these coping orientations tended to increase, rather than decrease, both demoralization and unemployment (Link, Mirotznik, & Cullen, 1991).

Fortunately, more effective strategies are also available. Corrigan and Lundin's (2001) book, *Don't Call Me Nuts: Coping With the Stigma of Mental Illness*, provides a wealth of information, inspiration, practical advice, and self-help workbook materials for consumers. Its targets are both the internal self-stigma and the stigma in society. Among their suggestions for coping with and countering self-stigma are the following cognitive strategies:

- Identify and counter (with facts) the myths about mental illness
- Directly counter self-stigmatizing attitudes
- Identify the assumptions behind the beliefs
- Check out the assumptions with trustworthy people
- Collect evidence that challenges the assumptions
- Question assumptions that add to self-stigma
- Get reality checks on beliefs about self
- "Talk back" to irrational beliefs
- Restate the attitudes so that they are not harmful (Corrigan & Lundin, 2001)

Among the many worksheets in that volume, the authors provide this "Stop Self-Stigma Worksheet" (page 116 of the book) for designing "counters" to self-stigmatizing beliefs.

Stop Self-Stigma Worksheet: Complete All Five Steps

1. State the hurtful belief:

I MUST BE _____ BECAUSE _____

2. Define the True-False Assumptions

3. Challenge the Assumptions by Checking Them Out With Whom?

4. Collect Evidence that Challenges the Assumptions

5. Restate the Attitude so it Does Not Injure Me. This is a COUNTER.

From Corrigan & Lundin (2001), *Don't Call Me Nuts: Coping With the Stigma of Mental Illness*, Tinley Park, IL: Recovery Press. Reprinted With Permission.

Like healing the stigma in society, healing self-stigma is also more difficult to accomplish alone. In their study of HIV-positive gay Latino men, Ramirez-Valles, Fergus, Reisen, Poppen, and Zea (2005) found that community involvement tended to raise self-esteem and mitigate the depression and loneliness associated with the experience of being stigmatized, even though it heightened people's exposure to and perception of stigma. In another study of depression among HIV-positive gay men, Hays, Turner, and Coates (1992) found that satisfaction with social support, particularly informational support, predicted lower levels of stress and depression even after a year had passed.

Helping professionals in the full variety of service fields can find a number of ways of adding to the resources of people who are challenged by self-stigma. Woll (2005) provided a very basic list of possible ways of helping people heal the effects of self-stigma within the boundaries of the professional role, including:

- Listening to people and seeking to understand their experience of stigma
- Listening to family members, to find out what they need in order to let go of stigma
- Bringing a patient and consistent message of hope and respect; focusing on recovery
- Helping people recognize and appreciate the importance of their personal strengths and resiliencies, both in their own histories and in their recovery
- Helping consumers and families accept the many wounds and limitations that all people have, and helping them see human imperfection as normal; encouraging them to use their spiritual and psychological resources to come to terms with their "humanness"
- Using non-stigmatizing language and helping people find non-stigmatizing language that feels comfortable to them
- Teaching about the brain's role in depression, so that people can understand and believe that depression isn't a form of laziness, weak will, immaturity, or inferiority
- Teaching people about the ways in which stigma contributes to depression
- Counseling people on the emotions raised by stigma, and training them in ways of coping with those emotions
- Relating the healing of stigma to other models that people are familiar with, like models of therapy or cultural healing traditions
- Avoiding judgmental, moralistic, or confrontational methods, language, and approaches
- Using culturally competent (race, age, gender, ethnicity, etc.) materials and approaches
- Bringing in recovering speakers who convey a positive image of recovery, particularly speakers who come from the same community as consumers
- Using recovering people effectively as examples of success in recovery
- Talking to people about safe vs. unsafe self-disclosure about their disorders (for example, the possible effects of self-disclosure to prospective employers), the timing of disclosure, and effective methods of disclosure

If some of the more intimidating information about the neurochemical changes associated with depression proves overwhelming, people who understand these changes can help others search out the more positive evidence that provides hope. For example, information about reductions in neurogenesis (growth of new brain cells) sometimes associated with depression

may be somewhat discouraging. However, studies have shown that antidepressant medication, psychotherapy, and even electroconvulsive therapy can in some cases re-start the process of neurogenesis (Lichtenstein Creative Media, 2006), with positive implications for recovery.

Questions for Reflection and Discussion

1. Among the people you know with depressive disorders, what seem to be the most common ways of trying to counter self-stigma, and how effective are these methods?

