



SELF-DISCLOSURE AND ITS IMPACT ON INDIVIDUALS WHO RECEIVE MENTAL HEALTH SERVICES



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“A bold but necessary move, self-disclosure is a first step toward successfully addressing the stigma associated with being mentally ill. Before we can reveal ourselves to others, we have to come out of our own dark closets.”


Steele and Berman, 2001



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CONTENTS

Executive Summary	7
Introduction.....	10
Purpose.....	11
Current Selected Literature.....	11
To Disclose or Not To Disclose?.....	13
Self-Disclosure in Employment	17
Disclosure Among Mental Health Field Professionals.....	21
Other Disclosure Experiences.....	25
Disclosure of Other Illnesses and Situations	29
Coming Out	33
Responses From Interviews	34
Recommendations	35
Conclusion	37
Appendixes	
A. Participant List	38
B. References and Resources.....	39
C. Interview Questions on Disclosure	45



“The most important thing to remember is that you are in control of how much you tell; do not let anyone manipulate you into sharing more than you feel comfortable sharing.”

—Sean Bennick, Webmaster of *Mental Health Matters*



Factors that may facilitate self-disclosing include the following:

- The need to become educated about one's own condition so that one can educate others as needed
- The importance of first disclosing to someone one trusts
- The recognition that one can decide to share less with those people who may appear judgmental
- The need to pick and choose when to disclose and under what circumstances
- The importance of feeling safe when one self-discloses
- The essential fact that each of us should be in control of how much to tell; we do not let anyone manipulate us into sharing more than we feel comfortable sharing.

What else do we know about self-disclosure?

A number of individuals who are professionals in the mental health field have themselves received mental health services. These professionals have offered a variety of strategies about disclosing in general and disclosing to consumers with whom they work. One such

“I’ve asked many of my patients what it has meant for them to know about my history, and there is one consistent and resounding refrain: HOPE!”

—Mental Health Professional

professional offered, “I’ve asked many of my patients what it has meant for them to know about my history, and there is one consistent and resounding refrain: HOPE!” If a person feels that the therapist has made progress with his or her own mental health issues, disclosure by the therapist may be beneficial to the consumers.

A number of individuals not associated professionally with the mental health field also have

written about their disclosure experiences. Much of the literature indicates that disclosing to others about one’s own mental illness is positive, although difficult.

People with other illnesses and life situations also have to make decisions about self-disclosure. Examining the literature about these issues provides useful suggestions. For example, tailor your information to fit the person you are telling: your child, your neighbor, and your oldest friend. It helps to remember that it will take time for the person you tell to absorb what you have said.

Many people find disclosing their mental illnesses or other illnesses or personal situations gratifying, beneficial to their own recoveries, and often helpful to others. It appears that the more open one can be and the more people disclose, the more possible it is to overcome discrimination and stigma in the greater society.

The findings from interviews of mental health consumers, some of whom are mental health professionals, others in the clergy, and another in politics, indicated that hiding information and worrying that someone will discover one's secrets consumes a lot of personal energy. A number of individuals felt it was important to tell their stories. In fact, they saw self-disclosing as a mission to give others hope, increase public awareness, and help make it easier for others to reveal their experiences with mental illnesses.

Recommendations

1. SAMHSA/CMHS should support consumer workshops, meetings, and seminars to address self-disclosure in further examining the pros and cons to disclosure and offering a dialogue for other consumers to hear how and when individuals have disclosed.
2. On the basis of these findings, SAMHSA/CMHS should develop guidelines on self-disclosure that will inform persons with mental illness about the pros and cons of disclosure. The guidelines should help individuals learn how and when to disclose in a way that is comfortable and beneficial within employment, social, family, and other arenas.
3. Once these guidelines have been established, educational programs should be supported to further understand the significance of contact strategies on reducing discrimination and stigma. Educational programs should be consumer driven with the goal to encourage and teach individuals how and when to disclose appropriately.
4. Professional and provider groups should join with consumers and family advocates in developing strategies for individuals with mental illnesses to self-disclose.
5. SAMHSA/CMHS Resource Center to Address Discrimination and Stigma (ADS Center) should offer Web site information and training in disclosure.
6. Public and private mental health organizations should promote dialogues on the topic of self-disclosure. These dialogues will provide vital information to individuals receiving mental health services who are contemplating or preparing to self-disclose and support to those who have already done so.



Introduction

The Substance Abuse and Mental Health Services Administration's (SAMHSA's) Center for Mental Health Services (CMHS) provides Federal leadership to improve mental health services. *Transforming Mental Health Care in America—The Federal Action Agenda: First Steps* identified discrimination and stigma as having a central impact on access to mental health services, and on the quality of life for individuals with mental illnesses (U.S. Department of Health and Human Services [HHS], 2005).

The final report of the President's New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America*, defines stigma as a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against individuals with mental illnesses (New Freedom Commission on Mental Health, 2003).

The stigma associated with mental illness is one of the most persistent problems people face. It is fundamental to discrimination in housing, employment, and health insurance. It prevents treatment, and it impedes recovery.

In this monograph, CMHS examines the role self-disclosure plays in reducing stigma and discrimination associated with mental illness.

Research has shown that public attitudes about mental illness improve when people have contact, or interactions, with people with mental illnesses. Meeting individuals who have received mental health services and who are productive members of the community challenges stigmatizing attitudes (Corrigan and Lundin, 2001). For these contact strategies to work, individuals must self-disclose or identify that they have received mental health services.

Researchers have begun compiling extensive information on the benefits of contact as a way to reduce discrimination and stigma.

Patrick Corrigan, Psy.D., a researcher on this topic, states that "contact between the public and people who have mental illnesses produces the greatest results with regard to positive change. Hence the more interaction between people with mental illnesses and the public, the more stigma will be torn down. This poses a challenge because the stigma of mental illness, like that experienced by gay men and lesbians, is largely hidden. People with mental illnesses need to weigh the real costs of coming out against the benefits to the community at large as well as themselves" (Corrigan, 2003).

