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Stigma is Personal

> All great things are simple, and many can be expressed in single words:
> freedom, justice, honor, duty, mercy, hope.
>
> Winston Churchill

Stigma is not some kind of heady abstraction experienced by an overly sensitive few. It is a social injustice that discredits many people with serious mental illness, terribly harming them in the process. Resulting injury is broad and cutting. Public endorsement of the prejudice and discrimination of mental illness robs people of such rightful opportunities as a good job, agreeable housing, and intimate relationships. Internalizing the stigma of mental illness and directing stereotypical negative attitudes towards one's self leave people feeling unworthy and incapable. Many people seek to avoid stigma altogether by keeping away from places where individuals are tagged mentally ill, perhaps most notably mental health clinics in their various guises. "That guy, Harry Black, just came out of Dr. Johnson's psychiatric clinic; Harry must be crazy." The threat of stigma, and the effort to avoid the label, are so powerful that more than half of the people with mental illness who would probably benefit from psychiatric services never obtain even an initial interview with a professional. Stigma hurts and it is personal.

We seek to give voice to stigma here by considering examples of personal stories; a collection of tales meant to illustrate private experiences of mental health and stigma. These personal stories especially make sense in the most blatant port for stigma – the media. Stigmatizing images of mental illness in

movies, newspapers, television, online, and advertisements are provided as especially poisonous sources of prejudice and discrimination. We attempt to make sense of stigma and the media by examining key points in history related to public impressions of mental illness and stigma. We then jump in with our first strategies for stigma change; sensitizing people to stigma which parallels a discussion about appropriate language. We end this chapter by revisiting the personal nature of stigma.

We imply by the very existence of this book that stigma continues to hurt. A series of population studies has allowed us to actually examine this assertion. In 1950, Shirley Star and colleagues from the National Opinion Research Center (NORC) conducted face-to-face interviews with a representative sample of 3,529 American adults (cf. Phelan, Link *et al.*, 2000). Of the many goals of the survey, Star (1952, 1955) examined public impressions of people with mental illness. Most important to the point here was whether research participants viewed people with serious mental illness as violent. In 1996, NORC repeated items from the Star survey as part of a snapshot of NORC's annual snapshot of contemporary life. On one hand, we expect to show a decrease in viewing people with mental illness as violent consistent with popular notions that the general public are more educated about mental illness than 1950 cohorts. A more sobering response would show no change in attitudes between 1950 and 1996.

What is found? Figure 1.1 summarizes relevant data analyses (Phelan *et al.*, 2000). Stigmatizing attitudes got significantly worse! People in 1996 were
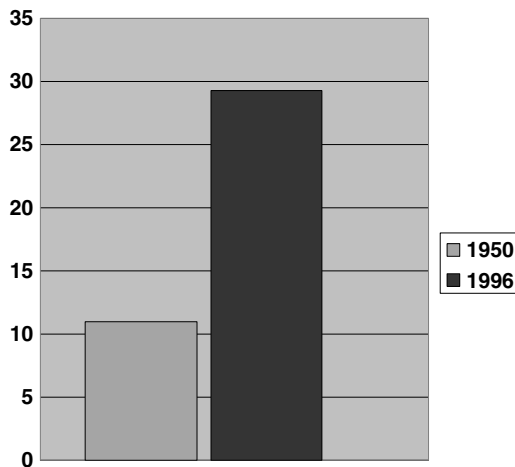

Figure 1.1   A summary of research on the dangerousness of people with serious mental illness. These data were collected in 1950 and 1996. Findings reflect percentage of survey participants whose description of mental illness includes perceptions of violence.

about two and a half times more likely to view individuals with serious mental illness as dangerous compared to 1950. Researchers in the 1996 study conducted a second interview in 2006 and had similar sobering findings (Martin *et al.*, 2009, personal communication). Comparisons of 2006 with 1996 data are not totally completed at the time of publishing this book. However, the investigators did report no significant reduction in attitudes between 1996 and 2006. Things have not really improved. Think how sobering these finds are. They fail to reflect the hope that more education would lower stigma. One reason is the change of the face of media around the world during these 40 to 50 years. We discuss this point more fully later in the chapter.

Some personal stories

Stigma is a personal thing that can have broad impact on people labeled as mentally ill. In part, it reflects the varying shades of mental illness. More importantly, the impact of stigma varies with the unique qualities of the person.

Bob was first diagnosed with a serious mental illness in high school which led to a three-day hospitalization. It was not until five years later that he showed signs of serious psychosis. One night, during a lightning storm, Bob was sure the United States was being bombed by the Russians. So, he went to tell the university's chancellor; luckily he was detoured to the local emergency room. Symptoms like these were followed by crippling anxiety attacks. Bob was hospitalized more than ten times in the subsequent decade or so. After a long struggle, Bob found a psychiatrist with whom he built a strong partnership, who identified Bob's illness as schizoaffective disorder, and found medications that helped him manage his disorder. Bob was then able to obtain a full-time job at a major university, lived independently in his own condo, and traveled greatly across America and to international ports of call. Flash forward to 1998. Bob has become an acknowledged journalist, with evident skills in reporting and photography. He developed his network as a freelance writer. He was worried that more face-to-face work with newspapers would lead to discovery that he is a person with mental illness, and as such is not competent to do the kind of work at which Bob excelled. So he would travel to newspaper headquarters early in the morning and slide stories and photos under office doors.

