
COMING OUT PROUD

to Eliminate the Stigma of Mental Illness

MANUAL

FOR PROGRAM FACILITATORS AND PARTICIPANTS

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Version: 8/26/12

PREFACE

Many people who live with mental illnesses, who have walked the walk and talked the talk, find themselves in a dilemma over the same questions:

- Who should I tell that I have a mental illness?
- To what degree should I disclose?
- Should I tell the whole ugly story or just bits?
- How quickly should I disclose, if at all?
- How do I deal with inquiring people wanting to know more about me?
- How will disclosure affect my career?

These are all very important issues. The implications are vast. Decisions to disclose one's mental illness—to COME OUT— will impact one's life in many ways. Finding a job or keeping a job may be at stake, so might be finding a place to live. Feelings of self-esteem and self worth may be hurt.

Mental illness often strikes like a two-headed serpent. On the one hand, are the harmful effects of the symptoms, the distress, and the disabilities caused by serious mental illness. On the other, is the equally troubling impact of stigma, and the pain that people struggling with these illnesses feel as a result of social disapproval. Stigma rears its ugly head in several ways, including public stigma, defined as the prejudice and discrimination suffered by many people with mental illness when the general population endorses stereotypes; and self-stigma, defined as the injury to self-esteem when a person with mental illness internalizes stigma. Many people decide to hide their illness from public eyes in order to escape social disapproval. In addition, many hide their illness as a way to manage self-stigma. Ironically, coming out with one's illness, or not keeping it in the closet, has beneficial effects. People who disclose their personal journey of recovery usually feel empowered and less troubled by self-stigma. Moreover, courageous souls

who are out are the foundation of programs that tear down public stigma. Hence, coming out proud is the foundation of erasing stigma at many levels. But, erasing stigma is not enough. We must also affirm opportunity:

- People with mental illness can recover and attain the same level of goals as everyone else.
- Their journey of recovery and achievement must be fully self-determined.
- Self-determination requires personal empowerment. People with mental illness need full control over their lives and appropriate influence over the communities in which they live.

The goal is not just less stigma, but more affirmation. Coming out may be one way to do this. The *Coming Out Proud* manual is a step-by-step program meant to guide people who are uncertain about whether or not to disclose their mental health background.

A Little Bit of History

Coming Out Proud started as a chapter on disclosure in Corrigan and Lundin's *Don't Call Me Nuts: Coping with the Stigma of Mental Illness (DCMN)*; published by Recovery Press, Tinley Park, IL, 2001). Corrigan and Lundin, a researcher and a consumer, respectively, were an energetic team that combined their wisdom into a practical text (*DCMN*) meant to address stigma change. In 2011, we began an effort to update the chapter into a stand-alone program with two overarching goals governing the task. First, we sought a panel of people with mental illness to review the program for relevance and utility, in the process asking them to try out program components. Second, we sought to do this with a collaboration of partners from around the globe. Our intent here was to construct a program with some attempt at cultural sensitivity and relevance. We have thus far received feedback from people with lived experience in Australia, Germany, Switzerland, the United Kingdom, and the United States.

Two Rules for Deciding About Disclosure

We propose two overall rules to guide any consideration of strategies for disclosing mental illness. Rule 1 suggests caution. To paraphrase an American Supreme Court Judge, *“It is hard to quiet the clanging bell.”* The truth can be glaring. Once you have disclosed, it is nearly impossible to retract the news. According to the *Rule of Minimal Risks with Little Information*, disclosing and then recanting is much harder than being conservative and letting people know slowly. An example of why caution is important/should be considered is the following:

“I told some people at the club about my manic depression. And then that guy murdered two guards at the U.S. capitol. Now, all my buddies are looking at me suspiciously.”

Some might think this man would not be in this predicament if he had waited to tell. Rule 1 counsels overall caution in disclosing such private information.

On the other hand, Rule 2, *Delayed Decision is Lost Opportunity*, suggests caution leads to unnecessary delay. There will always be hostile and ignorant people who will chastise you for talking about your mental illness. Don't let them keep you from coming out to people who are caring and supportive.

“To think, all this time I was afraid of telling my drama group that I was hospitalized for schizophrenia. They were amazingly supportive. I'm glad I finally got it out because now we're much more in tune.”

Although these rules represent wise advice to guide this tough decision, they obviously contradict each other. That's because there is no clear answer to the question about disclosure. Only you can know for sure what the right decision is for you. You must weigh all of the costs and benefits and decide for yourself what to do.

About Language

This manual is written directly for people with mental illness. Hence, instead of the third person language that typifies most programs and manuals, we write the

document in first (I and me) and second person (you) language, hereafter. Coming out is a personal decision. Thus, this manual is written in like fashion. We do not mean to suggest, however, that the ideas herein are irrelevant to those who are not people with mental illness. Anyone who seeks to help others struggling with coming out will benefit from this manual. Family members, service providers, or well-meaning friends might adopt principles and practices in this manual to assist others in decisions about whether or not to and how to disclose. Just remember: in the end, the ultimate decision lies with the individual, himself or herself.

A second consideration about language: the mental health community around the world varies in the way that it refers to people with mental illness. We adhere to the notion of “*person first*” language. In other words, we refer to people with a condition, not to “*patients*,” “*schizophrenics*,” or “*depressives*.” Person first language stresses the personhood of the individual as primary. Furthermore, we chose “*person with mental illness*,” rather than “*person with lived experience*,” a term/label that is growing in popularity. This decision was based on our belief that it is one’s mental illness that brings them to “*coming out*” concerns; and, thus, we did not want to distance the reader from this thought.

Workbook

A workbook has been written as a companion to this manual (*Coming Out Proud: To Eliminate the Stigma of Mental Illness – Workbook*). The workbook briefly summarizes the key points of each lesson, and also provides useful exercises that help participants to make decisions as well as implement actions surrounding/related to coming out. The workbook (as well as additional copies of this manual) will be available for free on the Resources page of www.ncse1.org.

Acknowledgements

The ideas herein are a draft in progress and are the responsibility of its two authors. Many thanks, however, to those who have given us feedback on drafts,

including Keith Mahar, Ingrid Ozols, Blythe Buchholz, Janice Parker, Nicholas Rüsçh, Eduardo Vega, and Natalie Gela.

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Conducting the Program

In this busy world, we have set up the *Coming Out Proud* program so that it might be done briefly in three lessons, with each lesson requiring 2 hours. The program is best run with four to eight participants. One or two people should facilitate, preferably people with lived experience. All that is needed is a private room, manuals for the facilitators, and paper copies of the workbook for each participant. All materials can be obtained for free on the Resources Page of the National Consortium on Stigma and Empowerment (www.ncsel.org).

Starting Each Lesson

The first thing we want to do at the beginning of each lesson is set the tone. To do this, we start by having facilitators provide their names and any other introductory information they would like to share with the group. Facilitators should then go around the room and ask each participant to share their first name (last names and titles are not necessary unless the person chooses to share this information with the group). After introductions, facilitators should state the overall purpose of the *Coming Out Proud* program:

“Our goal here is to consider what the costs and benefits are of disclosing one’s experiences with mental illness to some people. We also seek to discuss strategies for coming out most effectively should you decide to do so.”

Facilitators should also establish some general ground rules with the group:

- confidentiality- what is said in the room stays in the room,
- that everyone’s opinion counts, and
- we respect each other.

The facilitators should also discuss with the group whether other ground rules might be helpful. Consensus should be sought if extra rules are proposed. Introductions and ground rules should be repeated prior to all subsequent lessons. The goal is to create an open environment where people feel comfortable sharing their opinions and feelings should they choose to do so.

LESSON 1

Considering the Pros and Cons of Disclosing

LESSON OVERVIEW

Coming out proud is the right decision for some people, but not for everyone. This section is a guide to help people decide what the right decision is for them. We approach the decision in three parts:

1. We discuss the idea of IDENTITY and mental illness so you can decide how you frame your identity.
2. We note that secrets are a part of everyone's lives so that you can decide whether your experiences with mental illness should or should not be disclosed.
3. We help you weigh the costs and benefits of coming out so that you can decide whether or not to disclose.

1. Do You Identify Yourself as a Person with Mental Illness?

LEARNING OBJECTIVES

- Some people do not want to view themselves as a person with mental illness:
 - They do not view struggles with their illness as central to who they are.
 - Other parts of their life are more central to who they are.
- Other people clearly identify themselves as a person with mental illness.

IN THE WORKBOOK:

Worksheet 1.1 provides a review of “*Some Reasons Why People Decided to Disclose Their Mental Illness.*”

Here we consider two different ways in which a person might respond to this question:

Marie is 32 years old and has had more than a dozen years of struggling with schizophrenia. Despite this disability, things are working out well: she hasn't had a hospitalization in five years, she's working a good job, she's keeping a nice home, and she's living with a supportive husband. By many people's standards, she has beaten her mental illness. Still, Marie frequently attends mutual help groups where she provides support to peers who are struggling with more acute problems related to their illness. She is also an outspoken advocate against stigma. She testifies at government hearings where she identifies herself as a person with mental illness who is outraged by the disrespectful images of mental illness that are rampant in our society. **Marie is a person who identifies herself as “mentally ill.”**

John Henry has a very similar history to Marie. He has struggled with schizophrenia since he was 19. Now, he is 32, married, and working a great job in a law office. He has not been hospitalized in five years and almost no one at work or in his social circle knows about his illness. John Henry wants it that way. Not only does he choose not to let others know about his past, he does not view himself as a person with mental illness. *“I'm a complex being with only a very small piece of me having to do with mental illness.”* **John Henry is a person who does not identify himself as “mentally ill.”**

The focus of the question here is not whether people with mental illness should publicly label themselves as mentally ill. Openly disclosing one's experiences with mental illness is a complex decision that each person needs to make for him or herself. The purpose of the *Coming Out Proud* program is to provide strategies that will help people make decisions about disclosure and telling their story. The point for discussion here is how the individual responds to the question of self-identification: *“Yes or no! Do I view myself*

as mentally ill?” In our example, two people with the same experiences view themselves and their mental illness differently. Marie thinks it is a significant part of her identity. John Henry denies that mental illness is central to his core. Let's take a closer look at each of these responses.

I'm Not a Person with Mental Illness!

Unfortunately, there are many stigmatized groups in the world. Some people argue that mental illness is a significantly different kind of group from other stigmatized people, such as African Americans. African Americans have an honorable heritage, which black leaders encourage their children to actively embrace. One way to challenge a racial stereotype is for people to openly wear their history and ancestry on their sleeve, to shout out their membership in a stigmatized group, *“I'm black and I'm proud of it!”* The more people who identify themselves as black and let the rest of the world know of their honorable background, the faster the walls of prejudice will come tumbling down.