Research shows that the greatest effects occur when the average person comes out. Although there is some benefit when people with notoriety tell their stories of recovery from mental illness, public attitudes are most challenged when neighbors, coworkers, and fellow churchgoers admit that they, too, have struggled with and beaten mental illness stigma (Spikol, 2003).

Corrigan (2003) states that "contact effects should improve when the following elements are present:

1. Equal status among participants
2. Cooperative tasks define the interaction
3. Institutional support for contact
4. High levels of intimacy
5. The person with severe mental illness does not greatly differ from the stereotype."

Purpose

This monograph examines current literature related to self-disclosure and provides the findings from a series of key informant interviews to examine the factors that promote or hinder self-disclosure. Books, articles, and Web sites were analyzed in order to glean key findings and implications regarding the disclosure of mental illness in various arenas.


Some of the questions examined included the following:

- Why should a person disclose that he or she has received mental health services?
- What are the advantages and risks of disclosure?
- What factors facilitate disclosure?
- Is there a safe way to disclose?
- What impact does self-disclosure have personally and systemically?

In addition, the monograph also examines techniques used by other individuals and groups who have disclosed private issues to others. For instance, individuals with HIV/AIDS have had significant experience in this area. Individuals who are gay and lesbian have coined the phrase “coming out” to define when they tell others about their sexual orientation. Individuals with disabilities other than mental illness face disclosure issues as well. How do they address self-disclosure?

Current Selected Literature

The selections cited in this monograph include a compilation of references from books, magazine articles, research projects, and various Web sites addressing disclosure of mental illnesses (see Appendix B, References and Resources). Although much of the literature reviewed focuses on disclosure in the employment arena, consumers working in the mental health field made a number of significant statements about self-disclosure.



“One is what one is, and the dishonesty of hiding behind a degree, or a title, or any manner and collection of words, is still that: dishonest.”

—Kay Redfield Jamison

To Disclose or Not To Disclose?

“Disclosure is not a black and white choice. Mental illness is a complex experience. People need to decide which parts of this experience to disclose,” states the opening page of a chapter titled “To Disclose or Not To Disclose” in the book, *Don’t Call Me Nuts!: Coping With the Stigma of Mental Illness*, by Patrick Corrigan, Psy.D., and Robert Lundin (2001).

Some benefits of disclosure that the authors list and discuss include

- Not having to worry about hiding experiences with mental illness and being more open about day-to-day affairs
- Finding others who express approval, including those with similar experiences
- Finding someone who can provide assistance in the future
- Promoting a sense of personal power and acting as living testimony against stigma and discrimination.

Some costs discussed include

- Encountering disapproval of your mental illness or your disclosure, including the risks of social ostracism and gossip
- Being discriminated against in employment, housing, and other opportunities
- Having increased anxiety due to perceptions that people are thinking about you or pitying you
- Thinking that future relapses may be more stressful because others will be “watching”
- Experiencing anger from family members and others because you self-disclosed.

Corrigan and Lundin discuss two levels of disclosure: selective and what they call indiscriminate disclosure. Selective disclosure refers to choosing who specifically to tell about one’s mental illness and when to tell. Indiscriminate disclosure, the authors suggest, requires a change of attitude by the person who no longer conceals a mental illness in general. They suggest that “you have successfully changed your attitude about disclosure when talking about mental illness no longer evokes a sense of hesitancy or shame.” The book offers sample questions to determine whether an individual is able to cope with indiscriminate disclosure.



The authors view disclosure as a process. They conclude that there is no clear answer about whether to disclose or not to disclose; it is a personal issue (Corrigan and Lundin, 2001).

Among the key informants interviewed for this monograph, a majority of the respondents indicated that

1. The first time they disclosed was in a place where they felt safe or comfortable.
2. Some planned ahead what they would tell, whereas others said that it was done spontaneously.
3. It just felt natural to disclose at the moment.

First-time disclosure took place in a range of settings: from in front of a group for Congressman Patrick J. Kennedy to telling a good friend one-on-one for consumer advocate Russell Pierce. In each case, the aspect of trusting the group or the individual was an important aspect of the disclosure.


Disclosure does not have to be all or nothing. Disclosing one's mental illness is a very personal, subjective decision. It is important to look at your own feelings about mental illness before disclosing your personal information to others. Not everyone needs to know about a person's struggles, but sharing your mental illness diagnosis may garner support. It is also important to brace yourself for possible negative responses from people when you do disclose. You can agree to disagree, or you can try to educate the person. Many educational materials are available to assist you (Albert, 2005).

Michael S. Finkle, executive director of a statewide consumer advocacy group, said, "While the consumer movement consumes my life, I usually don't disclose one-on-one, unless there is a purpose to it. I don't disclose to strangers. If they ask what I do, I tell them, and if they seem interested, and ask more questions, then I make a judgment call. I tend not to disclose unless it would be beneficial and comfortable doing so." (Finkle, personal communication, 2005.)

“It freed me from the burden of having to hide a part of me, and it freed me from the shame that comes from feeling as though you have to hide and keep secret the illness.”

—Interviewee Response





“Another benefit of disclosure is that it promotes one’s recovery process by allowing one to form or join a self-help group and begin the relationships and conversations needed to reconstruct one’s self-image in a positive light. The more open one can be, the more possible it is to overcome stigma and discrimination in the greater society.”

—Daniel Fisher, M.D.

Self-Disclosure in Employment

A strategic analysis is important for a person receiving mental health services when making a disclosure decision, states Susan Goldberg in her presentation, “Experiences of People With Psychiatric Disabilities Around Employment Disclosure and the ADA: Research Findings and Their Implications.” She suggests that three kinds of considerations may be useful in the strategic analysis:

A. Personal Considerations

- How well you feel you can handle prejudice and discrimination
- Prior experience or discrimination that you or colleagues experienced
- Your sense of self
- Your employment history
- How well you feel you can handle maintaining a secret—and sometimes having to lie to do so
- Sense of disability pride or identity
- Other identity issues—including race, gender, culture, and age.