Bennett has a terrible fear of elevators. He panics and runs out of them before the door closes. It has become a major problem since his company moved to the 35th floor of a downtown building. He had to quit his job and is unable to find further work because of his phobia. Bennett's income is falling quickly and he has had to file for bankruptcy to handle delinquent bills. None of his classmates from Harvard thought he would end up with such problems. He is terribly ashamed of his weakness and has withdrawn from friends.

Nobody at work ever knew that about once a year, Emil would have a manic episode followed by a severe depression. He wasn't able to go out for about three weeks after. Fortunately, Emil had a close set of friends who would help him through the episodes. They would sleep over, cook, and otherwise keep him company. With appropriate help from his psychiatrist, Emil was eventually able to get back to work without ever being hospitalized. His support network helped Emil to avoid the harsh light of public stigma. This same network diminished a sense of shame for his "failings."

Betsy suffered from terrible test anxiety. Before she learned relaxation strategies, she could barely get into a classroom to take exams. However, after a few audiotapes, she learned breathing exercises and became a whiz at tests! Stigma never really became an issue for her.

Which one of these people has a mental illness and suffers the impact of stigma? Whose psychiatric disorder and corresponding experiences with stigma are the most severe? In some ways, Bob represents the prototype of mental illness; he has a diagnosis that includes psychosis which started in young adulthood and led to severe symptoms. Bennett has what is usually considered to be a milder psychiatric diagnosis, a phobia or irrational fear of something in his environment. But consider the impact of the two illnesses. Bob, despite having schizoaffective disorder, has learned how to manage the illness, has obtained a respectable job, and has become a world traveler. Unable to work, Bennett's world is tumbling down around him. Bob was able to box off stigma, sliding his work under the door in order to maintain a successful writing career. Bennett internalized stigma terribly, which only worsened the sense of alienation from family and friends.

Emil's experience with mental illness is like a tree falling in an empty forest; is it a mental illness if no one knows? He escapes the label and all the harm which stigma creates. Betsy suffered what professionals might consider

the minor headache of mental illness, test anxiety. Most readers might dismiss this altogether from the category of major psychiatric disorders. But, while in college, tests for Betsy were as painful as someone else's experience with major depression or psychosis. Moreover, the impact of test anxiety remaining untreated could have had major repercussions; failing classes, dropping out of school, and not attaining the career to which she aspired. Stigma will wax and wane with her experiences.

This book is about the stigma of persons with *serious mental illness*. What we have taken for granted is a definition of what exactly mental illness is and who is labeled mentally ill. Sorting out who is and is not mentally ill seems like such an easy task.

- Psychotics to the left; neurotics to the right.
- You're mentally ill; you're normal.
- Insane people are obvious!

However, when we take a closer look at these assumptions, we find that simple definitions distinguishing those with mental illness from those without elude us. The place to begin to make better sense of these definitions is history – how has the stigma of mental illness appeared over time and across cultures?

Why the stigma of mental illness

By no means is stigma a recent creation. Much of written history has examples of the broad-based prejudice and discrimination with which the public has branded people labeled with mental illness. Most often, stigma has emerged when people of different eras try to understand mental illness as a punishment of god or a mark of the devil. Two recent books (Hinshaw, 2007; Thornicroft, 2006) effectively review this history; prominent examples are presented here to orient the reader to the foundations of stigma. The authors trace stigma back to the Greeks of the classical era. The prominent belief of Homeric times was that mental illness represents displeasure of the gods. Dramas and comedies showed an angry and powerful deity damning a human with psychotic symptoms, for example, or those of depression and bipolar disease. As a result, people were robbed of the opportunities commensurate with their station in life. This kind of "theological" presentation had perhaps its most heinous history during the Middle Ages. People with mental illness were viewed as products of the devil with symptoms being outward manifestation of their wickedness. Mental illness was seen as a moral danger to society which had to be rooted out and

eradicated before the devil's work took other victims. Sometimes, this showed itself as exorcisms where the clergy forcefully tried to push out the demons in an emotional and spiritual war. Other times, a community sought to erase the wickedness of mental illness through executions, including such barbaric acts as burning the person at the stake.

Thus far, we have provided a Eurocentric review of mental illness and history. Sadly, there is compelling evidence that Asian, African, Middle Eastern, Native American, and Australian peoples also stigmatized, discriminated against, and harmed people labeled "mentally ill." Examination of relics from Egypt around 5000 BC has shown, for example, an attempt to cure a young princess of demonic possession, of mental illness. The Old Testament urges "disturbed" behavior to be punished by death. Hindu cultures dressed people with mental illness in religious garb and, in some settings, related to them as divinities. Mayan and Aztecan groups sought to throw out demons in an individual as well as in their community by human sacrifice. Evidence from the Koran and other Muslim writings framed some psychiatric behavior as a threat to the spiritual.

A second, oft-repeated alternative to mental illness stigma as moral shortcomings was mental illness as "illness." Classical Greece not only represented mental illness as a sin but also as a disease process. Contemporaries of Plato and Aristotle developed seemingly sophisticated models of psychiatric illness in terms of physiological or anatomic aberrations. Hippocrates described psychiatric behaviors as an imbalance in the humors. Galen, the great second-century anatomist, argued that relative temperatures of the brain accounted for mental illnesses.