2. What can you do to help others (and/or yourself) challenge the assumptions behind stigma and self-stigma?

Resiliency

One of the most effective roles that human service professionals can play is in helping people identify and believe in the strengths, resources, and resiliencies they already possess. The mental health field has been ahead of most helping fields in the movement toward a strength-based approach, with strong leadership from the SAMHSA Center for Mental Health Services.

Resiliency-based approaches take as a “given” the fact that people are born with, develop, choose to cultivate, and benefit from a variety of strengths, resources, and resiliencies throughout their lives. These can include “values, principles, inner qualities, skills, and personality traits that contribute to success in life, personal growth, emotional health, resiliency, recovery, and meeting the challenges of everyday living” (CPIC, 2006, p. 5).

The presence of an illness such as depression does not negate the reality of an individual's basic strength and resiliency, in spite of the fact that the illness may have compromised some forms of neurological resiliency for many years. Human resiliency is far too large to fit in the brain, or even in the body as a whole. It transcends illness, misfortune, and loss. Resiliency can be found, sometimes in the mere fact of survival, and sometimes in the dignity and courage that characterize a single action, a lifetime, or the facing of each new day.

Wolin & Wolin (1993) studied people who had been raised in highly troubled families and identified seven factors that seemed to promote resiliency:

- **Insight:** “The mental habit of asking searching questions and giving honest answers”
- **Independence:** A bargain among competing needs (the right to safe boundaries, the dictates of conscience, and the longing for relationship)
- **Relationships:** These include “intimate and fulfilling ties to other people” and “*attaching*, an ability to form and to keep mutually gratifying relationships”
- **Initiative:** “The determination to assert yourself and master your environment,” including “a lifelong attraction to *generating* projects that stretch the self and promote a cycle of growth”
- **Creativity and Humor:** “Safe harbors of the imagination where you can take refuge and rearrange the details of your life to your own pleasing”
- **Morality:** The “wish for a good personal life grown large and inclusive. By *serving*, or devoting time and energy to institutions, community, and the world, resilient survivors join their individual selves to the selfhood of humanity” (Wolin & Wolin, 1993)

Charney (2005) and Southwick studied 750 Vietnam veterans who had developed neither depression nor PTSD after being held as prisoners of war for a period of six to eight years, during which time they were tortured and/or kept in solitary confinement. The investigators identified the following elements that they considered critical characteristics of resilience:

- **Optimism:** “Those who are extremely optimistic tend to show greater resilience, which has implications for cognitive therapies that enhance a patient's positive view of his or her options, thereby increasing optimism.”
- **Altruism:** “Those who were resilient often found that helping others was one way to handle extreme stress, which can also be used therapeutically as a recovery tool.”
- **A Moral Compass:** A “set of beliefs that cannot be shattered”
- **Faith and spirituality:** “For some POWs, prayer was a daily ritual, although others were not at all involved or interested in religion.”
- **Humor**
- **Having a role model:** “Many people with role models draw strength from this; For treatment, using a role model, role modeling, or helping someone discover a role model can be beneficial.”
- **Social supports:** “Having contact with others who can be trusted, either family or friend, with whom one can share most difficult thoughts, was important in recovery.”
- **Facing fear:** “Leaving one's comfort zone”
- **Having a mission:** Finding meaning and/or purpose in life
- **Training.** “One can train to become a resilient person or to develop resilience by experience in meeting and overcoming challenges” (Charney, 2005 cited in Rosenbaum & Covino, 2005)

Simoni and Mayra (2003) found that 66% of their cohort of HIV-positive Puerto Rican women experienced symptoms above the threshold for a diagnosis of clinical depression, but that spirituality (including religious involvement), self-esteem, and a sense of mastery tended to correspond with lower levels of depression.

And Hinshaw (2005) reminded us of the importance of noticing and acknowledging resiliency within the family, regardless of mental illness: "...whereas nearly all of the relevant literature has emphasized family burden—related to the negative effects of coping with a relative with mental illness—anecdotal evidence suggests that, for at least a subset of families, the experience has fostered sensitivity, courage, and a more positive outlook on life. Just as the mental disorder itself may foster resilient responses...the existence of family coping may not inevitably be associated with despair, isolation, and silence" (Hinshaw, 2005, p. 721).

Questions for Reflection and Discussion

1. Think of someone you know with a depressive disorder. What are some elements of strength, resiliency, and resources that you perceive in that person?

2. What can you do more effectively to show this person his or her strengths, resources, and resiliency?

Empowerment

It is humbling to write even briefly about a subject that has become such a common buzzword, but empowerment is so critical to the healing of self-stigma that it would be irresponsible not to mention it. Contrary to what many helping professionals would like to believe, one human being cannot empower another. The power comes from within. We can, however, encourage empowerment, foster it, teach it by example, and simply choose not to stand in its way.