Perhaps, so some people believe, membership in the group of people with mental illness is different in this regard. Rather than embracing and declaring one's membership in the club of mental illness, it seems that the purpose of the entire mental health care system is to move people OUT of this group. Treatment, rehabilitation, and support programs are designed to help people overcome their mental illness. According to some definitions, recovery means, *“I'm not mentally ill anymore!”* People influenced by this perspective do not choose to identify themselves as mentally ill.

Let's consider this point another way. Identity is the way someone speaks about him or herself. Identity reflects answers to the question of *“who am I?”* In response to this question, John Henry said, *“I am male, African American, working in a law office, a college grad, married, and enjoying life.”* Nowhere in this definition does he respond with an *“I am”* statement that includes mental illness.

Experts believe that a person's identity is drawn from all of our life experiences. Some of these experiences are viewed as central to the *“who am I?”* questions, such as: work status (*“I'm a legal assistant.”*), educational accomplishments (*“I'm college*

educated.”), marital status (“*I’m happily married.*”), and recreational pursuits (“*I love golf!*”). People often exclude negative experiences from being part of the “*who am I?*” question. They may ignore such statements as “*I’m a high school drop out*” or “*I couldn’t make it in the Army.*” People who do not choose to identify themselves as mentally ill are not recognizing their experiences with psychiatric disability as central to questions regarding self-identity.

I’m a Person with Mental Illness!

The above may make it seem like excluding mental illness from one’s identity is the best course. Hence, John Henry is adopting a better view of his psychiatric experience than Marie, whereas Marie is hanging on to her past and needs to give it up, to move on in life. Others would argue that it is not wise for people to ignore an important part of who they are, whether that experience was positive or negative. Being in touch with one’s personal heritage is essential to understanding the history of one’s life, which, in turn, is necessary for making changes en route to life goals.

Consider if the widely accepted goal was to not identify with a minority group, for example, to support self-identification in race relations. About 30 years ago, “*color blindness*” was circulated as a way to deal with racial diversity. According to this view, the best way to surpass differences between black and white was to ignore differences in skin color, cultural heritage, and history. We are all of one bond, so the theory went; only our commonalities should be acknowledged. While, in principle, this message seemed constructive and tried to promote a melting pot ideal; in reality, it led to further repression. Discussion of commonalities typically reflected the majority group: European preferences in culture, history, literature, and art. In the process, African, Asian and other views were suppressed. Advocates for ethnic groups now realize that this color blind message actually created as much harm as it helped to blend racial/ethnic groups. Now, advocates encourage people to proudly embrace their ethnic heritage. This message would seem to be a justification for a person identifying with mental illness.

But wait a minute. We argued earlier that the experience of mental illness with stigma could not be compared to that of ethnic groups with stigma. Unlike people of color, people with mental illness seem to lack any affirmative aspects that define them. In fact, we found it difficult to identify any disabled group who embraced its disability as a positive force. Until about five years ago, that is, when an American TV show, CBS' *60 Minutes News Magazine*, ran a story about the cochlear implant. The cochlear implant is an electronic device which, when surgically inserted, can radically improve hearing in deaf people. The interesting part of the story was not the rave reviews of parents whose children benefitted from the implant. Rather, the memorable part of the story was the rage from members of the deaf community who believed the cochlear implant was robbing them of their dignity. They believed that being deaf was no less a competent way of being than, for example, being black. Hearing impairment was not a problem for their community, as they have a way of communicating (Sign Language) that permits the full range of expression. Embracing sign language is as noble an effort as enjoying African American music or history. In this case, Sign Language was the cultural experience that positively defined this group.

To our knowledge, there has yet to be a similar movement in the mental illness community. Few people admit that psychosis is an alternative, fruitful lifestyle, and one to be respected. Not many advocates believe that medication, which rids the person of voices and delusions, is robbing the mental illness community of an essential way of being. Nevertheless, parallels between the deaf community and people with mental illness remain. There are aspects of the experience of mental illness, including sharing this experience with peers, that defines who the person is. Admitting this, and acknowledging it to the rest of the world, may significantly enhance the person's self-esteem.

This kind of self-identification may also help people to further define their role in society. Public identification of one's self as mentally ill helps people recognize peers

with whom they can share their experiences. This kind of support helps people weather the storms of stigma and discrimination.

Self-Identification is Not a Yes-No Question

We may have erroneously given you the idea that identifying one's self as mentally ill is a simple, black and white decision: you either group yourself with others who have mental illness, or you don't. Actually, the decision is a bit more gray. On some issues, people may identify with mental illness entirely (e.g., the haunting impact of depression, and/or dealing with the side effects of medication), while on other issues, they do not (e.g. anger with a restrictive mental health system). Moreover, ways in which we identify ourselves with mental illness can change over time. Mental illness may have different significance to us depending on whether psychiatric disabilities are still present, or whether a person has recently experienced the stigma of mental illness.

2. Secrets are Part of Life

LEARNING OBJECTIVES

- Everyone has secrets and they keep them for a variety of reasons.
- There is nothing shameful about secrets like this; still, some of us beat ourselves up with the “*secret of mental illness.*”
- Many assumptions we hold about our secrets account for our bad feelings.
- Our assumptions, however, are often false.
- We can challenge these assumptions and break down our hurtful beliefs.

IN THE WORKBOOK:

Worksheet 1.2 provides a way to challenge stigmatizing attitudes in the “Change Our Attitudes Exercise.”

List some of the hurtful attitudes you hold about your experience with mental illness.

Like Rule 1 in the Preface—*Minimal Risks with Little Information*—as a person with mental illness, you can choose to keep your disability a secret. Unlike the stigma experienced by people of color or physical disability, usually mental illness can be kept private. People you meet everyday—from the stranger on the train, to the clerk at the bakery, to your co-worker at the office—don't know if you struggle with psychiatric illness. Hence, if you feel victimized by the stigma of mental illness you must decide whether to disclose your experiences with the public, and if so, with whom. You need to consider how disclosing your mental illness will benefit you, as well as how it may be harmful. Disclosure is not a black and white choice. Mental illness is a complex experience. You need to decide which parts of this experience to disclose.

Secrets are Part of Life

Deciding to disclose experiences with mental illness is not an easy decision. Sometimes, this choice is made harder by the guilt you may feel about having a secret: “*I must be a bad person to have to hide part of who I am.*” This kind of guilt doesn't make your decision-making process any easier. In fact, you may feel like a leper because you have these secrets. However, you can be consoled by the knowledge that most adults must deal/cope with secrets. Examples of these include:

- People who struggle with coming out of the closet: gays and lesbians, people with AIDS, and people from some non-traditional religious denominations.
- Individuals of family members and friends who are associated with stigmatized groups. Parents, brothers, and sisters may choose not to share this with the public.
- Individuals who make life choices that they wish not to discuss with others. For example, a person who works a job that others might criticize, or who lives in a neighborhood that is not considered fashionable. Additionally, smokers who work around health-conscious co-workers may not want peers to know that they smoke.

There is some comfort in realizing that many of the strangers you meet each day—people from whom you are trying to keep secret your own mental illness—are withholding a secret from you. You do not struggle alone.

Despite information like this, you may still beat yourself up about your dirty little secret: “*There must be something wrong with me if I have to keep my psychiatric history private.*” This kind of attitude can have an insidious effect on you. There is a strategy for challenging these kinds of thoughts, which is summarized in *Worksheet 1.2*.

There are five steps for changing attitudes about our secrets and ourselves. First, we begin with a clear statement of the hurtful attitude using the formula:

I must be _____ because _____.

“I must be a bad person because I have a secret about my mental illness.”

If you further define this negative attitude, two key assumptions seem to account for the bad feelings associated with keeping your mental illness a secret:

- (1) *believing that “normal” people don’t keep secrets* and
- (2) *it is shameful to have a mental illness.*

To challenge these two assumptions you want to first ask others whether or not they believe them to be true. You will likely give up hurtful attitudes when you discover that these underlying assumptions are actually false. So, let’s start by challenging the first assumption: *believing that “normal” people don’t keep secrets*. To do this, seek out a circle of trusted people for feedback- as an example, a bible study group. In this example, you would also decide to check with your pastor, who you think is reliable and is a “*straight shooter.*” From your bible study group you learn that six out of seven people admitted to keeping a secret at some time in their life. Then, your pastor tells you that, at times, he has kept secrets. Both your pastor and the people in your bible study group said there are many reasons why someone might keep a secret, for example, if disclosing the secret would be hurtful to someone. They also admit that some secrets probably don’t need to be kept. After speaking with them, you understand that your

hurtful belief (i.e. *that “normal” people don’t hold secrets*) is not true. The final step is to translate your findings into an attitude that **counters** the hurtful belief. For example:

“I’m not bad for having secrets. Everyone does.”

You may wish to write this saying down on a card so that you can remember it better. Then, the next time that you're questioning your integrity for keeping a secret about your mental illness, pull out the card. Remind yourself that everyone keeps secrets and that there is nothing wrong with it, as long as you aren't keeping your secret based on assumptions that might actually be false. Use the workbook, specifically *Worksheet 1.2* and the example provided by Alan (*Table 1.1* on page 11) to see how the second assumption: *it is shameful to have a mental illness*, was challenged and countered.

3. Considering the Pros and Cons of Disclosing

LEARNING OBJECTIVES

- There are both benefits and costs to coming out.
 - Only you can weigh them to decide whether it is worth coming out.
 - Costs and benefits differ depending on the setting; for example, at work versus among your neighbors.
-

IN THE WORKBOOK:

Tables are provided to list the costs and benefits of disclosing and of not disclosing your mental illness (see *Table 1.2* and *Table 1.3*).

See a completed table (*Table 1.4*) that shows the short- and long-term costs and benefits of disclosing for Alan.

Worksheet 1.3, “The Costs and Benefits Worksheet for Disclosing My Mental Illness” provides a way to lay out the short- and long-term costs and benefits of disclosing in different settings and to different people. This worksheet is designed to help you make a decision about how you would like to move forward with the issue of disclosure.

There are both advantages and disadvantages to disclosing mental illness. Consider the stories of George and Susan.

- George never talks about his illness; he never voluntarily discloses it. George has worked for years as a congressional aide with frequent episodes of depression. He has never breathed a word of his depression to his children, friends, colleagues, or boss. Why is George so secretive? He is in a high-powered job where showing so much as a glimmer of weakness could be fatal to his career. His symptoms are tolerable, so he carries on in silence.
- Susan, on the other hand, lives in a nurturing home with other people who also have a mental illness. Her mental illness is discussed freely and openly. Gathering strength from this group support, Susan is actively encouraged to disclose her schizophrenia. Susan has made great strides in managing her illness. She is proud and gets praise for sharing her recovery from the depths of psychosis and depression.