Current depictions of mental illness reflect a biological perspective that mostly evolved from the industrial age. The mechanical mind is a collection of processes and actions; events that interfere with these actions lead to mental illness. This paradigm calls for treatments and applications meant to halt diseased activity; unfortunately, many practices in the industrial age reflected the injustices and harms of earlier times rather than some enlightened and efficient process of the era. Practices of the eighteenth and nineteenth centuries included misguided notions of Celsus, actually a physician of ancient Rome. As transposed to the 1700s and 1800s, his followers emphasized restraints, extreme hunger, living in total darkness, and intentional fright.

Asylums were little better than prisons in the 1800s. People with mental illness were confined to cells or chained to walls, with little consideration to such very basics needs as food and clothing. Sadly, tourists of the times traveled to these asylums as a fun outing, similar to seeing animals at the zoo. Historians estimated that 19,000 gawking visitors toured through Bethlehem hospital in England in a single year. Physicians tried to address the suffering patient of the era but treatments were rarely effective and actually at times barbaric.

Common was bloodletting, opening a vein so that bad "humors" were ejected and replaced by sane fluids. There was also twirling people in a chair, tying them down for excruciatingly long periods, and dunking them in tanks filled with water. Also seizure-based treatments appeared, reflecting the rationale that the extreme chaos of seizures "resets" the brain, yielding normal brain processes. Insulin shock and electroconvulsive strategies were prominent examples. Despite what was hoped to be able approaches to stemming mental illness, treatments and places where these treatments occurred remained terrifying.

Convergence in the progressive ideas of societal leaders resulted in what has been called moral therapy. Pussin and Pinel in France, Chiarugi in Italy, Tuke in England, and Rush in America were all voices of anger believing that notions of asylum, confinement, and deprivation were fundamentally immoral and must be replaced by more humane approaches. Moral treatment led to the establishments of true asylums; pastoral locales removed from the stress of daily living where people could gently return to the noise of the contemporary world. Pinel coined the term "moral" treatment, based on two assertions. First, mental illness affected a person's moral (psychological and social) faculties, while leaving reason relatively intact. People with serious mental illness were, therefore, human at the core. Second, notions that people with mental illness were beasts needed to be replaced with visions of hope and opportunity. This could only be achieved in settings of kindness and respect.

Great leaps were taken with the development of psychotropic medications starting in the twentieth century. In 1952, two French psychiatrists – Jean Delay and Pierre Deniker – showed Thorazine to "tranquilize" the symptoms of schizophrenia without worsening the person's depression. Called antipsychotic medication, psychiatrists for the first time had a tool to help people with serious mental illness managing their symptoms. Length of hospital stay decreased significantly, returning people to the community. Unfortunately, Thorazine and drugs like it frequently had significant side-effects impacting almost every organ in the body. Prominent among these were marked emotional distress, as indicated by an inability to sit still, sensitivity to light, and a dry mouth. Atypical anti-psychotics emerged after several decades of research, first in Europe, and then in America in about 1990. These medications showed marked reduction in psychotic symptoms without the pronounced side-effects found with Thorazine, though it is important to note that the atypicals had a set of side-effects to be reckoned with in their own right.

Also in the 1950s, Kuhn and Kline introduced tricyclic or anti-depressant medications which were shown to control many of the symptoms of major depression. Unfortunately, these drugs also caused significant side-effects. The introduction of a set of medications called serotonin-specific re-uptake

inhibitors (SSRIs) reduced depressive symptoms with diminished harm. Towards the beginning of the 1950s, an Australian psychiatrist named John Cade introduced lithium as an effective medication for addressing the symptoms of bipolar disorder.

The significant achievements of medications fostered a medical model of illness and treatment. These models have largely defined the core of clinical research. They have dominated the twentieth-century clinical agenda; namely, identify, develop, and evaluate medical strategies (largely medications) that will heal the person by suppressing psychiatric symptoms. Consider some contemporary agendas. In 2008, the National Institute of Mental Health spent more than 1.4 billion dollars in research, with the overall agenda clearly dominated by physiological models and corresponding treatments. Their efforts were hugely advanced by drug companies in search of products that will ameliorate mental illness; they spent billions a year in developing and distributing effective psychiatric medications. Drug company commitment to this process is mostly driven by increasing profits for investors.

Stigma today

Many advocates believe *medical models*, which are often derisively described, are the source of much of the stigma of mental illness. Viewed traditionally, the medical model represents physicians and allied health colleagues as experts who should therefore dominate decisions about mental health treatment and psychiatric care. Supposed insight of the doctor spreads to more general life decisions; for example, people with mental illness are incapable of understanding their illness and thus need a parental figure to make appropriate decisions for them. These decisions are often conservative because the doctor-as-expert believes relapse to be the result of rapid and ill-considered treatment. Common is the recommendation that people with schizophrenia should not try regular work, should live in nursing homes where they can be carefully monitored, and should be dissuaded from forming intimate relationships.

Powerful reactions to models that rob people of self-determination and personal empowerment led to important grassroots approaches. Ex-patient Clifford Beers, for example, wrote about his experiences in hospitals in *A Mind that Found Itself* (1905). Beers' efforts led to the founding of what is now called Mental Health America, a group of community advocates seeking to improve the quality of services for persons with mental illness. In the 1950s, persons released from state hospitals in New York City gathered together on the steps of the Public Library to provide support and counsel; fundamental relationships like these were often dismissed in mental health care as not potent or germane

to the biological basis of the illness. This group of people called themselves WANA (We Are Not Alone) and built an essential support network that helped them when returning to the city. At about the same time, GROW began in Australia when Con Keogh and other former mental patients sought a group of peers in a sharing and caring community. They felt alienated from a community which could not understand their experiences and chose to view these differences as weird or wrong. GROW was set up as a 12-step program meant to develop a "sharing and caring community" to promote mental health where these people lived and belonged.