Empowerment may take the form of greater self-direction, a stronger sense of self, more powerful identification with a peer group, a stronger sense of spiritual empowerment, or a combination of all these things.

Camp, Finlay, and Lyons (2002) found one example of empowerment in a group of women with mental disorders whom they studied, members of a weekly women's group at a mental health drop-in center. These women were fully aware of the stigma directed at them because of their illness, but they rejected the stereotypes and rose above the stigma. The respondents' answers

to the interview questions showed a clear understanding of the forces behind people's stigmatizing attitudes, a strong ability to separate accurate from inaccurate characterizations of people with mental disorders, and healthy self-esteem (Camp, Finlay, & Lyons, 2002). In this case, effective peer support made the critical difference in mitigating the effects of stigma.

Information can be a key element in building empowerment. When stigma has discouraged people from seeking information about their illnesses, the Internet may help them navigate around that obstacle. In a study comparing people with often-stigmatized conditions (including depression) with people whose conditions are generally not stigmatized, Berger and colleagues (2005) found that people with stigmatized conditions were significantly more likely to have used the Internet for health information, to have communicated with clinicians using the Internet, and to have used health-care services at higher rates because of information they found on the Internet (Berger, Wagner, & Baker, 2005).

Sometimes empowerment includes the flexibility to accept that we do not always have to be strong. In a comparison of two studies, Schreiber and colleagues (1998) found that a cohort of women whose strategies for managing depression focused on “being strong” had less success in recovery from depression than an earlier cohort whose members had realized they did not need to be strong and capable at all times (Schreiber, Stern, Noerager, & Wilson, 1998).

Margaret Shih emphasized the important role of resilience and empowerment, not only in the process of overcoming the effects of stigma, but also in using that process to enhance life as a whole. In her (2004) review of the experiences of people who had flourished in spite of stigmatized identity, she found that these individuals tended to use three processes to great effect:

- **Compensation:** The development of skills for achieving goals and overcoming the disadvantages associated with stigma
- **Strategic interpretations of the social environment:** These include choosing to compare oneself with members of one's own stigmatized group, rather than with members of a less stigmatized group; and acknowledging the roles that prejudice and discrimination are playing in social interactions and in others' attitudes
- **Multiple identities:** The identification with many or all of the groups of which one is a member (e.g., gender, culture, age, religion, occupation, interest), rather than with the stigmatized group alone (Shih, 2004)

Shih identified a number of factors that can make it more likely that people will be more resilient and adopt an empowerment approach rather than a “coping” approach to stigma. These factors include:

- A perception of the stigma as unjust
- A strong identification with the stigmatized group, with the resulting heightened awareness of positive aspects of membership in that group
- Higher levels of intelligence
- Perception of the stigmatized condition as uncontrollable, thus reducing the sense of blame
- Acceptance by family members and key members of the community (Shih, 2004).

Questions for Reflection and Discussion

1. What can you do to become more empowering toward people with depressive disorders?

The Story

If stigma attempts to label, limit, and define people in terms of isolated negative experiences and characteristics, then healing self-stigma might include attempts to help people: 1) remove and/or transcend labels, limitations, and definitions that have been applied in the past; 2) expand the field of experiences and characteristics that contribute to their self-description and self-definition; 3) see the strengths that have existed all along and continue to grow; and 4) become—and believe in their ability to be—the ones who tell their own stories.

According to Lysaker & Buck, “this process, which may be at odds with stability-focused therapy, may involve conversations about what is wrong and not wrong, what has been lost, what is dreamt of, and what should be done” (Lysaker & Buck, 2006, p. 35). For the helping professional listening to the story, challenges in the listening role might include avoiding a parental or authoritarian stance; resisting the temptation to correct the story, supply missing information, or steer the story in directions that will support the prescribed treatment; and tolerating the pain and confusion that may be a central part of the story (Lysaker & Buck, 2006).

If people need prompting to “seed” their stories, the listener might paraphrase some of the questions that White (1996) developed in his efforts to help people in recovery from Substance Use Disorders (SUD) heal self-stigma through narrative:

1. Who was I before the onset of my symptoms?
2. Who and what did I become as result of my illness?
3. Why me? How do I explain what happened?
4. What has happened to break this pattern?
5. Who and what am I now?
6. Where am I going, and what do I need to do to get there? (White, 1996)

As stated earlier in this manual, the story is the opposite of stigma.

Recovery

The concept of recovery is newer to the field of mental health than it is to the treatment of SUDs. However, it is gaining ascendancy and interest from a number of groups, including consumers and former consumers of mental health services, family members, advocates, service providers, and the Federal and State agencies that support these services.