Some Costs and Benefits of Disclosure

There are a variety of reasons why you might choose not to disclose your experience with mental illness. These could be considered **costs**, or reasons why you may regret disclosing. On the other hand, **benefits** are reasons why disclosure will help you. Several of these are summarized in *Table 1.1*. Let us consider the benefits first, the reasons why letting other people know about your psychiatric disabilities may help you.

| Benefits | Costs |
|---|---|
| You don't have to worry about hiding your mental illness. | Others may disapprove of your mental illness or your disclosure. |
| You can be more open about your day-to-day affairs. | Others may gossip about you. |
| Others may express approval. | Others may exclude you from social gatherings. |
| Others may have similar experiences. | Others may exclude you from work, housing, and other opportunities. |

| | |
|--|--|
| You may find someone who can help you in the future. | You may worry more about what people are thinking about you. |
| You are promoting your sense of personal power. | You may worry that others will pity you. |
| You are living testimony against stigma. | Future relapses may be more stressful because everyone will be watching. |
| | Family members and others may be angry that you disclosed. |

The advantages of disclosing. One advantage to telling others is that *you won't have to worry anymore about your secret getting out.* The minute others know, the secret is gone. It frees the person of the fear related to keeping secrets as well as of the resentment that stems from having to hide a part of yourself. Disclosing to other people *helps you to feel more open about your day-to-day experiences.* For example:

“Wow, I used to fret about the guys at work finding out that I was leaving work early to see my psychiatrist. Now, it doesn't matter. Instead, I can complain to them about how I hate to wait for the doc just like griping about waiting for the dentist.”

The fear is that when others find out, they will disapprove or humiliate you. On the contrary, a pleasant benefit of disclosure might be *receiving approval and support from others.* For example:

“Oh my gosh, Carolyn. I didn't know you struggled with depression. I'm really impressed with how well you manage.”

Most people are coping with some kind of personal trial or tribulation, even if it is not mental illness. They may be impressed by your ability to cope and they may respect you for it.

You might be pleasantly surprised to find out that *others have similar problems.* Frequently, people discover that when they admit to psychiatric problems, others respond “*me too.*” Given that more than 20% of the population are struggling with some kind of mental illness at any one time (and 8% of the population are dealing with severe mental illnesses like schizophrenia or bipolar disorder), it is likely that you will have a “*me too*”

experience when telling others.

As a result of disclosing, you may build friendships with those who have similar problems. These friends can then be available to **help you in the future**.

“Betty told me she gets depressed sometimes, too. That really helped. Next time I was feeling a little sad at work, I dropped by Betty's desk and we talked. She was able to say the kind of things that would get me through the day.”

Disclosing your experiences with mental illness is often the first step to finding an entire support network of people with like problems. Self-help groups provide a place where you can let your secrets out. They are places where people with mental illness can find kindred spirits, not worry about disclosure, and get support. Alternatively, finding a small group of friends with whom you can share your problems can be equally liberating.

Keeping a secret about mental illness fosters a feeling of shame. **Telling your story promotes a sense of personal power**. As we will discuss later, a feeling of personal power is the opposite of being victimized by shame.

“I was surprised when I told the book group about my experiences with manic depression. I didn't feel like the meek lamb anymore. I had something to say, I looked them in the eyes, and I said it.”

This sense of power over your life is a major step towards dealing with stigma.

Finally, telling your secret actually **challenges many of the stigmatizing attitudes others have about mental illness**. You are a living testimony against many of the said and unsaid myths about psychiatric disability.

“It was such an education working next to Jim. I thought mental patients were all dangerous and could never work. Jim was the best employee in the shop and one of the biggest gentlemen a guy could meet.”

The costs of disclosing. Although there are several benefits to disclosing your experiences, you need to consider the costs as well—these are the reasons why you are not currently telling people about your experience. Costs are also reviewed in *Table 1.1*

and must be carefully considered so that divulging your secret does not end up harming you. One big group of reasons why you may choose not to disclose is the repercussions from others. ***Some people may disapprove of you for telling your experiences.*** They fear mental illness, or are offended by people that have been hospitalized. They may turn these emotions against you. ***Others may resent you for asserting your right to tell.***

“I'm sick and tired of all these oppressed people whining. Blacks, Latinos, guys in wheelchairs, and now Sid because he's mentally ill. Why do I have to bleed for all these other guys?”

People might start talking about you. Gossip is the bane of offices and neighborhoods. Telling people about your experiences with depression, hospitals, or medications may provide juicy material for the gossip line. ***Some people are going to shun you at social gatherings when they hear your story.*** They may have ignorant views about people with mental illness being dangerous and want to protect themselves. ***Some people may actually exclude you from work or housing opportunities.*** A supervisor might keep you from a good job because of hostility, for example: *“I'm not having that crazy on my squad.”* Or, the supervisor might become overly protective: *“I was going to promote him to the day shift but I don't think he can handle it.”*

The costs of disclosure are not just real for other people. You may also have trouble with disclosure. ***You may worry what others think because you told your secret.*** You wonder what people mean when they ask, *“How are you?”* or say they, *“can't join you for lunch.”* ***Others may be concerned that people who find out will pity you:***

“It was bad enough to have to keep my history a secret. But I told a couple of guys from the local café and they were patronizing. 'Don't stress yourself, dear. Don't work too hard, buddy.' I would have rather had their scorn.”

Some people who disclose may find future relapses to be more difficult. Rather than attending to your needs, you may worry what co-workers, neighbors, or friends are thinking.

Finally, some people might experience family anger about disclosing their mental illness.

“I didn't want everyone to know you had been hospitalized. Now, all the guys at the lumber yard are ribbing me about my ‘psycho’ son.”

Families have their own troubles with stigma, which will be affected by your decision to disclose.

The impact of disclosing in large cities versus in small towns. The size of your community needs to be considered when deciding to disclose your experience. It is fairly easy to be anonymous in a large city. There is truth to the stereotype of neighbors not knowing neighbors or citizens not caring about other's business in huge metropolitan areas. Conversely, information seems to spread quickly through small towns and rural areas. These communities typically have a small network and a long history with one another. Hence, new information about someone tends to have a big impact on the network and to quickly spread to all points. Telling your story in a place like London will have a more limited impact than sharing your experiences in Small Town, Australia. You need to consider how information might spread to others when deciding whether or not to disclose.

This effect is not limited to urban and rural communities. Even if you work in a large city, information will quickly spread through a work place, a church, or any small social group where members are familiar with each other. Just like comparing Small Town to London, information about your mental illness can spread much faster in a small business, like the “*Corner Restaurant,*” than in a large factory or package delivery company. Consider Ruth, who works for a telephone manufacturing plant, which employs 2,000. As long as her quotas are met and her absences are kept within permissible levels, her personal health problems are not of concern to management. Janice, on the other hand, works as a waitress in a small eatery. With no more than 12 employees, Janice's behavior is readily scrutinized, and her co-workers and the boss note her mood shifts and frequent absences.

Weighing the Costs and Benefits of Disclosing

Only you can judge what the various costs and benefits mean for your decision about disclosure. The *Costs and Benefits Worksheet for Disclosing My Mental Illness (Worksheet 1.3)* in the workbook is provided as a way to help you make this decision. But first, we want you to consider other issues associated with weighing the costs and benefits of disclosure.

The impact of costs and benefits are sometimes relatively immediate; at other times, the impact is delayed. For example, in *Table 1.2* on the next page, Alan identified short-term costs (“*If I tell my co-workers that I have been hospitalized for schizophrenia they may not want to meet me for lunch on Wednesday.*”) and short-term benefits (“*Perhaps other people in my office could help me deal with the boss if they knew about my mental illness.*”) related to telling co-workers. He also identified long-term costs (“*If I tell my supervisor I have regular bouts of depression, he may pass over my promotion next year.*”) and benefits (“*If I tell, my boss may be willing to provide me some on-the-job help after inventory is complete.*”). Generally, people tend to be more influenced by short-term costs and benefits because they happen sooner. However, long-term costs and benefits frequently have greater implications for the future. So, make sure you carefully consider those as well. Sometimes people censor themselves as they list costs and benefits. For example:

“I'm worried that people won't have lunch with me if I tell... Nah, that's a dumb idea. I'm going to take that off the list.”

Don't dismiss any cost or benefit no matter how silly it may seem. Put them all on the list so that you can consider all advantages and disadvantages together. Sometimes the items that you want to censor are actually important; you may just be embarrassed about the issue. Know that, if the item is really irrelevant, you'll ignore it in the final analysis. After listing all the costs and benefits, put a star next to one or two that seem to be particularly important. Two benefits stood out for Alan. First, he thinks that he will be

| <i>Table 1.2: Example for Alan</i> | | <i>Setting: at the office.</i> | |
|---|--|--|--|
| Short-Term Benefits | | Short-Term Costs | |
| <ul style="list-style-type: none"> - Others help me deal with our hostile boss. - Don't have to keep it hidden. - May identify co-workers with similar problems. - Make more friends at work. * | | <ul style="list-style-type: none"> - Co-workers won't ask me to lunch. - Worry about others talking about me. - Get left out of work opportunities. | |
| Long-Term Benefits | | Long-Term Costs | |
| <ul style="list-style-type: none"> - Boss provides on-the-job help. - With accommodations get better pay. - Stay on job longer. * | | <ul style="list-style-type: none"> - Supervisor passes over my promotion. - Rumors start about me. * - I quit in embarrassment. - I get fired. | |

able to stay on the job longer. In the past, he has quit good jobs after a few months, worrying that others were going to find out his secret. Second, staying on the job longer will help him get more friends. He also started one cost: Alan was concerned that people would talk about him and spread rumors about his mental illness.

Important items are the ones you spend a lot of time thinking about. You may want to star (*) the items that make you nervous when you think about them (“If I tell my buddies about seeing a psychiatrist, they’ll laugh at me just like they give Harvey a hard time about seeing a foot doctor.”). Or, you may mark items that suggest a lot of hope (“Maybe if I tell people on my softball team, my buddies will understand better why I don’t go to bars after the games; I can’t mix alcohol and meds.”). Some people consider the list of advantages and disadvantages in *Table 1.1* for additional ideas about possible costs and benefits. However, don’t limit yourself to these options. Frequently, you will come up with a cost or benefit that is not in the list, but that is especially relevant to you.