In the 1970s, survivor groups appeared such as the Insane Liberation Front in Portland and the Mental Patient's Liberation Project in New York City. These groups emerged frustrated with mental health services that did not see them as people. Efforts of survivor groups were crystallized in Judy Chamberlin's 1978 book, *On Our Own: Patient Controlled Alternatives to the Mental Health System*. Survivor has an interesting meaning here: not surviving mental illness! Survivor means having withstood the dehumanizing and disrespectful reactions of society and its agents charged with treating mental illness. MindFreedom International is a current and energetic group meant to carry on the survivor tradition (www.mindfreedom.org). One of its more provocative events was a 2003 hunger strike meant to highlight "challenges" to the American Psychiatric Association (APA), US Surgeon General, and NAMI. Prominent among these were a challenge to produce incontrovertible proof that mental illness is a brain disorder. Led by MindFreedom advocate David Oaks and seven peers, the group was able to sustain their hunger strike for more than a month. Notable from this effort was forcing the APA and NAMI into a public debate about these issues.

Other efforts to erase the stigma

Insights of people like Beers, Chamberlin, and Oaks are important in their historical significance. Their viewpoints challenged the very core of mental health practice. Other contemporary concerns about stigma and discrimination are not as radical. For example, NAMI – a group started by parents for persons with severe mental illness – completed a ten-year campaign to identify and correct misconceptions about severe mental illness. In no way does this group believe that biological models of schizophrenia are a myth and that psychiatry perpetuates this falsehood. NAMI is a major benefactor of research that seeks to identify and cure the biological causes of severe mental illness. Members of the group recognize the insidious effects of stigma and misconception.

Seeking a balance between medical models and personal empowerment are now echoed by many state mental health systems, traditional guardians of biological interventions for mental illness. States have developed, for example, offices of consumer affairs to promote interactions between persons with mental illness and the citizenry as a whole. These consumer advocates present themselves and peers as examples of recovery and successful living. The US Government further advances this priority. Its Substance Abuse and Mental Health Services Administration (SAMHSA) has an office on consumer empowerment and funds extramural projects that attempt to discount stigma. SAMHSA has gone online with a website that nicely lays out resources to address stigma in various different settings: work, housing, schools, and neighborhoods (www.stopstigma.samhsa.gov). SAMHSA has also sponsored two large media campaigns. Most recent is "What a Difference a Friend Makes!" The take-home message is that mental illness is around us all and therefore it needs not be frightening or avoided. Instead, family members and peers are a fundamental structure from which dealing with mental illness begins. About six years earlier was the Erase the Barriers Initiative, an eight-state effort to decrease stigma using public service announcement and public education strategies. Even service groups made up of private citizens have shown their concern about stigma. Rotary International, for example, inaugurated "Erase the Stigma," a campaign to educate business leaders from across the United States about the truths and misconceptions of severe mental illness.

Stigma and the media

The media are a large, some believe the principal, source of stigma. Hence, we examine their dominance to understand the twenty-first-century context. Media in its various forms have suppressed stigmatized groups since humans first began recording their thoughts and behaviors. Socially given stereotypes partly represent cultural lore about a group, handed down by community elders and others in authority; these are our myths and legends. Many centuries ago, these myths were learned around the campfire, often as stories from respected elders. Mass media serve this role in modern times. Noted social psychologist Sam Keen authored *Faces of the Enemy* (1986), where he reviewed ways in which the written word and artistic creations have been used to stigmatize groups beyond those labeled mentally ill. Prominent in Europe and America is the impact of media vehicles such as magazines, movies, television, and newspapers. Western countries, for example, have a truly horrible record of disrespecting

Africans and Asians as animals, frequently as monkeys. Such representations seem to legitimize laughing at or more directly harming people from these groups. Consider how most of the Western world, and across much of the globe for that matter, sought to hold down women through the media. Women who are demure, subservient, and obedient are the ideal; those who are assertive are portrayed as ignorant and out of touch. Lastly, consider the Western agenda about gays, lesbians, bisexuals, and transgenders. Gays are described as effeminate, child molesters who are met with disgust. Lesbians are another version of the assertive and disparaged woman. Governments, especially in America, believe single-sex marriage is an abomination and seek to stop gays and lesbians from sharing marital benefits (most notably, health care).

If there is a positive side to this picture, it may be that public media supporting the stigma of ethnicity, gender, and homosexuality have been muted. Less common is the stigma from television, movies, and the print media related to ethnicity and gender. Disrespectful images of women and people of color were gone from many newspapers and magazines, and greatly diminished in movies and television. The relationship between media and sexual orientation remains a bit troublesome, though there seems to be significant improvement here too. We do not mean to presume the stigma of gender, ethnicity, and sexual orientation has been erased.[1] Depictions of people with mental illness are still prominent, however, and frequently represent them as dangerous or inept. All the reader needs to do is listen to talk radio on the way home from work and count the number of times the host says "crazies," "daft," "wacko," or "nutters." The stigma of mental illness is in the forefront and hurtful.