In the words of the first Surgeon General's Report on Mental Health, "Recovery is variously called a process, an outlook, a vision, a guiding principle. There is neither a single agreed-upon definition of recovery nor a single way to measure it. But the overarching message is that hope and restoration of a meaningful life are possible, despite serious mental illness. Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society" (DHHS, 1998, p. 1).

"People do recover," said Patrick Corrigan in an interview for this manual. "Granted, recovery is a complex mechanism. For some people, recovery means moving on entirely. For others, it's a greater sense of self-determination and hope—making more decisions and taking responsibility for them."

Resiliency, empowerment, and recovery are important centerpieces of the SAMHSA Center for Mental Health Services (CMHS) initiative toward Mental Health Services Transformation. SAMHSA has developed ten "Fundamental Components of Recovery," based on a consensus process that included a panel of more than a hundred consumers, family members, providers, advocates, researchers, academicians, managed care representatives, accreditation representatives, and State and local public officials. The ten Fundamental Components are:

- **"Self-Direction:** Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals.
- **"Individualized and Person-Centered:** There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations. Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health.
- **"Empowerment:** Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life.
- **"Holistic:** Recovery encompasses an individual's whole life, including mind, body, spirit, and community. Recovery embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services, complementary and naturalistic services, addictions treatment, spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers,

organizations, systems, communities, and society play crucial roles in creating and maintaining meaningful opportunities for consumer access to these supports.

- **“Non-Linear:** Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage of awareness in which a person recognizes that positive change is possible. This awareness enables the consumer to move on to fully engage in the work of recovery.
- **“Strengths-Based:** Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave stymied life roles behind and engage in new life roles (e.g., partner, caregiver, friend, student, employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.
- **“Peer Support:** Mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery. Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.
- **“Respect:** Community, systems, and societal acceptance and appreciation of consumers—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery. Self-acceptance and regaining belief in one’s self are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.
- **“Responsibility:** Consumers have a personal responsibility for their own self-care and journeys of recovery. Taking steps towards their goals may require great courage. Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.
- **“Hope:** Recovery provides the essential and motivating message of a better future—that people can and do overcome the barriers and obstacles that confront them. Hope is internalized but can be fostered by peers, families, friends, providers, and others. Hope is the catalyst of the recovery process. Mental health recovery not only benefits individuals with mental health disabilities by focusing on their abilities to live, work, learn, and fully participate in our society, but also enriches the texture of American community life. America reaps the benefits of the contributions individuals with mental disabilities can make, ultimately becoming a stronger and healthier Nation” (SAMHSA).

In an interview for this manual, M. Fred Friedman provided one consumer/advocate’s summary of the recovery experience. “My present set of symptoms may or may not be reduced. In the long run, medications may or may not work, and therapy may or may not work. But I can make my life better. For me recovery is this: One, I acknowledge that I am mentally ill and am always going to be. And two, I get to decide what my life is going to be like, and what I want.”

Important sources of support for recovery include the many consumer-directed mutual-help support groups that have been formed, with many still in the formation process. Carpinello and colleagues (quoted in Knight, 2006, p. 1) identified the following qualities of self-help groups for recovery from mental disorders:

- "Self-help groups include people with a common bond who voluntarily come together to share, reach out, and learn from each other in a trusting, supportive, and open environment. The common bond is defined as the collective experience related to being diagnosed as having a serious mental illness...and receiving services from the mental health system.

- "Self-help is based on the principle of helping oneself and others at the same time. Thus, self-help is a mutual process, without a dichotomy between the helper and the person being helped. Membership in self-help is neither mandated nor charity.
- "Membership is a self-selection process. Self-help groups grow from the bottom up or at the grass roots. Decision making rests solely in the hands of the people in...need...(of being) together, that is, group members.
- "Self-help is about sharing common experiences among people with common problems, in this case, people with serious mental illnesses.
- "The role of professionals is to give referrals and engage in other supportive acts outside the group, not to run the groups, which would defeat the workings of self-efficacy."

According to Knight (2006), "The findings from research on self-help groups for people with serious mental illness consistently show: (1) reduced symptoms and substance abuse over time; (2) concomitant reductions in crises, hospitalizations, and use of services; (3) improved social competence and social networks; and (4) increased healthy behaviors and perceptions of well-being" (p. 2).