B. Considerations Involving a Potential or Actual Employer

- Type of business (e.g., whether prejudice is more or less likely)
- Size of employer (e.g., large company vs. small mom and pop business)
- Whether there are other persons with disabilities employed there
- Whether it appears the employer has adequately accommodated persons with other disabilities
- Whether staff or supervisors make positive or negative comments about people with disabilities, including those with psychiatric disabilities
- How competitive the employment position is
- How competitive the profession is (e.g., stockbroker)
- How much expertise you bring to a particular job (e.g., if you are the only person in the metropolitan area who has this particular skill)
- Whether the particular accommodation request will be seen as problematic or as matter-of-fact (e.g., request for part-time hours may not be problematic since many employees work part-time)
- Whether staff and supervisors seem to be friendly to one another and to you.

C. Societal Issues

At the time you are considering disclosure

- Has there been anything in the news or the media that might result in a period of increased prejudice?
- Has there been anything in the news or arts that might result in a period of decreased prejudice, for example, the movie *A Beautiful Mind* or a famous person disclosing a psychiatric disability (Goldberg, Killeen, and O'Day, 2005)?

Several Web sites on the Internet that discuss when and how to disclose often focus on the workplace. One interactive Web site for individuals with mental illnesses, developed by Boston University's Center for Psychiatric Rehabilitation, addresses issues and



reasonable accommodations related to work and school and other employment and education issues. This site features an article, “Disclosing Your Disability to an Employer,” which outlines considerations before disclosing a mental illness to an employer.

If and when one decides to disclose, an individual should determine how specific to be about the disability and should provide additional information accordingly:

- Be very general: refer to a medical condition or an illness.
- Be a little more specific: indicate a biochemical imbalance, a neurological problem, a brain disorder, or difficulty with stress.
- Mention mental illness specifically: mental illness, a psychiatric disorder, or a mental disability.
- Give an exact diagnosis: clinical depression, panic disorder, obsessive-compulsive disorder, and other conditions (Boston University Center for Psychiatric Rehabilitation, 1998).

Extensive information on the potential benefits and drawbacks of disclosure in the workplace can be found in an article, “Case Studies on Reasonable Accommodations for Workers With Disabilities,” in the chapter “Disclosure.” It offers the results from surveys of people who have disclosed, concluding that “decisions about whether or not to disclose, when to disclose, to whom, and how much to say, may be the most delicate and complex area of the Americans With Disabilities Act (ADA) implementation for workers with psychiatric disabilities” (HHS, 1993).

Susan Rogers, in an article titled “To Work or Not To Work: That Is Not the Question,” says that “even experts disagree about whether you should tell the truth or lie to a prospective employer about a ‘Swiss-cheese resume’—a work history with gaps you can drive a truck through.”

Rogers also states that “how to address gaps in resumes is still controversial. However, since it is illegal for employers to ask questions designed to elicit information about illness, many experts advise consumers to get the job first; they can disclose their illness and ask for reasonable accommodations later” (Rogers, 1998).

On the other hand, Ralph Bilby, director of employment services at Fountain House in New York City, has long believed that people “should not cover up.” He offered that “most personnel managers feel an honest approach is rare and refreshing, so I am not of a mind to counsel individuals not to disclose their illness. What you’re looking for in presenting yourself and your ‘Swiss-cheese resume’ is a chance to be up front about the fact that you have an illness, that you’ve had a tough life, but you have been doing things that are positive in terms of preparing yourself for working, and that you have your illness well under control and you are looking for a chance to work for a good employer and prove what you can do” (Rogers, 1998).

Important tips can be gleaned from an article by Sean Bennick, Webmaster of *Mental Health Matters*. In his introduction, he pointed out that one of the most difficult things people have to do is to admit to themselves that they have a psychiatric disorder. He said that he was still learning how to tell others close to him what he was going through.

Some points he makes include the following:

- You cannot avoid abandonment by a judgmental person, but you can decide to share less with those people who may appear judgmental.

- You should educate yourself about your condition so that you can educate others as needed.
- The most important thing to remember is that you are in control of how much you tell; do not let anyone manipulate you into sharing more than you feel comfortable sharing (Bennick, 2003).

Another article appearing online offers guidelines for disclosure. The intent of this site is to share ideas to cope with the variety of symptoms that people diagnosed with dissociative disorders contend with day in and day out. The article—“My Guidelines for Disclosure: Should I Tell People I Have Multiple Personalities?”—lists six disclosure rules based on the writer’s own experiences (Emily and Riversrages, n.d.).

The author relates that in a communications class, she learned that “self-disclosure is something you tell someone about yourself that they would likely not know or be able to find out about you. Self-disclosure should be reciprocal, meaning listening to the other person and using that to guide us in the amount of information we disclose about ourselves.”

In the book, *A Gift of Stories: Discovering How To Deal With Mental Illness*, Judith Leibrich, the editor, says that the “act of telling stories can restore people (re-store). The telling of our story to someone who is genuinely interested and who relates to the telling through their own experiences is a very special thing.” This book is a compilation of stories from individuals who at some point have been diagnosed with a mental illness and have agreed to share their experiences (Leibrich, 1999).


Carmen Lee, director of the consumer-driven, advocacy and educational outreach program, Stamp Out Stigma (SOS), in which individuals with mental illnesses conduct community presentations, offers this insight on the benefits of speaking out:

- Most people think we are courageous and that gives us a lot of self-esteem.
- Just doing this is liberating; I love speaking now.
- People ask questions, want to know. It's an entirely different perspective, and it's opened up my life a lot. (Lee, personal communication, 2005; see also www.stampoutstigma.org.)

The examples offered above do tend to suggest that individuals gain confidence by disclosing their mental illnesses. They often also gain the ability to cope with and combat the stigma associated with mental illness. An article written by Mayo Clinic staff suggests specific ways to cope with and help end stigma. They include the following:

1. Get appropriate treatment.
2. Surround yourself with supportive people.
3. Make your expectations known.
4. Don't equate yourself with your illness.
5. Share your own experiences.
6. Monitor the media.
7. Join an advocacy group (Mayo Clinic, 2005).