Your decision depends on the setting. Costs and benefits of disclosing your

experience vary by the situation that you are in. The example for Alan was his job at the office. Telling people your history with psychiatric experience is a lot different at work than it is in your neighborhood or with your rugby teammates. You could conceivably decide to tell people at work, but not in your neighborhood. Or, to tell your close friends, but not to tell your son's teacher. Hence, you need to list separately the costs and benefits of disclosing your mental illness, for each setting that is important to you. You can do this by making copies of the *Costs and Benefits Worksheet 1.3* and enter the name of each setting and the person to whom you might disclose on the first line at the top of the worksheet: work (your co-worker), neighborhood (your next-door neighbor), social groups (your good friend), synagogue (your rabbi), or family (your cousin). Then, write down the costs and benefits of disclosing to that people in each setting.

Actually, costs and benefits of disclosure might differ within a setting. A supervisor may react differently to your disclosure than would members of the construction team. Hence, you may have to define the setting even further. Look at the different settings Edwina considered in making her decision about disclosure:

“There's four different groups of people to consider at church. My pastor (1) is a very dynamic woman and clearly a moral leader. She'll respond differently than people in the choir (2), especially the choir master. And I know people in my bible group (3) real well. We've been meeting weekly for the past year. Finally, I don't know what to expect if I stand up and give witness to the congregation (4) during service on Sunday.”

What is your decision? The purpose of *Worksheet 1.3* is to yield a decision about whether to disclose your mental illness. Two decisions are straightforward:

- Yes, I want to let some people know about my experiences with mental illness.
- No, I don't want people to know about my mental illness.

Although the options are clear, there is no easy way to add up the costs and benefits and come up with a decision. Good decisions are more than the sum of the right and left columns in *Worksheet 1.3*. Clearly, some advantages or disadvantages will be more

important and, therefore, should weigh far more heavily in the decision - these are the items you starred in the list.

“Even though I came up with three benefits and nine costs, I can't get past the hope that I'll find other people who have similar problems. So I've decided to come out at work!”

Some people may not be able to make a decision about disclosure after reviewing costs and benefits; you may need to decide to postpone the decision. You may choose to use this additional time to gather more information about disclosure.

What is your goal in disclosing? After weighing the costs and benefits you listed, review what you found to be important in *Worksheet 1.1 (Some Reasons People Decided to Disclose Their Mental Illness)*. These reasons may have changed as you considered more costs and benefits of disclosing. When you come out, what do you want? List your goal in the box—*What is your GOAL in disclosing?*—at the bottom of *Worksheet 1.3*.

If you disclose, what do you expect? People who decide to come out have hopes and desires about the impact of their disclosure. These are among the benefits of coming out listed in *Worksheet 1.3*. One or two of these benefits are especially likely to drive your decision to disclose to someone. List these in the last box—*What Do You Expect Will Happen After Disclosing?*—at the bottom of *Worksheet 1.3*. These are such important questions that we think you should highlight them separately from the overall consideration of costs and benefits. In what positive ways are you expecting people to react? By the way, the answers to these questions will help guide the personal evaluation of how well coming out worked for you, in the next lesson.

Note that this consideration only matters IF you decide to come out. For some people, the decision to disclose is not right for them and, hence, disclosing should not be pursued at this time.

Can someone help you with the decision? Disclosing a mental illness is a difficult decision to make alone. Since there are so many emotionally charged factors to

take into consideration, it is hard for a person to calmly and rationally weigh all of the pluses and minuses. You may want to consider the judgment and advice of others before you plunge into disclosing. Remember, though, that if you decide to seek counsel, you are going to have to disclose your illness to the people from whom you seek advice.

Family members may be good sources of advice. That being said, don't forget that your decision may impact them and their standing in the community as well as yours. They may try to protect you from the potential pain and consequences of disclosure. Some families may not be supportive. Others, however, will understand the benefits of disclosure and will understand your right to disclose; they may encourage you. Your family members may give you great emotional and personal support just when you need it. Counselors are also a good source for advice on your decision to disclose or not. Experienced counselors have advised many people with mental illness, and they have seen the successes and problems of disclosure.

Peers who have mental illness, especially those who have disclosed, may offer positive advice or a warning, depending upon their own experience disclosing a mental illness. Those who are advocates and have succeeded in disclosing will likely advise you to tell. Those who have suffered negative consequences as a result of disclosure, such as loss of a job or failure of a broken marriage, might tell you to keep your lips sealed.

Disclosure is a journey. Disclosure is not a one-time decision. Depending on life circumstances, your interests in disclosing are going to change over time. You may decide today not to disclose, but change your mind in a month.

“You know, after I heard that mental health advocate talk about her experiences disclosing mental illness, I decided I wanted to let other people know.”

Conversely, you may decide to disclose today, but pull back later.

“I let my supervisor and immediate co-workers know at my old office. But, I'm starting a new job next week. I don't know whether I can trust them.”

Disclosing your experiences with mental illness is a ***journey***, just like any important life

decision. You must constantly decide how much energy to spend on your friends, family, work, and faith-based community. Sometimes, you are invested in work and ignore recreation. Other times, you focus on family and hobbies. You must do the same with disclosure. Hence, you may find yourself filling out the *Costs and Benefits Worksheet* several times in your life and coming up with different conclusions each time.

LESSON 2

There are Different Ways to Disclose

LESSON OVERVIEW

It might seem obvious, but there are different ways to come out.

1. We describe five ways here, and then guide you through considering the costs and benefits associated with each strategy.
2. We guide you through the process of selecting a person to whom you are considering disclosing.
3. We then consider how others might respond to your disclosure.

1. Different Ways to Disclose

LEARNING OBJECTIVES

- People might disclose their experience with mental illness and corresponding treatments in different ways.
- Understand the costs and benefits of disclosing in the five different ways.
- Remember, you will perceive different costs and benefits associated with each of the five ways. The costs and benefits you identify may vary by setting.

IN THE WORKBOOK:

Worksheet 2.1, “Costs and Benefits of the Five Ways to Disclose” provides a way to lay out the costs and benefits of the five ways of disclosure for Allison Miller.

Worksheet 2.2, “Costs and Benefits of the Five Ways to Disclose” provides a way to lay out the costs and benefits of the five ways of disclosure at your place of work.

Depending on your decision, there are a variety of ways in which you might disclose, or not disclose, your experience with mental illness; see *Table 2.1* for a short list. You will likely select from the approaches listed in *Table 2.1*, depending on the situation. For example, some people may choose to selectively disclose in certain situations (e.g., tell my church group and immediate supervisor at work), keep it a secret in other situations (e.g., not tell any of my co-workers), and avoid a third set of situations altogether (e.g., not go to bars after work—some of those people would make fun of me if they found out).

| Table 2.1: Five Ways to Disclose or Not Disclose | |
|--|---|
| 1. SOCIAL AVOIDANCE: Not telling anyone about your mental illness and avoiding situations where people may find out about it. This could mean working or living in a sheltered or supported work environment, where you only associate with other people with mental illnesses. | |
| Benefit: You don't encounter people who will unfairly harm you. | Cost: You lose the opportunity to meet new people who may possibly be supportive. |
| 2. SECRECY: Participating in work and community situations, but keeping your mental illness a secret. | |
| Benefit: Like social avoidance, you withhold information about your mental illness from others. But, you don't avoid important settings like work or the community in the process. | Cost: Some people feel guilty about keeping secrets. You may also receive less support from others because they are unaware of your mental illness. |
| 3. SELECTIVE DISCLOSURE: Disclosing your mental illness to selected individuals, like co-workers or neighbors, but not to everyone. | |
| Benefit: You find a small group of people who will understand your experiences and provide support. | Cost: You may disclose to some people who then hurt you with the information. You may have difficulty keeping track of who knows and who doesn't. |
| 4. INDISCRIMINANT DISCLOSURE: Making the decision to no longer conceal your mental illness; this does not mean, however, that you are telling everyone your story. | |
| Benefit: You don't worry who knows about your problems. And you are likely to find people who will be supportive. | Cost: You may tell people who then hurt you with the information. |
| 5. BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people about your experience with mental illness. | |
| Benefit: You don't have to worry who knows about your history of mental illness. You are promoting a personal sense of empowerment in yourself. You are striking a blow against stigma. | Cost: You are going to encounter people who may try to hurt you with this information. You are also going to meet people who disapprove of your political statement. |

1. Social Avoidance

Ironically, the first way to handle disclosure may be to not tell anyone. This

means avoiding situations where people may find out about one's mental illness. People who are victimized by stigma may choose not to socialize with, live near, or work alongside people without disabilities. Instead, they only associate with other people who have mental illness. This may include people with mental illness living in a therapeutic community, working in a sheltered or supported work environment, or interacting with friends in a social club developed for mental illness. In this way, the person can avoid the “*normal*” population that may disapprove of their disabilities or actively work to keep them out.

In some ways, this approach is similar to the old notion of *asylum*. A few people have such severe psychiatric disabilities that they need a safe and pleasant place to live and work, a place where they can escape the pressures and disapproval of society. What was known as the “*moral view of psychiatric care*” was originally envisioned by state hospitals for this purpose. This included nice homes, rural settings, and supportive caretakers who help people with extreme disabilities to escape the stresses of society, as well as to escape those citizens in society who will stigmatize them. Unfortunately, very few hospitals ever achieved this goal, in part because most state and private facilities are dominated by patients with acute symptoms, some of whom might potentially be dangerous to themselves or others. The predominant concern for protection of patients from violence frequently overrides many of the “*pleasant*” aspects of hospital living.

This kind of asylum could be more appropriately accomplished in community-based programs. People with profound disabilities, who choose not to address their community's prejudice against mental illness, could live in pleasant compounds and work in sheltered settings away from the rest of their neighbors. People could learn to cope with their symptoms or achieve their interpersonal goals in a setting relatively free of disapproving neighbors or co-workers.

Unfortunately, there are major negatives to social avoidance. People who choose to avoid the “*normal*” world lose out on all the benefits that it brings, such as free access to a broader set of opportunities and citizens who support your experience with mental

illness. Moreover, in some ways, social avoidance promotes stigma and discrimination. It endorses the idea that people with mental illness need to be locked away from the rest of the world. People who choose to avoid social situations may be putting off a challenge that they must eventually face. Social avoidance may be a useful strategy during times when symptoms are intense and the person needs a respite from the demands of society. But, avoiding the normal world altogether will likely prevent most people from achieving the breadth of their life goals.

Recognizing people to avoid. A more moderate approach to social avoidance might be to steer clear of certain groups of people—those who stigmatize—rather than steering clear of your community as a whole. This requires you to be alert for people who would be intolerant of people with psychiatric disability. *Table 2.2* (on the next page) lists several themes that bigots are likely to spout. You may wish to avoid social interactions with these kinds of people. Avoid the **bigot** who looks at all people, especially minorities and disadvantaged groups, from a stereotyped, cruel and disrespectful perspective. For example:

“All blacks are criminals, all Jews are money-hungry, the Irish are drunks, and gays deserve AIDS.”