Otto Wahl wrote a trenchant book called *Media Madness* (1995). He found that 70 to 80 percent of the time, media portrays people with mental illness as dangerous, unpredictable, or otherwise people to be feared. Wahl's book is now 15 years old; one might hope his examples are stale and irrelevant. His work might seem out of date because stigma should have mellowed since then. Findings from American research on violence perceptions reviewed earlier in the book shatter such notions. The stigma has been getting worse over the past 50 years. There are current and compelling examples of stigma and the media. In July 2002, for example, Trenton State Hospital in downstate New Jersey had a fire. The hospital is familiar to many because it is the setting that Nobel Laureate John Nash from *A Beautiful Mind* was admitted to when his illness worsened. Luckily, no one was injured in the fire but the damage was still significant. The next day, the local *Trentonian* ran a shocking headline.

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[1] Some social scientists have called this pattern of change "modern racism" (Blatz & Ross, 2009), namely social pressures have caused prejudice and discrimination to go underground. They are still active, just not apparently so.

"Roasted Nut!"

There are many, many examples like this. Groups have emerged that track these examples and respond, when especially disrespectful or otherwise harmful. The United Kingdom's Rethink assumes this role, a collection of volunteers organized into more than 340 services including its anti-stigma arm. StigmaBusters, part of NAMI, has created an online community dedicated to tracking and, when appropriate, responding to stigma in America. StigmaBusters posts monthly alerts listing troublesome examples. Consider this example from November 2008. In a recent episode of ABC's hit show *Desperate Housewives*, mysterious Dave Williams moves to the neighborhood; gossip quickly spreads that he was recently released from incarceration at a program for the criminally insane. In the same episode, Dave kills his psychiatrist and sets a popular nightspot afire. Examples like these perpetuate the most difficult stigma; namely, people with mental illness are dangerous, unpredictable, and hence should be avoided. Many more examples follow from television, but also from movies, newspapers, advertising, and magazines.

Headlines in the *London Evening Standard* read "Maniac killed twin sisters" in April 2005. At the same time, the *Daily Mail* posted "Knife maniac freed to kill. Mental patient ran amok in the park" in February 2005, "Violent, mad. So Docs set him free" (*The Sun*, February 2005), and "Royal stalkers are 'dangerous psychotics who need help'" (*Telegraph*, October 2008). The news media are similarly harsh in Asia. In response to a murder in May 29, 2009 by a suspect thought to be mentally ill, the *Hong Kong Apple Daily* printed comments by a legislative councilor: "Government discharged those psychos to the society in an inappropriate way may endanger the safety of the innocent citizens."

There are too many examples

Halloween is a yearly event where the stigma of dangerousness and mental illness is exploited. Fright Night Scream Park in Clovis, California is an example. In 2009, the park included two attractions:

> *The Asylum*, a psych ward gone very wrong. Recently the patients have taken over. Nurses and doctors are being twisted into the very patients they meant to help. Enter the Asylum and test the limits of your sanity!

> *Psychosis*, where the clowns are out to play! This world of sensory alteration and fantastic perceptions is not "clowning around." Dazzle your senses in a world of three dimensional doom as the freaky circus psychos roam.

In 2007, entrepreneurs bought the Weston Hospital in Weston, West Virginia, renamed it the trans-Allegheny Lunatic Asylum, and provided year-long venues for being exposed to the dangerous patient. They provide ghost tours, but not for the faint of heart. "The Asylum has had apparition sightings, unexplainable voices and sounds, and other paranormal activity reported in the past by guests and staff. Step back in time and see how the mentally insane lived, and died, within these walls." Even civic-minded groups unintentionally fall into the fright-fest trap. In 2004, the Gainesville Jaycees advertised an Insane Asylum Haunted House for the holiday. October 2004 featured Universal Orlando Theme Parks as hosting the most terrifying Halloween event ever. Media kits marketing the event included committal forms and straitjackets for journalists reporting the program.

Recent movies are troublesome, perhaps mostly because they engulf viewers in disrespectful portrayals. In *Batman: The dark night*, Batman describes one of the Joker's henchmen as a paranoid schizophrenic, "the type of mind attracted to the villain." Three years earlier was *Batman begins*. Here a corrupt psychiatrist had planned to put a drug in the water supply which would cause people to have psychotic episodes. In the comedy *Tropic thunder*, characters in the movie repeatedly use the word "retard." Lionsgate Entertainment distributed a dark comedy called *Wrist cutters: A love story*. Of particular concern to about 20 advocacy groups was their media campaign which included cutouts of characters jumping off a bridge, electrocuting, and hanging themselves.

Commercial ventures also use mental illness stigma. Advertisements are background noise that faintly, but repeatedly, influence the public. Wahl listed examples in his 1995 book: a clothing store uses an image of Beetle Juice saying, "Maniac out of control: All our merchandize is first quality." A car dealership has a man in a straitjacket with the headline, "To offer these deals we'd have to be committed." A record store uses a silhouette of a person with mental illness with the tag "Crazy Eddie Record & Tape Asylum." The message in advertising is subtle but widespread. More recent examples can also be found. About five years ago, a printing company in a small town in Ohio dressed up its front window in a horrid way. The storefront showed a desk and kicked-over chair with someone's legs hanging from above, obviously suggesting a recent suicide. At the bottom of the window was the message, "*Contemplating Suicide*?" Get your notes printed here. More recently, Burton Snowboard Company of Vermont unveiled its Promo line in 2008. Their snowboards prominently included graphic images of self-mutilation on the top surface of the board.