Corrigan encourages professional and provider groups to join with consumers and family advocates to strategize about the best ways for people with mental illness to “come out” (Corrigan, 2003).



“I would encourage people to self-disclose with caution. To self-disclose whenever possible, but not if it puts one at risk. I would say take the temperature of the person or the company that one is disclosing to and adapt the way you do it (self-disclose) to that temperature.”

—Interviewee Lydia Lewis, 2004

Disclosure Among Mental Health Field Professionals

Daniel Fisher, M.D., in his article, “A Psychiatrist’s Gradual Disclosure,” writes, “A person’s freedom to disclose is also contingent upon the individual’s power, status, and position.” He did not disclose his illness or hospitalization until he completed his residency. He advises prudence in disclosure. “Pick someone you can trust—someone who is tolerant, understanding, and fearless about the experiences. More often, this will be a peer who has been through a similar experience and is in the process of recovery. Try to discuss your thoughts and feelings about past episodes and the treatment you received. Try to gain enough understanding and objectivity that you can then develop a strategy for further disclosure” (Fisher, 1994).

Fisher notes that another benefit of disclosure is that it promotes one’s recovery process by allowing one to form or join a self-help group and begin the relationships and conversations needed to reconstruct one’s self-image in a positive light. The more open one can be, the more possible it is to overcome stigma and discrimination in the greater society.

In addressing the issues of also working in the mental health community, Fisher states, “Disclosure, when it is geared to the needs of the client rather than the provider, can nourish hope and add a valuable human dimension to the relationship. The questions of how and when to make such disclosures are best addressed through discussions with peers.”

Fisher’s comment about consumers working in the mental health community led to a further examination of literature on that topic. The following article focusing on self-disclosure of therapists with personal histories of eating disorders appeared in a special edition of the publication, *Perspectives: A Professional Journal of the Renfrew Center Foundation* (2000).

“With regard to self-disclosure, the question is more when and how, rather than whether I tell my patients,” states Beth McGilley, Ph.D., psychiatrist. “I have no pat formula, no hard and fast rules for sharing this part of my history. It only makes sense not to lock myself into any rigid guidelines, because the therapeutic relationship, as I conceive it, is a dynamic, unique, and intimate connection in which exchanges occur as the relationship allows and demands.”

She further states that “coming out to my professional colleagues then outweighed any experience I’ve had dealing with the same considerations with my patients....I’ve asked many of my patients what it has meant for them to know about my history, and there is one consistent and resounding refrain: HOPE!”



In the same issue of *Perspectives*, Andrea Bloomgarden, Ph.D., states that she was initially afraid that if she disclosed with her clients, it would get back to her colleagues, and that they would not respect her if they heard about her past. Since becoming outspoken with her colleagues, Bloomgarden feels free to really think about what is best

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—Marion Bilich, Ph.D.

for her clients. She says, “I am open to the possibility that sharing some information about my eating disorder experience might be helpful, but would still prefer to err on the side of caution. In general, it seems extremely important to consider whether sharing or disclosing personal information will be attuned to the client’s needs....Since I don’t believe there is a clear decision-tree to guide self-disclosure, I use those therapists who’ve helped me the most as a model in my therapeutic work. For the

most part, I’ve chosen to self-disclose in response to a specific question and after I’ve explored with the client the ramifications of answering the question” (Bloomgarden, 2000).

“The recovering therapist is in a unique position to help this patient,” states Thomas Holbrook, M.D. “His knowing what it’s like to be eating-disordered gives him an intuitive sense of what’s going on with his patient. He has a chance of establishing a trust early on...self-disclosure is a useful tool, but it calls for a word of caution....Self-disclosure could unwittingly be used more for the therapist’s recovery than for the patient’s. The timing of self-disclosure is also critically important. The choice of what’s disclosed will determine whether it’s a meaningful and helpful offering, and not just an ‘I’ve been there too’ story” (Holbrook, 2000).

Marion Bilich, Ph.D., in another article in this publication, states that some 20 years ago, she disclosed her eating disorder in the *Daily News*. “Overall,” she said that “the therapist who self-discloses through the media must always be prepared to deal with the issues that may arise out of that disclosure.” She also points out that by disclosing “publicly through the media—newspaper articles, books, television appearances—we lose control over timing.” She further says that “as long as I have kept in mind the possible pitfalls of my personal revelations in the media, the therapeutic good that has resulted has far outweighed any harmful consequences” (Bilich, 2000).

Fred Frese, Ph.D., in an online discussion, notes that a “small but growing number of psychiatrists, psychologists, social workers, and other mental health professionals who are in recovery from mental illness have decided to openly identify themselves as such. If these professionals could begin to be more open about their experiences, those of


their family members and consumer advocates could better realize that mental health policy and research decisions are not being made as much in isolation from consumer influence as it may appear” (Frese, Stanley, Kress, and Vogel-Scibilia, 2001).

Notable among mental health professionals, Kay Redfield Jamison, Ph.D., has published a number of books disclosing her mental illness. *In An Unquiet Mind: A Memoir of Moods and Madness*, which is a first-person account of manic-depression, Jamison (1997) states:

I have had many concerns about writing a book that so explicitly describes my own attacks of mania, depression, and psychosis, as well as my problems acknowledging the need for ongoing medications. Clinicians have been, for obvious reasons of licensing and hospital privileges, reluctant to make their psychiatric problems known to others. These concerns are often well warranted. I have no idea what the long-term effects of discussing such issues so openly will be on my personal and professional life, but, whatever the consequences, they are bound to be better than continuing to be silent. I am tired of hiding, tired of misspent and knotted energies, tired of the hypocrisy, and tired of acting as though I have something to hide. One is what one is, and the dishonesty of hiding behind a degree, or a title, or any manner and collection of words, is still that: dishonest.

She further relates:

There is no easy way to tell other people that you have manic-depressive illness; if there is, I haven't found it. So despite the fact that most people that I have told have been very understanding—some remarkably so—I remain haunted by those occasions when the response was unkind, condescending, or lacking in even a semblance of empathy.



“Self-disclosure had a most positive impact on my life. Through self-disclosure, I have accepted that something had changed and that I was different. It was too difficult and painful to deny what was happening to me.”