It seems to be a fundamental spiritual principle that, when we allow ourselves to be conduits in the healing of another human being, we ourselves are healed in the process. Mutual-help recovery roles and relationships are making this expanded healing process a reality. People in recovery from Substance Use Disorders (SUDs) have benefited from a far longer and more widespread experience of organized non-professional recovery from these disorders, beginning with the birth of Alcoholics Anonymous in 1935. Recovery groups had a significant influence in shaping the early development of the SUD treatment field, and a new recovery advocacy movement has been gaining power in the past several years (White, 2007). The treatment field has also just begun to explore the concept of professional, paraprofessional, and peer-directed recovery management services, largely under the leadership of its historian, William L. White.

That movement might have much to offer to the mental health recovery field, including the concept of "recovery capital"—"the quantity and quality of internal and external resources that one can bring to bear on the initiation and maintenance of recovery" (Granfield & Cloud, 1999). Recovery support services based on finding and nurturing people's recovery capital—rather than on identifying and eliminating problems—have great potential for healing self-stigma, fostering resiliency, and promoting empowerment.

According to White, Kurtz, and Sanders (2006), the principles and values that guide SUD recovery management include:

- Emphasis on resilience and recovery (as opposed to pathology and disease processes)
- Recognition of multiple long-term pathways and styles of recovery
- Empowerment of individuals and families in recovery to direct their own healing
- Development of highly individualized and culturally nuanced services
- Heightened collaboration with diverse communities of recovery
- Commitment to best practices as identified in the scientific literature and through the collective experience of people in recovery

Questions for Reflection and Discussion

1. Look at the Fundamental Components of recovery on Page 137. Which components seem most challenging to achieve, and why? How might you work toward these?

2. How might you work to foster these more challenging components in your own life, in the lives of your loved ones, or in the lives of the people you serve?

In Closing

If in reading the five sections of this chapter you have noticed some of the same concepts appearing in all five, it is no wonder. Separating the healing of self-stigma from resiliency, empowerment, the telling of the story, and recovery is every bit as difficult as separating the effects of self-stigma from the symptoms of depression. Fortunately, it is not necessary to separate these concepts. Rather, it is essential to let healing, resiliency, empowerment, the story, and recovery fall in together as the whole that they really are.

Stigma and stereotypes would relegate people with depression—as they would people with so many disabilities—to the roles of recipients of help and support. But now, empowerment and recovery are casting consumers in the roles of helpers, supporters, scholars, mentors, creators, contributors, taxpayers—responsible and concerned citizens.

Is it true what they say, that the whole of society is enriched when people who have been wounded are allowed to contribute on an equal basis? How can it not be true, when we have all been wounded? Our wounds do not define us, but add to our strength and compassion. We all need examples of hope and courage.

If humankind has learned nothing else from all our fledgling attempts at human and civil rights, we have learned that each of us suffers from the fact of unfairness in the world, and each is less free because some have so little freedom. Our suffering may not take place on a practical or financial level—or even on a conscious level—but we still pay the price. Something of what we are is diminished.

To work toward healing the stigma is to join a force that can help heal us all.

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Resources for Advocacy and Support

ADS Center (The Resource Center to Address Discrimination and Stigma)
A SAMHSA/CMHS project to help people design and implement anti-stigma and anti-discrimination campaigns

ADS Center

11420 Rockville Pike

Rockville, MD 20852

(phone) 1-800-540-0320

(email) stopstigma@samhsa.hhs.gov

<http://www.stopstigma.samhsa.gov/>

AIDS Education and Training Centers (AETC)

Tools for professionals on Management of Depression and HIV, including:

- Diagnostic and Treatment Algorithms
- Guidelines for selecting medications
- Guidelines for managing co-occurrence
- Reference tools
- Patient health questionnaires
- Medication interaction charts
- Guidelines for prescription

http://www.aidsetc.org/pdf/workgroups/pcare/pcwg_depression.pdf

The Anti-Stigma Project

Jennifer K. Brown

On Our Own of Maryland

1521 South Edgewood Street, Suite C

Baltimore, MD 21227

(410) 646-0262

<http://www.onourownmd.org/>

The Awakenings Project

“Begun in 1996 as an annual show of art by persons with mental illness, this consumer driven program now includes a literary magazine, The Awakenings Review, and a music program.

Based near Chicago” (p. 4).

Five Forest Hill Drive

Suite 201

Glen Ellyn, IL 60137

www.theawakeningsproject.org

Bazelon Center for Mental Health Law

"A non-profit legal organization that advocates for the civil rights and human dignity of persons with mental disabilities. Provides many links to state advocacy resources."

1101 15th St., NW

Suite 1212

Washington, D.C. 20005

(phone) 1-202-467-5730

(fax) 1-202-223-0409

(email) webmaster@bazelon.org

(www.bazelon.org)

The Chicago Consortium for Stigma Research (CCSR)

A consortium with an extensive website that includes descriptions and links to all of the agencies, organizations, and groups listed in this resource list, as well as research information, publications, and more.