Stay away from these people. The “*mentally ill*” are derided by bigots who have contempt for everyone outside of their own narrow spectrum of acceptable people or races.

People with mental illness are sometimes heckled by citizens who we might refer to as **thoughtless speakers**, another narrow minded and disparaging group of bigots. These people may pepper their language with incorrect and insensitive words, such as “*wackos*,” “*crazies*,” “*psychos*,” and “*maniacs*.” Worse, thoughtless speakers perpetuate myths about mental illness with phrases like, “*Wackos oughta be locked up and the key thrown away*,” or “*Look, that guy needs his head shrunk!*” Unfortunately, many talk radio shows are overrun with these kinds of thinkers.

Table 2.2: People to Avoid

General Bigots: People Who Disrespect Everyone

“Those black people; they’re all lazy.”
“Jews will take your money.”
“Irish are all drunks.”
“Why do people in wheel chairs get all the breaks?”
“Homosexuals deserve punishment with AIDS.”

Thoughtless Speakers: People Who Use Disrespectful Language

Frightening Language:

“What do you expect from wackos?”
“Crazies can’t take care of themselves.”
“Murderers are all maniacs.”

Inappropriate humor:

“Split personalities have two people to talk to.”
“I’m a wild and crazy guy.”

Fear Mongers: People Who Say Social Problems Are Caused by Mental Illness

“Many famous people are killed by psychos who should be locked up.”
“The homeless are all displaced by mental patients.”
“Pedophiles are all mentally ill.”
“Schools are dangerous because of all the crazies.”

People Who Oppose Fair Chances

“I don’t want a halfway house in my back yard.”
“I’m against laws that protect the rights of mental patients.”
“I’d never hire a mental patient.”

There are also people who we refer to as **fear mongers**. Their negative attitudes toward mental illness emerge when they alarm friends and neighbors about the supposed dangers of people with mental illness. They might think that the streets are full of psychos who, since they're not locked up, will try to assassinate presidents or other public figures. According to their limited perspective, the homeless population is completely mentally ill, and child molesters are invariably psychotic.

And, finally, there is a population of people to avoid who do not want to give people with mental illness a **fair chance**. “*I don't want a group home on my block,*” they might say. They may write their legislator and tell her not to pass laws that benefit people with mental illness. They may tell their boss that they don't want to work next to

co-workers with mental illness. Since they appeal to everyone's prejudices, people who oppose fair chances can inflict a lot of damage.

2. *Secrecy*

There is no need to avoid work or community situations in order to keep your experiences with mental illness private. Many people choose to enter these worlds, but to not share their experiences with others. Jose was a popular employee at a large food store for six years and never told co-workers he had been hospitalized for schizophrenia. Cynthia car pooled her kids with neighbors for 18 months and never let them know about her depression. Fariq went to mosque weekly and never let others know his history with manic depression. It wasn't too hard to hide their psychiatric history.

But can't they tell I'm mentally ill? Sometimes, it seems like everyone can tell that you are struggling with symptoms. The reality, however, is that your experience with mental illness can be hidden. Keeping mental illness a secret is much easier than hiding one's gender, ethnic background, or physical disability.

- ***Many of your experiences with psychosis and depression are private.*** Most people do not know whether or not you are hearing voices. They don't know your beliefs. They cannot determine whether you're sad or worried... unless you tell them!
- ***Many of the signs of mental illness are overlooked.*** Co-workers may think you're depression is temporary blues. Neighbors may think your confusion is being sleepy-headed. There is a central tendency in the human condition that protects your privacy; namely, most everyone is tuned into themselves and misses much of what is going on around them.
- ***Many of the signs are misunderstood.*** The public misunderstands mental illness and frequently labels eccentric or unusual conduct as wrong. People who are dressed poorly are homeless and mentally ill. Individuals who punk their hair or pierce their ears are crazy. If you dress within

customary bounds, you'll be overlooked.

How do I keep it private? There are two parts to keeping your experiences with mental illness a secret. The first part seems easy: *don't tell anyone*. Don't share your history of hospitalizations, doctors, medications, and symptoms.

"I'd been playing in this poker group for seven years. We'd talk about work, wives, our kids, hobbies, our college years. But whenever we touched on the time after college—those few years I was in and out of the hospital before my mania was under control—I clammed up. Or better yet, I asked my buddy a question about his days in the Army. I could always count on Sol taking off on a topic."

For some people, not talking leads to big gaps in their life story. For example, work resumes have blank years when you were in the hospital; or photo albums do not include years of pictures when you were coping with your illness.

There are costs to not talking about your experiences. You may find it difficult to always be vigilant about what you say about yourself. This kind of vigilance may lead to resentment. *"I've done nothing wrong. How come I have to be so careful all the time?"* Nevertheless, this simple act of keeping parts of your experience to yourself may greatly open up work settings and communities. *"I could go to the job and not worry about people thinking I was crazy."*

The first strategy for keeping your experiences secret is an act of omission; the second is an act of commission. ***You may need to fill in some gaps in your past and current experience.*** For example, many people wrestle with holes in their work history. Consider Tamiko's experience; she had two years between discharge from the Navy (she was in computer operations) and her 26th birthday, when she was in and out of hospitals for schizoaffective disorder. Instead of leaving these years blank on her resume, she wrote, *"Advanced training in computers."* When asked during job interviews what this training meant, she truthfully discussed the adult education courses she completed in systems management. She did not, however, talk about how these courses were

interspersed with psychiatric hospitalizations.

You also must decide how to discuss current experiences related to your mental illness. Plan your responses to the following types of questions:

- “*Why do you leave early to see a doctor every month? What are those medicines you take at lunch for?*”
- “*How come you never drink alcohol at company parties?*”

Without answers, these current gaps may stick out for some co-workers or neighbors.

Table 2.3 provides examples of common questions and possible answers that you might want to use in situations like this.

| Table 2.3: Sample Answers to Questions About Your Mental Illness |
|--|
| SITUATION: You are heading out the door to your monthly psychiatrist’s appointment. Question: <i>Where are you going?</i> Response: <i>I have a doctor’s appointment.</i> |
| SITUATION: You are on your way to your weekly therapist’s appointment. Question: <i>Where are you going?</i> Response: <i>I have a weekly appointment for my hair.</i> |
| SITUATION: You are taking some pills at lunch. Question: <i>What are those for?</i> Response: <i>A long-standing health problem.</i> |
| SITUATION: You are one of the few people not drinking at a party. Question: <i>C’mon have a drink.</i> Response: <i>No, I’m the designated driver.</i> |
| SITUATION: Your depression has returned and you are a little tearful at work. Question: <i>Why are you crying?</i> Response: <i>I had a loss in the family.</i> |
| SITUATION: You are a little more disoriented and having trouble with your job. Question: <i>What’s wrong?</i> Response: <i>I’m a little dizzy from not sleeping well last night.</i> |

Friends and family members who are familiar with your experiences may need to be included in the secret. At a minimum, you cannot permit your parents to tell co-workers or neighbors your psychiatric history if you are trying to maintain your privacy. In

addition, you may want them to join you in your subterfuge.

“Dad, I told everyone at the office that I take you to the doctor once a month, rather than telling them that I go to my psychiatrist. I need you to back me up when Pedro from work comes to the party tonight.”

For some, these acts of commission are a disadvantage of secrecy: *“Why do I have to lie about my mental illness?”* It can be even harder for some when they ask family members or friends to participate in the secret. As a result, many people choose to forego this aspect of secrecy. Others, however, see filling in the gaps less as a lie and more as a process of telling one's life experiences in a manner that is palatable to others. Recall Tamiko's work resume. She did not lie about her time in the psychiatric hospital. Rather, she focused on something positive from that time: the coursework that she completed related to computers. In other words, it's a matter of refocusing your story on information that will not lead to stigmatizing responses from others.

3. *Selective disclosure*

When you keep your experiences with mental illness a secret, you are not able to avail the support and resources of others. To rectify this problem, some people take a chance and disclose their mental illness to selected co-workers or neighbors. These people are taking a risk, however, as those who find out may shun them.

- *“I don't want to work next to a mental patient.”*
- *“I don't want someone who had to be locked up in my bible study group.”*
- *“I'm pulling my kid out of the car pool. You can't drive safely when you take meds.”*

With the risk comes opportunity. People who disclose may find people who are supportive. *“Now that I told Maria about my depression, I can talk to her about the side effects to my medications.”* Moreover, you won't have to worry about keeping a secret from those to whom you've disclosed. *“Once Annette knew, it was such a freeing feeling to open up to her.”*

4. *Indiscriminant Disclosure*

Selective disclosure means that there is a group of people with whom you are sharing your mental illness experiences, AND a group from whom you are keeping the information secret. More than likely, the group who is not in on the secret is much larger than those with whom you have shared the information. This means there are still a large number of people who you have to be wary of, individuals who you don't want to find out about your experiences. Moreover, this means that there is still a secret that could represent a source of shame.

“Even though I told my boss, guys on my work team, and my best friend, most people don't know. Every time I meet someone, it seems like there is this big secret between us. I have to be careful about what I say.”

People who choose indiscriminant disclosure abandon this secrecy. They choose to disregard any of the potential negative consequences of people finding out about their mental illness.

“I got tired of wondering who knew and who didn't. I finally got to the point where I didn't care. I stopped trying to keep my past a secret. I stopped concealing my meds and doctors appointments.”

The decision to no longer conceal your mental illness is not the same as telling everyone your story. Not keeping a secret means that you are no longer trying to hide it. The person is relieved of the burden posed by the secret.

If you choose indiscriminant disclosure, you must still identify people to seek out and with whom to actively share your experience. Not everyone will respond to your message well. Hence, the three reasons why you might disclose (see *Table 2.4*) are still relevant for selecting people to tell. The difference is that you no longer worry about hiding your history from the world.

Reframe your experience. Most people have to change the way they view their mental illness if they are to opt for indiscriminant disclosure. This may mean adjusting a lifelong attitude about the place of mental illness in society. In the past, you probably

viewed mental illness as something that is disparaged by others and, therefore, should be kept secret. The desire to keep mental illness a secret needs to change radically for you to partake in indiscriminant disclosure.