—Interviewee Response

Other Disclosure Experiences

A number of individuals not associated professionally with the mental health field also have written about their disclosure experiences. Some of the individuals are famous, and some are not. Overall, the literature seems to indicate that disclosing to others about one's own mental illness is positive, although difficult.

Author William Styron, in his book, *Darkness Visible: A Memoir of Madness*, notes that in 1987 he was so annoyed about the press coverage of the suicide of Primo Levi, a famous Italian writer, that he wrote a short article for the op-ed page of the *New York Times*. Styron (1990) states:

The overwhelming reaction made me feel that inadvertently I had helped unlock a closet from which many souls were eager to come out and proclaim that they, too, had experienced the feelings I had described. It is the only time in my life I have felt it worthwhile to have invaded my own privacy, and to make that privacy public. And I thought that, given such momentum, and with my experience in Paris as a detailed example of what occurs during depression, it would be useful to try to chronicle some of my own experiences with the illness and in the process perhaps establish a frame of reference out of which one or more valuable conclusions might be drawn.

“I'd recommend coming out about depression. Having secrets is burdensome and exhausting, and deciding exactly when to convey the information you have kept in check is readily troublesome.”

—Andrew Solomon

The Noonday Demon: An Atlas of Depression, by Andrew Solomon, discusses disclosure and stigma in a chapter titled “Politics.” Solomon states, “I would have to say, however, that talking about my depression has made it easier to bear the illness and easier to forestall its return. I'd recommend coming out about depression. Having secrets is burdensome and exhausting, and deciding exactly when to convey the information you have kept in check is really troublesome” (Solomon, 2001).

Until the time of his death, Ken Steele was a mental health advocate and editor and publisher of *New York City Voices: A Consumer Journal for Mental Health Advocacy*. His book, *The Day the Voices Stopped: A Memoir of Madness and Hope*, relates his personal story of illness and recovery. “Most striking about *New York City Voices*, however, has been the inclusion of personal stories by people with mental illness,”



Steele states, “written in our own words and under our own bylines (often accompanied by a photograph of the contributor). A bold but necessary move, self-disclosure is a first step toward successfully addressing the stigma associated with being mentally ill. Before we can reveal ourselves to others, we have to come out of our own dark closets” (Steele and Berman, 2001).

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—Ken Steele

Along the lines of Steele’s New York program, NAMI (formerly known as the National Alliance for Mental Illness) has a program titled “In Our Own Voice” that offers opportunities for consumers to speak to the community. The Web site offers information on this outreach program in which consumers make presentations

to various audiences. It also presents an explanation of how the program works and testimonials of the program. NAMI notes that “it is also an opportunity for consumers to gain self-confidence, self-esteem, and income while serving as role models for the community.”


Mindy Lewis, author of *Life Inside: A Memoir*, found herself speaking in public at grand rounds to more than 100 mental health professionals at a hospital where she lived from age 15 to 18. She was invited to talk about what it was like to be hospitalized as an adolescent. In an article in *Newsweek*, she discusses the experience and says, “I am overcome by a surreal ecstasy at unlikelihood and privilege of this my prodigal return. But I also know that this day will pass, and many of my questions will go unanswered. All I can do is tell my story, and in so doing, make reparations to myself” (Lewis, 2003).

The power of self-disclosure is chronicled in a Maine newspaper article about a 46-year-old man, Tom Shumate. His mental illness had been mentioned in a local paper. After his initial reaction to being “outed,” Shumate decided to share his experiences with others at a local coffee shop. He had concluded that he would neither conceal his experiences nor apologize for them. Shumate emphasized that it is important for individuals who are having symptoms to tell someone so that they can get the best treatment. He commented, “It’s hard enough as it is—when you try to hide it, it gets even harder.” This article points out that sometimes disclosure comes out whether a person is ready for it or not, but one can turn the disclosure into something good and set an example for others (Nemitz, 2004).

Jeffrey Widom smiles in a picture featured in the *Washington Post*. In an accompanying article, Widom describes how he tries to educate friends and colleagues about attention deficit hyperactivity disorder (ADHD) and depression by being a standup comic. For him, finding the right therapy has helped, as well as practicing coping skills like the self-deprecating humor he uses on stage. He tosses a challenge to society: “Take the time to say hi and ask what I’m going through, and have a laugh with me” (Guzy, 2004).

Liz Spikol in her article, “Mad as Well: People Need Labels. Now You Have Mine,” gives her first-person account about writing a column in a Philadelphia newspaper in which she “comes out” about her mental illness and describes the reactions she received. She said that there were a number of inquiries about her specific diagnosis. She contended that people were more comfortable with labels (Spikol, 2003).

Although the subject of mental illness is not as taboo as it once was, stigma and discrimination are still highly prevalent. But the brave individuals who either have been forced or pushed to self-disclose, or have volunteered to tell their stories, seem to find it liberating and an important part of their recovery.



“The brave individuals who have either been forced or pushed to self-disclose or have volunteered to tell their stories, seem to find it liberating and an important part of their recovery.”

—Quote From the Monograph

Disclosure of Other Illnesses and Situations

People with other illnesses and situations also make decisions on what and how to disclose information. One such article, titled “Disclosure: The Basic Facts,” appeared on the National Multiple Sclerosis (MS) Society’s Web site. The article covers many of the same concerns individuals with mental illnesses address (National Multiple Sclerosis Society, 2004).

A similar article in *Inside MS*, a magazine about multiple sclerosis, discusses whether to tell or not to tell about MS, and these topics again are similar to issues that individuals with mental illnesses face (Donoghue, Siegel, and Van Abel, 1994):

How to tell? Blurting out “I have multiple sclerosis” communicates poorly, possibly even falsely. The person you tell needs information, not a label that provokes frightening images. . . . You will need to tailor your information to fit the person you are telling: your child, your neighbor, your oldest friend.