In 2006, Archie McPhee & Company in Seattle distributed an offensive toy called the Obsessive Compulsive Action Figure. It included a surgical mask and sanitary towelette as well as a 10-point self-assessment of obsessive–compulsive disorder on the back of the box. A recent advertisement for Wendy's, an American hamburger chain, has a customer who cannot decide what to order

because he suffers from multiple-personality disorder. The Vermont Teddy Bear Company featured the "Crazy for you Bear in a straitjacket." It comes with a committal report and symptoms that include "Can't eat, Can't sleep. My heart's racing." A Nintendo full-page advertisement featured a scene from a community room in a mental institution. The advert showed a patient with a horrified facial expression, wrapped in a straitjacket. Two uniformed guards, each with a superimposed grotesque cartoon head and facial expressions, were standing watch, with the headline asking, "Ever had the feeling you're going bonkers?"

The media source with the greatest impact on Western nations is television. In October 2007, contestants on *America's Next Top Models* perfected their runway walk while wearing straitjackets on a set laid out as a psychiatric ward and coaches decked out as nurses. Show producers reasoned that contestants had to be able to withstand the high-stress, high-stakes world of super-modeling. In 2006, Fox TV aired a reality show – *Unanimous* – where contestants in an underground bunker determined who would receive a $1.5 million award. One of the contestants named Richard admitted that he had once been treated in a mental ward (for depression and alcohol abuse). Reactions among contestants soon degenerated into a stigma fest; Richard is "crazy as a crap-house rat," "a whole bunch cuckoo," and "not working with a full deck."

The Women's Entertainment Network aired an original reality short called *Bridezilla* in 2006. Brides on the show change from sweet and innocent to dangerous and "certifiable." A bride on their website is viewed as "engaged" to "enraged" to "committed" where she ends up in a straitjacket. A September 2004 episode of *Dr. Phil* showed the program's host blaming parents for the serious psychiatric disorders of their children. The *2004 MTV Movie Awards Show* was troubling. The show's opening scenes featured fast-moving animated clips of people in a psychiatric hospital, including a person chained to a wall, another receiving electroshock therapy, an evil-looking girl in a room with blood-smeared walls, a set of fighting dogs that apparently were delusions, and people sitting in a "group room" laughing maniacally.

Let us reconsider the surprising research discussed at the beginning of this chapter; namely, survey research showed the dangerousness stigma of mental illness had increased by almost 2.5-fold. In response to findings like these, we would expect social advocates to be discouraged and wondering how this could happen. After considering the breadth and depth of media and mental illness, an alternative question seems more appropriate. "How could people do anything but fear and want to avoid people with mental illness?"

Newspapers and magazines. It is especially ironic to think that the arm of society entrusted with providing facts often perpetuates stigma. News sources are expected, perhaps naively so, to print honest and objective information. Unfortunately, research shows that this is not the case. Consider a 2008 issue of

the *Reader's Digest* which titled an article: "Normal or Nuts?" The author provided a silly and sophomoric discussion of ways in which people experience mental illness.

1. Chances are, you don't sound stupid most of the time.
2. Even if you do say something idiotic once in a while, so what? Everyone does.
3. Most people are so self-absorbed, they aren't paying as much attention as you think.

In 2006, the same magazine published a distasteful joke: "How do crazy people go through the forest? They take the psychopath." Comics in newspapers also run storylines that disrespect the experiences of mental illness. Consider a cartoon by Gary Larson, a very talented humorist of the 1980s and 1990s. The single panel showed a therapist taking notes in his chair with the patient talking freely on the couch. On the pad of paper, the doctor writes, "Just plain nuts." Not only does the public laugh at people with mental illness, but so too the therapist; the person with years of education and an expert on psychiatric ideas sees the client's troubles as funny.

Tabloids run blatant examples of stigma almost every day. Headlines from the *New York Post* screamed "Freed Mental Patient Kills Mom." The *Daily News*, also from New York City, had these headlines: "Get the violent crazies off the street." But these are what tabloids do, write provocative and hurtful things to get people to pick up and buy them. Unfortunately, more respected newspapers make similar errors, though not for such a blatantly economic reason. Chicago's *Reader*, a highly esteemed and recognized weekly, ran this headline in 2001: "Is this man a monster?" The story recounts Lee Robin who killed his wife and daughter in a drug-induced psychosis. Robin then spent 13 years in a forensic inpatient unit. At the time of the story, the author noted that Robin's symptoms were well controlled by medication. His prospective neighbors, however, believed him still to be a monster. The *Reader* example is important. By most standards, the journalist did a balanced job in considering the issues. The author was trying to cover both sides of an important argument. But the headline was the concern. It was sensational and we suspect that most people who glanced over the front page most recall the equation of mental illness and monster.

Positive use of media

Since 1997, the Jimmy and Rosalynn Carter Center in Atlanta Georgia has administered the Rosalynn Carter Fellowships for Mental Health Journalism.

The Fellowship endows a project proposed by active journalists from all imaginable media. Fellows are paired with experts in mental health policy and the stigma of mental illness for guidance during the year-long venture; Otto Wahl was one such expert. Journalists then use the year to finish their product. The program has an international following. Paul Diamond from New Zealand produced a radio piece interviewing two Maori women who surmounted significant hurdles to become leaders in their mental health system. Subashni Naidoo, a reporter with the *Sunday Times* in Durban, South Africa, wrote about how white male suicides seemed to be on the rise, perhaps because of economic challenges. American Kathi Wolfe wrote compellingly about mental illness and the gay community.