Chicago Consortium for Stigma Research

3424 State Street

Chicago, IL 60616

(phone) 1-312-567-6751

www.stigmaresearch.org

Consumer Organization and Networking Technical Assistance Center

www.contac.org

888-825-Tech

304-345-7312

Depression and Bipolar Support Alliance (DBSA):

Includes information, support, and educational information in the areas of outreach, advocacy, NewsWatch, and training, among other areas regarding both depression and bipolar mental illnesses.

www.dbsalliance.org

730 N. Franklin Street, Suite 501

Chicago, Illinois 60610-7224

Toll free: (800) 826 -3632

Fax: (312) 642-7243

Depression.com

"Includes several searchable databases that will be of interest to both consumers and professionals." (p. 1)

Depression and Bipolar Support Alliance

730 N. Franklin St., Suite 501

Chicago, IL 60610

(phone) 1-800-826-3632

<http://www.dbsalliance.org/site/PageServer?pagename=home>

Depression and Related Affective Disorders Association (DRADA) 2330 West Joppa Road Suite

100 Lutherville, MD 21093-4605 410-583-2819

email: drada@jhmi.edu

www.drada.org

Depression is Real Coalition

A group of seven nonprofit organizations representing doctors, people living with mental illness, and American communities.
www.depressionisreal.org/

Double Trouble in Recovery

A 12-step mutual-help organization for people with co-occurring psychiatric and substance abuse disorders.
www.doubletroubleinrecovery.org

Dual Recovery Anonymous

A 12-step mutual-help organization for people with co-occurring psychiatric and substance abuse disorders.
www.draonline.org

Emotions Anonymous (International)

P.O. Box 4245
St. Paul, MN 55104-0245
www.emotionsanonymous.org
(phone) 1-651-647-9712
(fax) 1-651-647- 1593
(email) info@EmotionsAnonymous.org
(fax) 1-630-752-1064
(email) il@namidupage.org

Mental Health America

2000 N. Beauregard St., 6th Floor
Alexandria, VA 22311
(phone) 1-800-969-6642
(crisis line) 1-800-273-8255 (TALK)
(TTY) 1-800-433-5959
www.mentalhealthamerica.net

Mental Health Net

www.mentalhelp.net

Mental Health Works

180 Dundas St., West, Suite 2301
Toronto, ON M5G 1Z8
(phone) 1-416-977-5580
1-800-875-6213 ext. 4120
(email) info@mentalhealthworks.ca
www.mentalhealthworks.ca

NARSAD: The Mental Health Research Association

60 Cutter Mill Rd., Suite 404
Great Neck, NY 11021
(phone) 1-800-829-8289
(email) info@narsad.org
www.narsad.org

National Alliance on Mental Illness (NAMI)

The nation's largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. Extensive web site includes links to state and local NAMI affiliates.

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
(phone) 1-703-524-7600
(information helpline) 1-800-950-6264 (NAMI)
(Member Services) 1-888-999-6264
(fax) 1-703-524-9094
www.NAMI.org

NAMI Stigma Busters

A campaign to end stigma and discrimination

http://www.nami.org/Template.cfm?Section=Fight_Stigma

National Alliance for Research on Schizophrenia and Depression (NARSAD) 60 Cutter Mill Road Suite 404 Great Neck, NY 11021 800-829-8289

email: info@narsad.org

www.narsad.org

National Anti-Stigma Campaign (NASC)

ADS Center (The Resource Center to Address Discrimination and Stigma)

A SAMHSA/CMHS project to help people design and implement anti-stigma and anti-discrimination campaigns

ADS Center
11420 Rockville Pike
Rockville, MD 20852
(phone) 1-800-540-0320
(email) stopstigma@samhsa.hhs.gov
<http://www.stopstigma.samhsa.gov/>

National Coalition of Mental Health Consumer/Survivor Organizations

1300 L St. NW, Suite 1000
Washington, DC 20005
(phone) 1-978-590-2014
(email) info@ncmhcsso.org
www.ncmhcsso.org

National Depressive and Manic-Depressive Association (NDMDA)

www.ndmda.org
(see also www.dbsalliance.org)

National Empowerment Center

599 Canal St.
Lawrence, MA 01840
(phone) 1-978-685-1494
1-800-769-3728 (POWER2U)
(email) info@power2u.org
www.power2u.org

National Foundation for Depressive Illness, Inc. (NAFDI) P.O. Box 2257 New York, NY 10116-2257 800-239-1265 (Recording of symptoms of depression) www.depression.org