This redefinition may require accepting mental illness as part of *who you are*. Mental illness is not a bad part of you that needs to be rejected. It is one of many qualities that describe you: right-handed, brown haired, skilled in math, fair-skinned, blue eyed, tall, poor at sports, and schizophrenic. We do not mean to make light of your mental illness; it clearly affects your life and your life goals. But, it is still only a small part of what defines who you are and what your future portends. If mental illness were all that mattered, then all people with schizophrenia would be alike (Not true! People with schizophrenia are as diverse a group as Africans, artists, and Anglicans), and your other qualities would have no relevance (which is wrong; your ability to cope greatly affects the course of your disability).

You have successfully changed your attitude about disclosure when talking about mental illness no longer evokes a sense of hesitancy or shame. It should lead to the same kind of matter-of-fact feelings as a discussion of your childhood home, your physical health, or your hair color. It's not bad or good; it just IS. People who have accomplished this kind of reframe say things like:

- *"I'm more than a bag of symptoms."*
- *"I don't care what others think."*
- *"Take me as I am."*

Can you handle disclosure? Disclosure, specifically the indiscriminant type, requires a hardy personality. Many more people are going to find out and react negatively to your mental illness. Hence, you need to be able to cope with the disapproval that results from bigoted reactions. One way to tell whether or not you are up to this is to role-play bigoted situations, like the one in *Worksheet 2.4*.

5. Broadcast Your Experience

Indiscriminant disclosure means no longer trying to hide your mental illness. On

the other hand, you are not likely to go out of your way to inform people about it. Broadcasting your experience means educating people about mental illness. It's similar to coming out of the closet in the gay community; the goal is to actively let people know your experience with mental illness. This kind of disclosure is much more than dropping your guard and throwing away any notion of secrecy. Your goal is to seek out many people with whom to share your past history and current experiences with mental illness.

Broadcasting your experience has the same benefits as indiscriminant disclosure. You no longer need to worry about keeping a secret. You will also find people who may provide understanding, support, and assistance to you because of your message. However, people who choose to broadcast their experience seem to derive an additional benefit. Namely, it seems to foster their sense of power over the experience of mental illness and stigma. No longer must they cower because of feelings of inferiority.

“I'm equal to everyone else. I have nothing to hide.”

This kind of consciousness-raising may help you to understand that your problems with mental illness are not solely a function of biological limitations. Society's reactions are equally to blame. Shouting this out relieves you of community oppression. In fact, many people who choose to broadcast their experience wish to surpass the limited goal of talking about their mental illness. They also express their dissatisfaction with the way they have been treated because they have a mental illness.

“I'm angry; every time I question my meds, my doctor thinks I'm acting out and puts me back in the hospital. I'm able to be a partner in my treatment.”

This discontent is also aimed at society: anger at being viewed differently, losing opportunities, and having to keep secrets.

“I've done nothing wrong. I'm no criminal. Don't steal my chances from me because I have been hospitalized.”

Be prepared for anger and distancing. Broadcasting your experiences will yield hostile responses, just like indiscriminate disclosure, and more. Citizens who hear

someone's story about mental illness frequently battle the message and the messenger. Like the person choosing indiscriminate disclosure, broadcasters get hostile reactions to their messages.

“Why do I have to live next to a crazy guy like you? You're dangerous to my family. I'll be keeping an eye on you.”

Broadcasters also get angry responses to the message.

“I don't want to hear this stuff. I'm not a bigot. I give money to charities to keep the hospitals open. Why do you have to go stirring up trouble? Just live in your community quietly and don't go telling me all your troubles.”

Civil rights leaders have experienced similar reactions for decades. Challenging messages from racial groups about economic equality and political injustice upset the status quo. People in power don't want to hear this. In a similar manner, talking about your mental illness and your displeasure with society's reactions is disquieting. Citizens may rebel against the messenger with angry denials.

“You're making things out to be a lot worse than they are. Life in state hospitals isn't that bad.”

Once again, you need to make sure you are up for this kind of reaction. You may wish to complete the role-play exercise in *Worksheet 2.4* to find out. Determine whether your emotional response is excessive.

2. To Whom Might You Disclose?

LEARNING OBJECTIVES

- Some people are better to disclose to than others.
- Learn how to identify a good person to whom you might disclose.
- Understand the procedure for “testing out” the person before disclosing.

In the previous section, we showed that people might disclose their experience with mental illness and corresponding treatments in different ways. If you are considering selective disclosure, this section helps you to identify a possible person for disclosure. Two things are considered:

1. How might you identify a good person to whom you could disclose?
2. We propose a way in which you might “test out” the person before fully disclosing.

IN THE WORKBOOK:

Worksheet 2.3, “Testing a Person For Disclosure” provides a way to test whether a person might be a good person to disclose to.

Who is a good person to disclose to? Selective disclosure does not mean sharing your experiences with everyone. You need to identify people who are likely to respond positively to your message. There are several reasons why you might pick a specific person for disclose to. *Table 2.4* on the next page groups these into three types of relationships. The **functional** relationship represents an association with some person in which your mental illness serves as a conduit for establishing that relationship. Your relationship with a psychiatrist is an example of this type of relationship. He or she sees you in order to diagnose and treat your mental illness. Thus, addressing the mental illness is the grounds for developing the relationship. The same type of relationship might be true with your family doctor, a minister, a teacher, or even your supervisor at work.

You might consider disclosing to a person with whom you have developed a **supportive** relationship. You can be fairly certain that the friendly and kind person will support you when they discover that you live with a mental illness. You may identify supportive people by their pleasantness, concern for others, and open-mindedness. When someone takes an interest in you and seems to want to know more about you other than

your name and hometown, they may be a good candidate for a supportive relationship.

Then there are others who **empathize** with you. Often they've lived closely to people with similar experiences, or have a mental illness themselves.

“I know what the humiliation is,” they might say. “I’ve had my depressions, too.”

Look for people who seem to be willing to listen, to understand, and who have a look of recognition when they hear talk about mental illness.

| |
|---|
| <p>1. FUNCTIONAL RELATIONSHIP</p> <p>The person provides some function for you where knowing your experiences with mental illness might help accomplish the function.</p> <p>Sample functional relationships include:</p> <ul style="list-style-type: none">▪ psychiatrist▪ doctor▪ minister▪ car pool member▪ supervisor▪ co-workers▪ teacher▪ team member |
| <p>2. SUPPORTIVE RELATIONSHIP</p> <p>The person seems to be friendly and will provide support and approval to you when they find out about your experience.</p> <p>Characteristics of this kind of person include:</p> <ul style="list-style-type: none">▪ pleasantness▪ concern for others▪ trustworthiness▪ open-mindedness▪ loyalty▪ helpfulness |
| <p>3. EMPATHIC RELATIONSHIP</p> <p>Some people to whom you might disclose have had similar, though perhaps less painful, experiences: “I know what it’s like to be depressed.” These kinds of people can provide an empathic relationship.</p> <p>Their characteristics include:</p> <ul style="list-style-type: none">▪ willingness to listen▪ kindness▪ an understanding nature▪ honesty |

This demonstrates one facet of consumer empowerment that is gaining increasing acceptance in today's mental health world: self-help or mutual support groups. Perhaps participating in a group like this will be helpful for the person deciding to come out. Mental illness can be a very lonely disease. It behooves many people with mental illness to seek out and develop friendships with other people who have similar disorders. There are many organizations where this can be done; examples in the United States include the National Alliance for Mental Illness, the Depression and Bipolar Support Alliance,

Emotions Anonymous, GROW, and others.

Testing a Person for Disclosure. There is a nice and unobtrusive way to test whether or not a person might be a good person for disclosure. Namely, write down an example from recent news stories, magazine articles, TV shows, or movies related to mental illness; and then share it with a friend. Consider this example:

“Hey Mary. Did you see E.R. on Channel 5 last week? Sally Fields was in it. She portrayed this woman with bipolar disorder trying to help her adult son struggle with the first signs of mania. I was really impressed by the show; it seemed to do a nice job of describing the symptoms of their psychiatric illness; you know, in a fair way. What do you think? Do you know anyone like this? What do you think about people sharing their experiences with mental illness?”

Then, stop and listen to Mary’s response. How might you rate her answers if she said,

“Yeah... I saw that. I have a friend with bipolar disorder and shows like that one from ER really help me better understand what she must do to be successful.”

Some might rate her responses as high on being sensitive and kind and, thus, a person to whom you might disclose. How might your ratings be different if Mary said,

“You know. I am sick and tired of these kinds of cry baby shows where they make mental illness look so noble.”

Some might view this reaction as less sensitive and, hence, Mary might not be a good candidate for disclosure.

What will you disclose? A decision to disclose to someone does not mean you must disclose everything. Choosing to disclose does not mean giving up all your privacy. Rather, you are sharing information to break the secret, get some help, and enjoy some interpersonal closeness. Hence, just as you decided to whom you might disclose, so you must decide what you will and will not share. You need to determine which experiences

in your **past** you wish to discuss, and what **current** experiences you want to keep private. The purpose of disclosing your past is to give people some knowledge of your problems with mental illness. The goal is not confession. Don't feel compelled to share things that you are embarrassed about. Everyone has skeletons in their closet; you do not have to air these skeletons in order to get others to understand that you have recovered from a serious mental illness. Specific issues you may wish to share include: your diagnosis, symptoms, history of hospitalizations, and medications.

“I have a serious mental illness called schizophrenia. As a result, I have heard voices, had some strange beliefs, and been agitated. I was hospitalized four times in two years because of this. My psychiatrist and I have tried several different medications. Right now, my symptoms are managed well by a drug called Zyprexa.”

Remember! Don't share past experiences that make you feel embarrassed or ashamed.

The purpose of sharing current experiences with mental illness is twofold. First, you may want to impress upon the person that the serious mental illness of long ago has much less impact on you now; and you want to let the person know that you can control small problems that occur in your life.

“No, I'm not still mentally ill in the sense that I need to be hospitalized. Sometimes I get a little depressed. But I can handle it.”

The message here is that mental illness may not go away entirely. However, you are still able to work, raise a family, and be a responsible member of society.

The second goal of sharing current experiences is to alert the person that you may have troubles in the future and need some assistance. Some people may respond with empathy: *“I know what it's like to have problems with depression and I'm here for you.”* Others may offer support: *“What can I do for you when you're having a panic attack?”*

Disclosing is a process, not a one-time act. Hence, as you get to know the person with whom you shared information, you may decide to provide more detail.

“As I got to know Miguel, I told him more and more about my

hospitalization. He had never been hospitalized but he still knew what I was talking about. He was in the Army and felt pushed around, told what to do there.”

Conversely, you may decide to withdraw from people who disappoint you after you disclose to them. Deciding to share information doesn't prevent you from deciding to stop later.

“I made a mistake with Rayette. I thought she was open-minded. But it didn't seem like she could handle it. So I decided to stop sitting with her at lunch and sharing my experiences with mental illness. I was cordial but became a bit more distant.”