There are also examples from the entertainment field that challenge the stigma and promote more positive conceptions about mental illness. Since 2005, SAMHSA has sponsored the Voice Awards, hosted annually in Hollywood. The Awards recognize movies and television that actually challenge the stigma of mental illness. Television examples from 2008 include episodes from *Dirt* (a central character of the show, the photographer, overcomes schizophrenia and visual hallucinations as he successfully does his job), *General Hospital* (where the central character, Sonny Corinthos, successfully struggles with bipolar disorder), and *Monk* (a perennially respected show where the detective astounds viewers with his deductive skills all the while struggling with obsessive–compulsive disorder). The Voice Awards also recognize feature films and documentaries.

Is there a place for sarcasm? Many of our readers are from the West where lampooning groups is central to our culture. Hence, we might expect social critics to dismiss our summary of the media as political correctness and that mental health advocates should back off. We would not be surprised if some readers quietly chuckled at the punch-lines. Do mental health advocates need to lighten up a bit? Sarcasm serves an important goal in many societies. It provides a chance for the common person to poke fun at those in power. When an editorial cartoonist helps us to laugh at government officials, we remind politicians and ourselves that we are all from the same stock. No humans can view themselves as higher caste.

Unfortunately, sarcasm and the media do not help those who suffer prejudice and discrimination rise to similar middle ground. Instead, it further reminds those one step down that below the threshold is where they remain. Recall that the "step-n-fetch it" humor of previous generations had this purpose for African Americans. Humor that represented Blacks as less intelligent, or less hardworking, or more brutish, were trying to, and in effect did, keep this group down. We would be horrified if ethnic humor continued today. In like fashion, humor against persons with psychiatric disability keeps them under the thumb. It dehumanizes their troubles and allows a frequently

hostile community to continue in its disrespectful and discriminatory actions against them.

It is also important to state here that answers to the question of "What is stigma?" hugely surpass concerns about language and the media. Disrespectful images hurt the person, but changing the media will not wipe away stigma's harmful impact. If anything, the media reflect society. Media depictions will decrease when cultures are able to corall their disrespectful images. That is the focus of much of the rest of the book. The next chapter provides a common conceptual base for understanding stigma. Stigma is a complex phenomenon that has been described from such diverse perspectives as social psychology, sociology, cultural anthropology, and socio-cultural history. Indepth review of these perspectives far exceeds the goals of our book. Even more, digging into theoretical models may distract readers from our purpose: erasing the stigma. Hence, most of the book's remaining chapters focus on ways to challenge the stigma. We seek to balance findings from the research literature with hands-on techniques meant to advance an advocate's agenda.

Where to begin stigma change

There are some overall issues that we address here with strategies meant to generally orient the reader. The first is an exercise to sensitize a person to the stigma of mental illness. Stigma is both a subtle and broadly felt experience. The advocate needs to make obvious the stigma before attempting to change it. A second bit of evidence shows everyday language to perpetuate stigma. Hence, we review an approach to help make the person aware of language effects.

Sensitizing persons to mental illness stigma

Most people are unaware of how commonly mental illness is stigmatized. Figure 1.2 provides an exercise that sensitizes persons to what might seem to be relatively minor statements about mental illness. It includes two steps. First, individuals filling out the worksheet are asked to list various statements about persons with mental illness heard on the radio, seen on television, or read in the daily newspaper. Rather than asking the individual to listen for *stigma*, they are encouraged to identify "over-generalizations and misattributions about mental illness." Most participants are quickly amazed at how

Make a list of over-generalizations and misattributions about mental illness that you hear on the radio or see on television. For example:

"That person acts that way because he's crazy."

"All psychos are violent."

"Crazy people can't take care of themselves."

"Psychotics should all be locked up."

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Replace terms like crazy and psycho with the name of an ethnic minority group. For example:

"That person acts that way because he's Black."

"All Latinos are violent."

"Irish people can't take care of themselves."

"Jews should all be locked up."

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Most people who might have thought these were harmless statements about mental illness quickly become horrified at the similarity between disrespecting persons with mental illness and persons of color. In fact, some advocates for disability have equated the experience of mental health stigma with the injustice of disrespecting ethnic and religious minorities.

Figure 1.2   An exercise that sensitizes persons to mental illness stigma.

many stigmatizing attitudes they can generate and how many the media still perpetuates.

Second, individuals are asked to replace key words in statements that represent mental illness (e.g., crazy, wacko, mental case, psychotics) with a term that describes an ethnic (Latino or Black) or religious minority (Jews). Most Westerners have become sensitized to inappropriate language used against people of color. Hence, they are frequently dismayed to discover the injustice that has been perpetrated against an ethnic minority still continues when such language is used to describe mental illness. This kind of exercise works effectively in schools with youngsters as well as at church gatherings and adult service club meetings. Participants soon become aware of the disrespectful language about mental illness that permeates our culture.

Language and stigma change

Many advocates support person-first language to challenge stigma. In this view, people are referred to as a "person" plus the condition: a person with mental illness, people with schizophrenia, people taking medication. This language reminds us that individuals with mental illness are people first; namely, their character and assets centrally reside in their identity as a person. Experiences with mental illness and the mental health system are incidental and in many ways extraordinary. Perhaps they have relevance in a service setting, but in much of the rest of the world they are just people, or perhaps also spouses, parents, co-workers, and neighbors. We always teach our students that people with mental illness share infinite goals, interest, desire, and skills. "They" are very much like "us." Only a small aspect of their life – albeit a prominent part for many people – defines their mental health experience.