National Institute of Mental Health
Public Information and Communications Branch
6001 Executive Blvd., Room 8184, MSC
Bethesda, MD 20892
(phone) 1-301-443-4513
1-866-615-6464
(TTY) 1-301-443-8431
1-866-415-8431
(email) nimhinfo@nih.gov
www.nimh.nih.gov

National Mental Health Association
2000 N. Beauregard Street, 6th Floor
Alexandria, VA 22311
(phone) 1-703-684-7722
1-800-969-6MHA(6642)
(TTY) 1-800-433-5959
(fax) 1-703-684-5968
www.nmha.org

National Mental Health Consumer Self-Help Clearinghouse
1211 Chestnut St., Suite 1207
Philadelphia, PA 19107
(phone) 1-800-553-4539
(email) info@mhselfhelp.org
www.mhselfhelp.org

National Resource & Training Center on Homelessness & Mental Illness
(phone) 1-617-467-6014
(email) nrtc@samhsa.hhs.gov
www.nrchmi.samhsa.gov

National Stigma Clearinghouse
245 Eighth Ave., #213
New York, NY 10011
(phone) 1-212-255-4411
(email) stigmanet@webtv.net
<http://community-2.webtv.net/stigmanet/STIGMAHOMEPAGE>

National Suicide Prevention Hotline: 1-800-273-8255 (1-800-273-TALK)

Next Steps

An advocacy organization for homeless people and people with mental illnesses

6513 N. Sacramento

Chicago, IL

(phone) 1-773-274-2150

(email) MFFriedman@nseh.org

www.nextstepsnfp.org

Open Minds Open Doors

A Pennsylvania campaign to end discrimination against people with mental disorders, an initiative that some other states are also adopting.

OpenMindsOpenDoors

c/o MHAPA

1414 N. Cameron Street, 1st Floor

Harrisburg, PA 17103

(Phone) 1-717-346-0549

(email) info@openmindsopendoors.com

www.openmindsopendoors.com

Real Men, Real Depression

Anti-stigma and public education campaign by the National Institutes of Health, National Institute of Mental Health

<http://www.nimh.nih.gov/health/publications/real-men-real-depression.shtml>

Recovery Circles

A mutual-help organization for people with mental illness and people with co-occurring mental illness and substance use disorders, their families and friends, and helping professionals.

www.recoverycircles.org/

Recovery, Inc.

A self-help mental health program .

802 North Dearborn

Chicago, IL 60610

www.recovery-inc.com

(phone) 1-312-337-5661

(fax) 1-312-337-5756

(email) inquiries@recovery.org

The Resource Center to Address Discrimination and Stigma (ADS Center)

A SAMHSA/CMHS project to help people design and implement anti-stigma and anti-discrimination campaigns

ADS Center

11420 Rockville Pike

Rockville, MD 20852

(phone) 1-800-540-0320

(email) stopstigma@samhsa.hhs.gov

<http://www.stopstigma.samhsa.gov/>

SAMHSA Center for Mental Health Services
P.O. Box 42557
Washington, DC 20015
(phone) 1-800-789-2647
(TTY) 866-889-2647
<http://mentalhealth.samhsa.gov/cmhs/>

SAMHSA/CMHS Web Page for Consumers/Survivors
<http://mentalhealth.samhsa.gov/consumersurvivor/recovery.asp>

Sowing Seeds of Hope – Agriwellness, Inc.
An organization that links rural crisis survivors with affordable behavioral health services
1210 7th St., Suite C
Harlan, IA 51537
(phone) 1-712-235-6100
www.agriwellness.org

Starting a Self-Help Group (ideas from *Undoing Depression*, O'Connor, 1997)
www.undoingdepression.com/self-help.html

Stigma.org
British anti-stigma website and organization
www.stigma.org
Contact Richard Hornsby at editor@defeatdepression.org
(phone) 0207 881 9003
0207 881 9009

Suicide Prevention Hotline: 1-800-273-8255 (1-800-273-TALK)

Suicide Prevention Resource Center
55 Chapel Street
Newton, MA 02458
(phone) 1-800-438-7772
1-877-GET-SPRC
info@sprc.org
www.sprc.org/

UIC National Research & Training Center on Psychiatric Disability (NRTC)
www.cmhsrp.uic.edu
Center on Mental Health Services Research & Policy
1601 W. Taylor St.
Chicago, IL 60612
www.cmhsrp.uic.edu

What a Difference a Friend Makes
Initiative to encourage, educate, and inspire people ages 18-25 to support their friends who are experiencing mental illnesses
<http://www.whatadifference.samhsa.gov/>