Why I wanted you to know? It may not be enough to tell your private history. You also need to tell people what you want for letting them in on your secret, “*Why do I want you to know?*” Knowing the answer to this question will enable you to judge whether or not telling your story was successful by comparing the person's response to your hopes.

“I was scared about letting people know at work. I wanted Marie and Francie in the steno pool to understand why I had to leave work early on Wednesdays for my therapist's appointment. More importantly, I just didn't want to have to keep my illness a secret to them any longer. Their reaction was a pleasant surprise. Francie has sought me out since then to discuss my trips to Doctor Harrison's office. And Marie told me that sometimes she suffers from depression. I feel less alone now.”

This means you need to carefully consider your reasons for telling others about your mental illness. You may have touched on these reasons when you listed the benefits of disclosure (*Worksheet 1.3*). These reasons need to be translated into requests. Other common reasons and requests for telling peers are summarized in *Table 2.5* on the next page.

Many people with mental illness are moved to disclose their condition as a way to

disperse the secret. They don't like to keep the secret of having a mental illness to themselves. They feel relieved to have the secret off of their shoulders. Others disclose with the hope that others will better understand them as a result. They want friends to comprehend their condition and, in doing so, understand them. A person with mental illness hopes that he or she might tap into a vein of empathy, where someone else might disclose to them that they too have a mental illness.

| <i>Table 2.5: Some Reasons People Disclose</i> |
|---|
| <p>To tell the secret “I just wanted someone else to know that I get hospitalized for manic-depression.” “I don’t want to have to feel like I’m sneaking around with a secret.” “I felt bad for having to keep a secret. I don’t want to feel bad anymore.”</p> |
| <p>Understanding “I’m hoping others will understand not only my mental illness, but the difficulty trying to keep it a secret.” “I’d like someone to say to me, ‘I’ve had problems too.’”</p> |
| <p>Support and Assistance “Sometimes I get sad. I’m looking for friends who can be supportive.” “Can I get a ride to the doctor.” “Sometimes, I just need someone to talk to.”</p> |
| <p>Reasonable Accommodation “It’s a law. When I ask for sensible help at work, you need to give it to me.” “Can I come in a half hour late this week? I’m feeling a little down. I’ll make it up next week.”</p> |

A person with mental illness might hope for support and assistance when disclosing a mental illness. This might be in the form of direct assistance, and as simple as asking for a ride to the community center. It might be emotional assistance, such as gaining someone to talk with about his or her illness. Finally, there can be legal reasons for disclosing a mental illness. The Americans with Disabilities Act, for example, says that businesses must give reasonable accommodation to people with disabilities if they request it. Before reasonable accommodation can be requested, an employee with a debilitating mental illness needs to disclose the condition to their employer.

3. How Might Others Respond to Your Disclosure

LEARNING OBJECTIVES

- Disclosure will impact the people around you.
- People may respond in different ways to your disclosure.
- Consider the different ways that people will react to your disclosure.

IN THE WORKBOOK:

Worksheet 2.4, “Are You Able to Cope With Disclosure?” provides a format for role-playing people’s negative reactions to your disclosure as well a place to rate your feelings in response to these statements.

Be certain of one thing: disclosure will impact the people around you. Whether you choose selective disclosure (where information is cautiously shared with a carefully chosen person) or broadcasting (where you announce your experiences to as many people as possible), those who discover the facts are likely to react strongly. You need to consider the varied ways in which people may respond, and plan your reactions accordingly. *Table 2.6* on the next page lists a variety of reactions to disclosure, which are sorted into groups by two factors.

- Factor 1. Emotional Response: Peoples’ emotional responses to you may be positive or negative.
- Factor 2. Behavioral Reaction: People may decide to seek you out to express their emotion, or they may pull away and try to avoid you.

Positive Experiences

Citizens hearing your disclosure can respond positively in a variety of ways. Three of these involve reaching out to you. They may express **understanding** of or empathize with your experiences.

“Dealing with mental illness must be very tough. I’m impressed with how

well you handle it.”

Along with understanding, they may provide **interpersonal support**. Support may include explicit commitments to be available to you if you need them. Interpersonal support might also include **assistance**.

“Let me know if I can provide you a lift to the drug store or if you'd like to come and hang out some time when you're felling blue.”

| Table 2.6: How People Might Respond to Your Disclosure | |
|--|--|
|  EMOTIONAL RESPONSE  | |
| Positive | Negative |
| <p>Understanding <i>“It must be hard living with your illness and the secret.”</i></p> <p>Interpersonal Support <i>“I’m here for you if you need someone to talk to.”</i></p> <p>Assistance <i>“Can I give you a lift to the doctor?”</i></p> | <p>Disrespect <i>“I don’t want some dangerous loony like you around.”</i></p> <p>Denial <i>“I’m not giving you any special breaks because of your mental illness.”</i></p> <p>Retribution <i>“I’ll get you fired. I don’t have to work next to a crazy guy like you.”</i></p> <p>Fear/Avoidance <i>“You’re dangerous. I’m staying away.”</i></p> <p>Gossip <i>“Hey, did you hear about Joe? He was committed to the insane asylum.”</i></p> <p>Blame <i>“I have the same kind of problems as Gayle but I don’t go around and blab about it.”</i></p> |

Oddly, another positive experience might take the form of someone **pulling away** from you. Someone with similar problems with mental illness and stigma might let you know that they understand. However, they may also let you know that

they do not currently share your resolve to disclose and, hence, wish to keep their experiences a secret. This might mean occasionally backing away on interactions so that they are not discovered.

“I really am impressed with the guts you show for letting other guys in the shop know about your psych problems. I got them, too. But I’m worried how people will respond. So, I might back away if you’re talking about a doctor’s visit at the lunch table. I don’t want anyone turning to me and asking questions.”

Negative Experiences

Unfortunately, hearing your story of self-disclosure will lead to negative responses too. Some of these responses may occur when citizens seek you out in order to share their reactions. This includes **disrespect** (“*People like you are all loony.*”), **denial** (“*You’re just looking for sympathy. You don’t have any problems.*”), and **retribution** (“*I’ll make sure the other guys in the poker club hear about this. You’re out pal.*”). Negative experiences also occur as a result of pulling away. People may **fear** you (“*You’re dangerous, you have a mental illness.*”) and **avoid** you as a result. Even though they avoid you, you may become the butt of **gossip** (“*Did you hear about Sophie? She has to see a psychiatrist!*”). People may **blame** you for your decision to disclose (“*Why did you have to stir everyone up with talk about your mental illness?*”).

Like all other points we have made about disclosure in this manual, coming out has its costs and its benefits. Only you can decide whether disclosing to others is worth pursuing.

LESSON 3

Telling Your Story

LESSON OVERVIEW

As a result of Lessons 1 and 2, you might have decided that you want to come out. Hence, this last lesson has several goals.

1. Learn a way to tell your story in a personally meaningful way.
2. Identify peers who might help you with the coming out process.
3. Review how telling your story felt.
4. Put together all you've learned in order to move forward.

1. How to Tell Your Story

LEARNING OBJECTIVES

- Read through one example of how to tell a story of one's experience with mental illness.
- Use the provided guide to construct your story of experience with mental illness.
- Understand the values and issues related to public speaking.

IN THE WORKBOOK:

Worksheet 3.1, "A Guide to Setting Up a Story About Your Experiences With Mental Illness" provides a template for constructing your story about your experiences with mental illness.

Worksheet 3.2, "Quality of Experience" provides an opportunity to evaluate the quality of your experience telling your story about your experiences with mental illness.

Many people who have come out decide to tell their story by publicly speaking to groups about their experiences. This active decision helps a person to promote a sense of his or her own personal empowerment. Furthermore, speaking publicly helps to tear down the public stigma that harms people with the label. The goal of this lesson as well as the next lesson is to consider strategies that make the coming out experience as effective as possible.

Telling your story to a group works best when you are clear on that group's agenda. You do not want to be added to a program as an afterthought. In a typical presentation of this kind, you might be given an hour's time. Thirty minutes could be used to present your story, followed by 30 minutes for questions and answers as well as general discussion with the audience.

As an example, we include a story developed and presented by Kyle Uphoff-Wasowski in the workbook (see *Table 3.1* on the next page). Kyle has struggled with bipolar disorder for more than fifteen years. She is a wife and mother of two children who lives in the Western suburbs of Chicago.

Elements of a good story. Kyle's story illustrates some of the essential elements of stigma-busting presentations that are likely to change public attitudes. First, *your story needs to be personal*. It needs to reflect your experiences and impressions. This is accomplished by using first person words like “*me*”, “*I*”, and “*my*”. Don't talk about your experience in the third person or steep it in formal language, for example: “*The experiences of people like yours truly, the speaker, are comparable to those exigencies unfavorably put upon all alienated out-groups.*”

Bring it home by **telling good stories illustrated with concrete experiences**. Note how Kyle did this: she illustrates her story with specific people, places, and times. People learn much better by explicit example (“*Sometimes I would get so depressed that I would lie in my bed and cry for three days or more.*”), as opposed to heady abstraction (“*Depression is like a dark cloth causing utter sadness.*”). Listeners can clearly imagine being in bed for 72 hours, whereas the dark cloth metaphor is vague and more difficult

to make sense of.

Table 3.1: Kyle Uphoff-Wasowski's Story

Hi. My name is Kyle Uphoff-Wasowski and I'm here to tell you about a disease called bipolar disorder or manic-depression.

The disorder I have, when it's untreated, can cause severe mood swings. The actual disorder occurs in the brain and neuro-pathways. Illnesses like depression, manic-depression, and schizophrenia are referred to as neurobiological brain disorders.

I was diagnosed with manic-depression seven years ago now – shortly after the birth of my first child. I had one severe depression that was so devastating I began thinking about ending my life. This is not a depression that most people think of as depression. There should be a different word for what those of us with a mental illness experience. It is like a paralysis of the whole brain – nothing like what I used to call depression! I honestly felt physically disabled – as though I'd had a stroke or something. Just getting out of bed and brushing my teeth was an unbelievable challenge. There was no joy in anything! – even my newborn son who I loved more than life itself, and who through no fault of his own, was a constant reminder to me of how useless I was.

Before my illness struck I lived a life much like anyone else, I guess. I am one of five children in my family. We have loving and supportive parents and come from an upper middle class background. I was always active in school with sports and friends and was quite popular in high school. I was cheerleader and a gymnast and hung out in the “popular crowd.” I don't tell you any of this to impress you, but to impress upon you that my life was not abnormal from the get-go!