The MS article on disclosure further recommends writing down what you want to convey and doing some role-playing with someone you trust:

Issues of disclosure and romance—Because timing is critical, telling every person you date could be a bore, but not telling when the relationship progresses is unfair to both persons. We suggest this rule of thumb: Tell not too soon as to be unnecessary, not too late as to be a threat to trust. It helps to remember that it will take time for the person you tell to absorb what you have said. Think how long it has taken you to accept your illness.

Disclosure at work—The emotional climate of the workplace is different from telling your family and friends. There you confront the question of disclosure in the context of concern about your present and future livelihood.

When to tell on the job? If your MS has not created any limitations for you, you may decide to say nothing. But if you feel disclosure will not be used against you, and that telling your boss and your coworkers is more relieving and better for you than remaining silent, then you should tell. If your job performance is threatened by your symptoms . . . then you need to tell in order to seek accommodation provided by the ADA.

The MS magazine suggests that it is essential to get technical advice before you tell your employer—get the facts about the ADA provisions and advice about the kinds of accommodations that have worked for other people:

Be specific, brief, and nonapologetic. Stay focused on your employer’s need to know about your ability to do your job. But as with telling anyone else, rehearse what you are going to say. Role-play with someone from the business world. Then speak confidently and positively of your ability, experience, and desire to do your job. It is extremely important to have rehearsed a disclosure statement that does not overembellish the disease or the disability.



What to tell in a job interview? Unless you are visibly disabled, the article further suggests not disclosing MS in a job interview. “You are not required to do it legally. Moreover, your interviewer does not yet know what you can do and who you are. Trust has not been established. Many people with MS feel irrational guilt that can prompt premature disclosure. But nearly everyone interviewing for a job has something they would prefer not to tell: their blood pressure, their drinking habits, their family problems.”

Thomas Arthur, in his article, “Issues in Culturally Competent Mental Health Services for People of Color,” discusses the barriers relating to attitudes about privacy among people of color with reference to emotional and mental health issues. The article offers suggestions on ways the mental health system should address those barriers. Although his article does not examine disclosure per se, it implies that the privacy and attitudes of other cultures to even privately seek services is an issue to be addressed before disclosure (Arthur, 2000).

Russell Pierce (personal communication, early May 2004), a consumer who was interviewed for this monograph, points out:

Self-disclosure is a matter of concern not only for those of us in the mental health community, but also for those who are re-entering the community from jails and prisons. Self-disclosure presupposes that there is something about us that we want to keep private or unknown—because if made known it will hurt us or put us in a bad light. Self-disclosure also presupposes that something will be done to us if made known. He suspects “this latter issue is what many of us grapple with when we consider self-disclosure—that something will be taken from us if we make known something about us—our dignity or self-respect.”

On the other hand, SAMHSA’s 2004 Road to Recovery series focuses on how people in recovery from addictions can provide testimonials and recount their successful recovery journeys and still be respectful of 12-step traditions. It also addresses myths and misconceptions that silence the voices that could give others hope and the courage to recover (U.S. Department of Health and Human Services, 2004).

“Contact between the public and people who have mental illnesses produces the greatest results with regard to positive change. Hence the more interaction between people with mental illnesses and the public, the more stigma will be torn down.”

—Patrick Corrigan, Ph.D.



Coming Out

Another informative Web site from the United Kingdom discusses World AIDS Day and offers individuals' personal stories of disclosure regarding HIV/AIDS as well as a discussion of discrimination and stigma (worldaidsday.org, 2004).

There are many similarities in disclosing a mental illness and “coming out of the closet” if one is gay, lesbian, bisexual, or transgendered (GLBT). In a review of the kinds of information available to someone who is gay or lesbian and in consideration of self-disclosure, there is a plethora of material.

Of particular note is the Human Rights Campaign (HRC) Web site, www.hrc.org, which includes information available on “coming out” in a separate section noting that, “If you are questioning whether you really need to come out to others, remember that it is one of the most powerful things you can do for yourself. It is also a powerful thing you can do for others, as public opinion shows that people who know someone gay are more likely to support our quest for equality. Coming out may be one step in your life but it contributes to a giant leap for all GLBT people, today and in the future.”

This also was emphasized within a letter from the HRC's executive director which stated, “Let me assure you that being an openly gay, lesbian, bisexual, or transgender person in this society is not always easy. But disclosure is so much more gratifying than being in the closet. Hiding information and worrying that someone will discover your secret consumes a lot of personal energy. It also detracts from the quality of your life.”

In addition, the HRC supports a National Coming Out project. Many people of color face unique challenges when they come out as GLBT. To address these issues, the National Coming Out project has developed new resources on coming out in the African American community, the Latina/Latino community, and the Asian Pacific American community.

Another Web site from the United Kingdom features an article, “Coming Out and Staying Out: Information for Gay and Bisexual Men.” This article gives a step-by-step analysis and suggestions and resources to “coming out” in England. It is a very clear example of how to proceed and what considerations to make. For example, it offers, “This is a nerve racking time—the fear of rejection is likely to be immense. Bear in mind that there are many ways to tell someone” (Gay Men's Health, 2004).

Still another Web site offers what it calls a good basic model for the coming out process. In an article titled “The Stages of Coming Out,” it states, “Coming out lets others know that gays and lesbians exist around them; we are to a large extent an ‘invisible minority.’ Coming out makes us visible, and gives others the chance to be aware of and work through their own biases, to see the discrimination in the world, and to consider these issues on their own before being confronted with them somewhere else by someone else in a less understanding fashion” (Niolon, 2005).

This article includes words that also might be considered by individuals who are disclosing their mental illnesses: “Overall, ‘coming out’ is a normal process that is crucial to accepting who you are and feeling good about yourself. You can be more ‘out’ in some settings than in others; ‘come out’ in different ways to different people, and expect it sometimes to go well and sometimes to go badly. It is a significant part of the process of identifying and becoming closer to your friends and loved ones.”



Responses From Interviews

Key informant interviews with a number of people who receive or have received mental health services were conducted about their experiences with self-disclosure. The interviews were conducted by telephone (see Appendix C, Interview Questions on Disclosure).