World Federation for Mental Health
Secretariat:
6564 Loisdale Court
Suite 301
Springfield, VA 22150
(phone) 1-703-313-8680
(fax) 1-703-313-8683
(email) info@wfmh.com
www.wfmh.org

About MATEC and the Great Lakes ATTC

The Midwest AIDS Training and Education Center

Since 1988, the Midwest AIDS Training and Education Center has provided training and support services for HIV clinical providers in seven Midwestern States: Illinois, Indiana, Iowa, Michigan, Minnesota, Missouri, and Wisconsin. The mission of the Midwest AIDS Training and Education Center (MATEC) is to enhance the capacity of HIV clinical services and improve the quality of those services for people living with HIV in our region.

The MATEC service area is defined by existing referral and service patterns between the Chicago metropolitan area, the five large cities in the surrounding States (Detroit, Milwaukee, Minneapolis, Indianapolis, St. Louis, and Kansas City), and the surrounding less-populated areas. In this region, the AIDS epidemic has had significant impact on several large metropolitan areas (especially inner-city minority communities), smaller cities, and isolated rural communities. Each community has unique needs and challenges for HIV training, technical assistance, and consultation.

MATEC's Central Office is located in Chicago's Near-West-Side Medical Center at the University of Illinois at Chicago, Jane Addams College of Social Work (JACSW). This site is viewed as a "neutral home," closely affiliated with the major HIV clinical centers. In this position, MATEC has been able to play a key role in facilitating change within the clinical care system. With the mission "to develop knowledge, and provide leadership in the development and implementation of policies and services on behalf of the poor, the oppressed, racial and ethnic minorities, and other at-risk urban populations," JACSW is a supportive and enabling home for the Center.

The Great Lakes Addiction Technology Transfer Center

Recognizing its overarching role as a catalyst for creative partnerships in the field, the Great Lakes ATTC recently defined its individual mission as "building bridges that foster the advancement of treatment and recovery."

The Great Lakes ATTC is dedicated to making effective, culturally competent, research-based treatment services available to people with substance use disorders. This highly collaborative multi-state center promotes: 1) state-of-the-art addiction science and the infusion of that science into professional practice, using ongoing needs-assessment processes to remain responsive to the field; and 2) effective partnership between addiction treatment and criminal justice, health care, academia, and state and local governments.

The five-state Great Lakes region includes Illinois, Indiana, Michigan, Ohio, and Wisconsin. The single-state agencies for substance abuse in all five states are active partners in the Center's regional efforts.

The Great Lakes ATTC provides culturally competent didactic, clinical, and experiential training; services to develop the workforce and upgrade professional standards; curriculum development; information dissemination through a regional Web site; a quarterly Bulletin; and a Center for Excellence in Criminal Justice. Special focus areas include the Center's work with William L. White on Recovery Management, a series of products and workshops on healing the stigma of addiction, and a variety of neuroscience products and presentations.

About the Author

Pamela Woll, MA, CADP is a Chicago-based consultant in writing, training, and instructional design, serving as Senior Technology Transfer Specialist for the Great Lakes Addiction Technology Transfer Center (ATTC). She has been writing books and manuals in addiction treatment, prevention, and other human service fields since 1989, on topics including addiction, stigma, trauma, strength-based treatment, cultural competence, evidence-based practices, violence, disaster human services, addicted families, and resiliency.

Pam is the author of many manuals published by the Great Lakes ATTC, including the self-study workbook, *Healing the Stigma of Addiction: A Guide for Treatment Professionals*. Her latest project (in press) is a series of materials entitled *The Power and Price of Survival*, designed to help people de-stigmatize post-trauma reactions. She is also the primary author of *Worth Protecting: Women, Men, and Freedom From Sexual Aggression* (with Terence T. Gorski) and second author of *The Call to Write: An Invitation to Aspiring Writers* (with William L. White).

Along with her consulting role for Great Lakes ATTC, Pam is the founder of Human Priorities (www.humanpriorities.com), the organization through which she publishes and provides training on various materials. One of Pam's more recent ventures is a collection of materials for general audiences and consumers of mental health and addiction treatment services, including the full-color illustrated booklet, *How to Get the Piranhas Out of Your Head*.

Pam's interest in stigma comes from her long-term recognition of stigma as one of the most significant obstacles to human health and well being. Her interest in depression comes from her concern for so many friends and colleagues who have suffered from severe forms of this disease, and from episodes of mild and moderate depression in her own history. These experiences have left her with an indelible respect for the power of depression and an abiding sense of gratitude for every day she wakes up without it.