Back to the personal story

The stories earlier in the chapter were written to highlight important and recurring questions about stigma. Many of these stories represented a mix of people we (the authors) have encountered personally or professionally. The first one, however, is true; it is about friend and colleague Bob Lundin (pronounced Lun-deen). Bob has struggled with schizoaffective disorder for more than 30 years. One of us (PC) worked with Bob for almost a decade while we were employed at the University of Chicago Center for Psychiatric Rehabilitation. His thoughts were extremely important to us as Center faculty and peers sought a felt model of recovery and empowerment. Bob and I wrote the first edition of *Don't Call Me Nuts!* Of special importance to us then were Bob's life experiences, what it means to struggle with a serious mental illness and, despite his successes, the ongoing pain of dealing with stigma. As part of his job at the University Center, Bob led colleagues on advocacy projects regarding mental illness stigma. We remember one time he got a group together at a movie house in DuPage County to protest the release of *Me, Myself, and Irene*. Strategies on tackling problems like these were immensely useful for the rest of us.

Mental illness and mental illness stigma are personal for the authors of this book too, especially PC. I have been struggling with mental illness that is somewhere between Emil and Betsy. During college, I showed the signs of major depression and anxiety. Despite some significant emergencies, most times I was able to stay out of the hospital with the support of family, friends,

mental health professionals, crisis programs, and psychiatric medication. Nevertheless, my struggle with mental illness took its toll. During a seven-year period, I dropped in and out of colleges and jobs, moving repeatedly in the process, all in an effort to deal with my symptoms. It is interesting to note that despite many years of graduate school and earning a doctorate in clinical psychology, I did not realize I had a major mental illness until meeting a young resident who asked me during a crisis interview how long I had been struggling with depression. Are the subtle effects of stigma so treacherous that I would not and could not recognize the mental illnesses thwarting my life goals?

I did not publicly *identify* myself with mental illness for more than 25 years. I think it is likely that my professional interests in research and practice related to psychiatric disability and rehabilitation resulted from these experiences. Until only the past few years, however, have I publicly discussed my encounters with mental illness. Perhaps the pressure for mental health professionals to seem above the fray has led to some of this reluctance; I am a licensed clinical psychologist after all who has learned to help people with other problems, not my own. Moreover, I have always felt that my struggles with mental illness were not as severe as the experiences of people like Bob. Framing my challenges at their level somehow lessens the stories of others. For many years I believed that mental illness was only a small part of me and my past. Hence, while I might include my experiences with mental illness as part of the "I am" statements that describe Pat (I am a person who has been overwhelmed by depression; I am a person who has had to live with mental illness), these kinds of statements have been far down on a list of preferred ways in which I would describe myself (e.g., I am a husband and father and have a good career). But, as I work more on issues related to stigma and stigma change, both as a social scientist and as an advocate, I better recognized "I am" statements about mental illness.

One might think that both my scholarly and personal interests and actions about stigma would protect me from some of the prejudice traps that are discussed in this book. Unfortunately, this is not so. I remember the piercing shame of having to seek out a professional during crisis times; a mixture of I must be weak and my family is embarrassed. One might think this kind of stigma would ameliorate as I live with the disorders. More recently, I was sharing my experiences with depression and anxiety among a men's group at our Unitarian church. Bob, sitting to my right, and a close friend, patted me on the shoulder and sincerely said, "You have done pretty well for yourself, Pat, given everything!" "Oh, no Bob," I replied, "No, no, I'm not like them!" I remember about a year ago when I was being admitted to a hospital, this time for a physical problem, that I told my wife on the phone, "Make sure you tell Abe and Liz (our children) this admission is for an infection. I am not going into the hospital this time because I'm nuts again."

Mental illness stigma has been personal for another author of this book (DR). I experienced the stigma of being a family member, as my beloved younger sister, Becca, with whom I was very close, suffered from serious manic depression. In addition to the pain and concern for her, I felt ashamed and defensive. What did the fact that Becca suffered from a mental illness imply about me and the rest of my family? Becca's illness, so I felt, meant that something must also be wrong with me, or alternatively that my family or even I myself might have caused Becca's illness. Feelings of guilt and shame were common and I struggled with how much to share with others and concern about how they might respond. Becca took her own life at the age of 23. A few weeks before that, in one of her last letters she wrote, "I wish people were more understanding towards people with mental illness." Nearly 20 years have passed and a major force in my life has been to try to do what Becca wished for – try to make people more understanding.

Mental illness stigma is personal! We authors shout out this assertion. Some of the ways we have learned to deal with our own stigmatizing experiences make it to the pages herein. But, we bring an important and perhaps more unique perspective to these problems. Namely, we examine many of the assumptions of stigma and stigma change with the bright light of social science. Sociologists of the research enterprise know that "knowledge is power"! We seek to arm the world of advocates with the tools that emerge out of this knowledge. We must admit: stigmas are interesting theoretical phenomena, stimulating many of our research juices. Frankly, we believe our group has put together some interesting perspectives on mental illness stigma. But this is personal. Advocates do not want to understand stigma better. They want to erase it. We do begin with overall information about what stigma is. But we do that only as a platform from which stigma change strategies supported by research are proffered. They are questions that demand action. Some of these answers are the focus of the remaining chapters.