The interviewees were each sent their responses for editing and approval. Three men and four women were interviewed. The interviews included individuals who were for the most part actively working on mental health issues now either professionally or as volunteers. They were all candid about their experiences with disclosure.

In response, some individuals found the experience of self-disclosing very freeing. One respondent offered, “It freed me from the burden of having to hide a part of me, and it freed me from the shame that comes from feeling as though you have to hide and keep secret the illness.”

Another stated, “Self-disclosure had a most positive impact on my life. Through self-disclosure, I have accepted that something had changed and that I was different. It was too difficult and painful to deny what was happening to me. Therefore, I chose to be very honest with others and myself about what I was going through. I think self-disclosing my story helps other people feel comfortable. Honestly, I believe that I have recovered, at least to a point where I can participate in life again.”

Others who have disclosed selectively still pick and choose when to disclose and under what circumstances. One individual offered, “Self-disclosure has to be an individual’s choice. It is different for everyone. You have to look at the pros and cons. Mine was more spiritual. I feel responsible to tell people who are going through something similar to what I have been through that I have survived self-disclosure, and it has been healing for me. My suggestion would be to make sure you feel safe when you self-disclose.”

Lydia Lewis, former president of the Depression and Bipolar Support Alliance, expressed, “I think it is wonderful, but I would encourage people to self-disclose with caution. To self-disclose whenever possible, but not if it puts one at risk. I would say take the temperature of the person or the company that one is disclosing to and adapt the way you do it (self-disclose) to that temperature.”

One person said, “Most of the time I want people to see me as high functioning. I disclose when it may be helpful for people to let them know that it may take me a little more time to get things done. I do not have any personal friends who are not consumers or related to consumers. It’s because I don’t seem to need any. Most of my personal friends already know my challenges.”

Another perspective came from an individual who said, “Persons can self-disclose when they feel they have accomplished something other than the designation of being mentally ill. . . . I may be a good artist, cook, or a good friend. People have a multitude of characteristics. I resent organizing among ourselves—balance of support of other consumers is good, but can be limiting. People shouldn’t resist the pull of being a part of the larger community.”

A few individuals commented that the health professional community, including health care providers, seemed to be the least compassionate in responding to disclosure. One person had an experience when being treated in the emergency room and another when seeing a grief counselor after a close relative died. In each case, the professional acted inappropriately.

Several individuals felt it important to tell their stories. They felt it was their mission and felt compelled to disclose to give others hope.

Congressman Patrick J. Kennedy offered, “One of the things I have gained is the response from the people that I have met who have thanked me for being so out front personally. I think my profile of being so public, coming forward gives them more comfort because there was a lot written about it. I think that it won’t be long before we look back and think how foolish that we carried so much guilt to this illness. I think if each of us works in our own way to be an example to others as to how it is to live with the illness, it may help others to get support in their own lives.”

Sister Ann Catherine Veierstahler started an educational Web site after disclosing her mental illness in a local newspaper interview. The Web site features stories of individuals who have received mental health services and are doing well.

Veierstahler says that “disclosing offers hope to others, an opportunity to have an impact on discrimination and stigma, and an opportunity to educate others about mental illnesses and the positive experiences of people who are making progress.” She further states that “we don’t want any people to live as long as I did without help. I try to get to the youngest people right away. I would love to have thousands of stories on our Web site to give hope and healing to others. The trouble is, those who are doing so well have all the things they needed to get well so they do not even see their lives as special or significant to help others.”

Gail Hornstein, Ph.D., not an interviewee, but a Mt. Holyoke psychology professor, also sees value in studying consumers’ experiences. She has compiled a bibliography of “first-person narratives of madness,” which lists more than 500 titles. Hornstein says,



“All of us need to have a more humble, appreciative, and respectful attitude toward the contributions patients can make in general and especially toward the accomplishments they’ve been able to make from the agony of their illness” (Hornstein, 2005). She and University of Massachusetts professor Lee Edwards teach a seminar, “Patient Narratives of Mental Illness.” “It is,” she believes, “the first course anywhere whose texts consist entirely of the writings of mental patients.”

The following are specific responses to the question posed to the key informants:

Would you encourage others to self-disclose?

Respondents had the greatest differences in their replies to this question. Some encouraged individuals to disclose; others issued cautions.

Below are a few of the comments:

I do, so long as it is consistent with their values.

It is so healing to me. It is a great relief and release to tell others. So liberating. Sometimes it feels like butterflies. It has to be an individual choice, because everyone is different and the reasons for self-disclosure are different.

Absolutely, I would encourage it for people in terms of how they can help others. You can feel better about it if you disclose—you are helping change society and helping to save people’s lives.

There are many levels of sharing and a lot depends on the personality of the person. I don’t think you can say if it is right for one person to disclose or not. How do you know? It’s like when a person gets married, how do they know it’s the right person—it’s a very personal thing. . . . Timing is important. I hated not having a correct diagnosis, but once I had a treatment that worked, I was much better and could tell my story. I had stomach cancer seven years before. I was very open about that and told everyone to pray for me. It depends on the individual’s comfort level. When people are ready, they will disclose. I’m so glad I have the opportunity to share.

Recommendations

SAMHSA's CMHS should support consumer workshops, meetings, and seminars to further address self-disclosure issues that include examining the costs and benefits of disclosure, discussing strategic approaches, as well as documenting individuals' experiences disclosing. The literature does not seem to indicate that this topic is substantially discussed. Although there is a plethora of first-person accounts in which individuals discuss their illnesses and experiences, there appears little or no centralized resource on promoting and educating consumers about disclosure. Use of this report as a starting point can bring about a comprehensive examination of the subject. The report may offer the opportunity to put the topic of self-disclosure and its impact on the radar screen.

Professional and provider groups should join with consumers and family advocates to strategize about the best ways for professionals with mental illnesses to self-disclose. Information should be made available to those professionals who are in recovery from mental illnesses on how to openly identify themselves. Their experiences, in many cases, could offer hope and promise to the people they serve and their families.

From the suggested meetings, SAMHSA/CMHS should develop guidelines on self-disclosure that will inform a person with mental illness about the pros and cons of disclosure. It is known that the most effective way of countering stigma and discrimination is interpersonal contact; therefore, it is important to help people learn how and when to disclose that they have received mental health services in a way that is comfortable and beneficial for the person disclosing. This step could be done with the development of guidelines on self-disclosure, offering a chance for individuals to connect with others and teaching them about mental illnesses in a nonthreatening and purposeful way.

Once there are guidelines and suggestions in place, SAMHSA/CMHS and other public and private organizations should establish educational programs to further understand the significance of contact strategies on reducing discrimination and stigma. Such educational programs should be consumer driven with the goal to encourage individuals to share their stories and thus reduce discrimination and stigma surrounding mental illnesses.

The SAMHSA Resource Center to Address Discrimination and Stigma (ADS Center) should offer Web site information and training in the topic of disclosure. The establishment of a centralized repository of information on self-disclosure and training in disclosure would promote self-disclosure and provide a much-needed service.

Public and private mental health organizations should promote dialogues on the topic of self-disclosure. Such dialogues could offer vital information to people receiving mental health services who are contemplating or preparing to self-disclose as well as support those who have already done so. As one of the interviewees said, "Mutual support groups can help with a lot of these issues. Go to mutual support groups and talk to others who have disclosed. Ask them how they did it. A paper can't give you dialogue. Other people can."

Conclusion

The purpose of this monograph is to begin a much-needed discussion addressing a crucial issue in the lives of people with mental illnesses. It is known that the most effective way of countering stigma and discrimination is interpersonal contact. If individuals who receive mental health services are encouraged to share their experiences, what are the factors that would facilitate self-disclosure? The literature suggests that telling one person or many people about oneself, particularly one's mental health issues, is always a "lump-in-the-throat" dilemma. But knowing that others have done so in a myriad of circumstances, and learning from other consumers' experiences, can be enormously helpful and can make the road so much easier for those who are about to tell a relative, neighbor, friend, colleague, or employer.

A number of seemingly simple ideas seem to repeat themselves throughout the monograph; however, the recurring theme seems to be that self-disclosing is a complex and personal issue that individuals must address only when they feel strong and ready to do so.

In keeping with this theme, the paper offers the following considerations for those contemplating self-disclosure:

- Initially, it is a good idea to tell someone you trust, who is tolerant and understanding.
- Timing has to be right, and only you can determine when it feels right to self-disclose.
- It is helpful to educate yourself about your mental illness and to be ready for questions and concerns from those you tell.
- You may want to practice by role-playing what you will say, before you actually have the conversation, and know how you will refute any negative responses.
- If you are disclosing to your employer, the decision to disclose may wait until you feel comfortable in the workplace or until a reasonable accommodation becomes necessary.
- It is important to remember that you are in control of how much you disclose; don't let anyone manipulate you into sharing more than you feel comfortable sharing.
- Often, telling your story is especially rewarding and liberating.
- Self-disclosure can promote confidence and a discovery of yourself while acting as living testimony against stigma and discrimination.
- It is also important to remember that sharing your own experiences may offer someone else hope that they too can recover.

Overall, the literature seems to indicate that disclosing to others about one's own mental illness is positive, although difficult. Thus, it is of the utmost importance for individuals to learn from each other not only how to cope with mental health issues, but how to disclose that they have or have had problems to others in a way that is liberating, helpful, and rewarding. The more contact and openness on the topic of mental health in our society, the more people who receive mental health services will be able to avoid the stigma and discrimination.

Sensitive issues that were once taboo to discuss have been tackled by discussions in public; disclosing to others about receiving mental health services should be the next "open forum."



APPENDIX A

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APPENDIX B

References and Resources*

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*This list is provided as a resource. It is not exhaustive, and it does not imply endorsement by SAMHSA.



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Private Resources

Boston University Center for Psychiatric Research
www.bu.edu/cpr/jobschool/disclosing.htm (accessed April 2008)

Chicago Consortium for Stigma Research
www.stigmaresearch.org (accessed April 2008)

Consumer Organization and Networking Technical Assistance Center (CONTAC)
www.contac.org (accessed April 2008)

Judge David L. Bazelon Center for Mental Health Law
www.bazelon.org (accessed April 2008)

Mental Health America National Consumer Supporter Technical Assistance Center
www.ncstac.org (accessed April 2008)



NAMI

www.nami.org/template.cfm?section=In_Our_Own_Voice (accessed April 2008)

NAMI Support, Technical Assistance, and Resource Center (STAR)

www.consumerstar.org (accessed April 2008)

National Empowerment Center (NEC)

www.Power2u.org (accessed April 2008)

National Mental Health Consumers' Self-Help Clearinghouse

www.mhselfhelp.org (accessed April 2008)

Stamp Out Stigma

www.stampoutstigma.org (accessed April 2008)

APPENDIX C

Interview Questions on Disclosure

The author spoke to a number of people who receive or have received mental health services about their experiences self-disclosing. The following questions were posed:

- Has self-disclosure had a positive or negative impact on your life? Explain why.
- What do you think you have risked and what do you think you have gained by disclosing?

More specifically,

- To whom did you first disclose? Why? What led you to self-disclose? Did you prepare to disclose, or did it just happen?
- When did you decide to disclose to others about your receiving mental health services? Was it a particularly significant moment?
- Do you remember where you were? What was the setting?
- Looking back on it, what was the response/result? Was it a positive or negative experience?
- Disclosing is not a one-time occurrence, so can you recall some different circumstances when you disclosed and to whom? For example: to family, friends—why? Was it your choice? What led to disclosure?
- If self-disclosure was on the job, when was it done, why, and what was the result? What words did you use?
- Would you do it differently if you had the chance to do it again, that is, the first time?
- Have you been in a situation in which you wanted to disclose receiving mental health services and did not? Can you explain why you did not disclose?
- Would you do it differently if you had the chance to do it again, that is, the first time?
- Have you been in a situation in which you debated internally about disclosing? What were the pros and cons?
- Would you encourage others to self-disclose?
- What factors make it more comfortable to self-disclose? What suggestions do you have on when, how, and what to say when you self-disclose?