My own stereotypes of mental illness made it impossible for me to accept the diagnosis at first. I didn't fit the stereotypes, so how could I have a mental illness? I was not a loner as a child. I had loving supportive parents and had not been sexually abused or traumatized as a child- nothing “twisted” happened to me at all. Therefore the doctors must be wrong!

When I was 28 years old I had my first child. My son, Luke, was born in Edison, New Jersey, and we lived happily there for another seven months. We wanted to move back to the Midwest because that's where we were both raised, and our families were there. My husband got a transfer. The stress of moving, having an infant, the physical challenge going on in my body (at the time, my son was gradually weaning from nursing) and the fact that I was pre-disposed to having a mental illness – all created the right environment for this illness to emerge.

Before the move to Illinois, I felt tremendous lethargy and was also losing weight as well as having trouble sleeping. I attributed all of these symptoms to what was happening in my life – not to a mental illness. The unrecognized “blip” of depression that occurred in New Jersey was replaced by a full-blown manic episode in Illinois. At first my husband and I thought it was wonderful! I went from having no energy and feeling low, to feeling great and unpacking the entire house we'd moved into, painted rooms, and got the whole house organized in a day! Who would not love this?

I was very verbal and had tremendous insight about all kinds of things. My husband thought I was brilliant. Then my wonderful, insightful talks became hard to follow and somewhat bizarre. I had lost a lot of weight and was having trouble sleeping too. But having

just had a baby I thought it was a good thing I was losing weight – and just figured I was having trouble sleeping because of stress. We still owned our home in New Jersey and we were unhappily paying the mortgage on both homes! My husband was concerned but kept telling himself I'd be O.K. Finally one day he came home from a business trip to find the house a mess (very uncharacteristic of me), and I was laughing and crying very inappropriately about things. Somehow as sick as I was, I always took good care of my son – he was not sitting in a dirty diaper somewhere in the corner!

By this time, my husband was quite frightened of my rapid mood swings and called 911. The ambulance came and took me to the hospital and held me there against my will. It's interesting to note that my illness became much more severe the moment I was forced to stay in the hospital. I became delusional and paranoid and was convinced the whole staff was plotting some story about why I had to stay on the psychiatric ward when I really didn't need to be there- and they all knew it! I thought there was literally a key I had to find to get out of there and the only way I could get it was to get the information from the staff. When I got the "information" I would find the key. The first hospitalization was the most painful thing that's ever happened to me – to know your mind can go off like that with no warning and that you could think and do such goofy things is terribly frightening. There is so much shame involved with this illness. I went home from the hospital and fell into a severe depression that lasted 9 months. I lost all my self-confidence and was so ashamed. My only focus was to make sure no one found out about my illness and try to look "normal" at all times. It was the beginning of hiding my big ugly secret.

So much of this illness has to do with stigma. In my experience most of the stigma was self-induced. I did more damage to myself than anyone could have! I worried so much about what people would think if they knew and convinced myself I wouldn't be accepted. I lived in utter fear that people would find out. I worried my friends wouldn't want to hang out with me if they knew, or the neighbors wouldn't let their kids play with mine. I worried about what my family "really" thought of me. I even went so far to think of what my mail carrier thought of me because I got mail from the National Alliance for the Mentally Ill. I was consumed by fear of being found out.

I began to get better the more I grew to accept my illness! I did this through educating myself. I read all the books I could find about manic-depression. I also joined a support group which helped me see that people do recover. I found a new doctor who is very supportive and encouraging and has never made me feel that I'm in any way responsible for my illness. Nor has he made me feel my parents are!

The one thing I've done that has improved my recovery the most is talk about my illness. What I have come to find out is that mental illnesses are extremely common and nothing to be ashamed of. In talking about my illness privately and publicly now for four years I feel totally liberated and healed.

I coordinate the Speaker's Bureau at the National Alliance for the Mentally Ill and encourage other people with mental illness to speak out about their experience. We go out to colleges, high schools, church groups, etc. I have actually found that my illness is something I can derive tremendous reward from; that in fact without the illness I would never know the reward I now experience. I would not be someone who would be doing public speaking otherwise! I am consistently amazed and pleased by the number of people who come up to me

after I speak and share their stories of mental illness—either their own or family member and friends.

I have, since my diagnosis, had a second child, my daughter, Madison. She is such a gift. Not only did I think I would never have any more children after my son was born, and I felt tremendous sadness and loss because of this, but I felt my life would never be the same and was irreparable. My daughter was born in the same hospital where I've had my hospitalizations and has helped change the way I see it. The hospital is a place of health and life!

At the same time, ***don't avoid professional terms when they illustrate a point.*** It may provide an opportunity to inform listeners about an important issue related to mental illness. Kyle uses her story as an opportunity to educate the listener on the experience of bipolar disorder. This communicates to the audience that people with mental illness have expertise about mental illness worth learning from.

Presentations need to be truthful; don't try to embellish them. ***You shouldn't tell your story in an overly positive light:*** “*Mental illness isn't that bad. I survived my three suicide attempts easily.*” Listeners might get the idea that your depression was not really challenging or that you did not have a “*real*” mental illness. ***Nor should you try to paint too bad a picture:*** “*Being in a psych hospital is like living in a rat-infested slum.*” Although it is true that losing the liberty to come and go from an inpatient ward is demoralizing, some people are likely to think that you have a political agenda and are misrepresenting experiences when you use extreme examples. Moreover, when you stray from the facts, you are likely to say something that is not truthful—“*Were you really in restraints and not fed for an entire week?*”—and lose your credibility as a result. Be reassured that your story of struggles with mental illness is compelling enough to get most listeners’ attention.

There may be some aspects of mental illness that you are still struggling with and do not want to talk about publicly. ***Don't feel that you have to discuss everything.*** Respect your own sense of privacy. If, for example, you feel uncertain or embarrassed about an unrealistic fear of riding in elevators, there is no need to air this problem with others. Only share those concerns that you have already resolved in your life. Don't get pushed into telling your story in public until you are ready. Talking to citizens about

mental illness can be an empowering activity, but it can also be risky. Don't expose yourself to these extra challenges unless you feel that you will benefit from the experience.

Kyle's story included several areas in which the speaker might want to provide specific examples. **List some events in your youth that are typical of most peoples' lives and/or that might reflect the beginnings of your mental illness.** Kyle, for example, noted that she had loving parents and was not traumatized as a child. This kind of message challenges the notion that mental illness always results from bad parents and stunted development. **Share your feelings about the sudden impact of mental illness.** This discussion elicits empathy from listeners. Everyone understands the terror of a successful life grinding to a halt because of the sudden intrusion of serious mental illness. **Talk about how the impact of your mental illness lasted beyond the relatively brief period of onset.** Listeners need to hear that this is not just another short-lived emotional crisis. You were struggling with a biological disorder that derailed life goals just like any major physical illness.

“The illness was disastrous to my life. I had never been a quitter. I had never failed at anything I put my mind to. But things were very different.”

You might also describe how your experiences with mental illness affected the family. Speakers may relate to how parents and siblings are frequently overwhelmed by mental illness. Family members may progress through a variety of reactions that include anger at the person for his or her mental illness, sadness at the interloping symptoms, and acceptance of the disability. This kind of message opens the door to a discussion of the stigma experienced by families.

The take-home message in Kyle's story comes next; this should be a climactic moment in your presentation. **Despite the challenges of mental illness, you have come to grips with your disabilities, and are now achieving your life goals.** Kyle talks about the meaning of her achievements.

“I have, since my diagnosis, had a second child, my daughter Madison. She is such a gift... My daughter was born in the same hospital where I've had my hospitalizations and has helped change the way I see it now!”

This point directly challenges the myth that mental illness is insurmountable. Disabilities can be overcome. Most people with mental illness live fruitful lives.

The story cannot end here, however. ***You need to also tell listeners how stigma worsened your experiences of mental illness.*** Kyle said,

“I lived in utter fear that people would find out. I worried my friends wouldn't want to hang out with me if they knew or the neighbors wouldn't let their kids play with mine.”

You need to punch the audience with this point; a stigmatizing public only makes the already tough course of mental illness that much worse. These assertions lead to the moral of your story: ***I work, live, and play just like you!*** People with mental illness are capable and can accomplish life goals. You look for no special favors. With appropriate support, all you need are the same opportunities granted to all citizens.

Suggestions on how to tell your story. Public speaking can be a daunting task, even when telling your own story. There are several values, listed in *Table 3.2* on the next page that may help to improve the style of your presentation. First, you need to feel confident. This feeling is achieved by telling yourself that your story is important:

“My story challenges society's stigma.”

You should also recognize that your presentation is interesting. Masters of public speaking say that relaying a personal story is one of the best ways to get an audience's attention. As one toastmaster put it,

“People like to hear human-interest accounts, blow-by-blow details about what happened in your life.”

Also recognize that your story is humble. You are not trying to give the definitive statement about mental illness. Nor are you are trying to bring down all stereotypes in a

30-minute presentation. Your goal is to provide listeners with a brief glimpse into the life of a person with mental illness who does not act in the manner that stereotypes suggest.

Table 3.2: Some Values for Public Speaking

- | | |
|--|--|
| <ul style="list-style-type: none">○ Confidence○ Importance○ Interest | <ul style="list-style-type: none">○ Humility○ Enthusiasm○ Energy |
|--|--|

Handling the Jitters of Public Speaking (phrases people might say to themselves)

- I'm glad I'm here.
- I'm glad you're here.
- I know what I know.
- And I care about you. (from Dorothy Sarnoff)

Preparation

- Is essential to calm and effective public speaking.

Issues Related to Preparation

- Extensive preparation may lead to a stale presentation because of rote practice.
- Repeated consideration and critique of one's story may be anxiety producing.
- Extensive planning requires several hours of preparation, time which many people do not have.

Remember the importance of enthusiasm and energy; they are infectious and make an audience carefully hang on the words of your story. Enthusiasm shows the audience that you believe your message to be important and interesting. Enthusiasm is communicated through your energy. Never sit down when you present: stand up, walk around, and gesture when needed. Meet your audience head on and look them in the eye. Speak loudly and vary the emotional tone of your voice, as well as your facial expression.

Perhaps the single most important public speaking consideration is preparation. Regardless of the amount of pre-speech planning and legwork, you need to feel prepared and ready to face your audience.

How much should I prepare my presentation ahead of time? The workbook includes an exercise that will help you to write out a biography that reflects the key parts of your story. Some of you may want to use this exercise to carefully plan all of the details of your presentations. Others may wish to use it as a loose outline for an extemporaneous, off-the-cuff speech. There are advantages and disadvantages to

extensive preparation versus extemporaneous speech; these need to be considered so that you can choose the style that works best for you. By extensive preparation, we mean writing out the presentation entirely, or preparing a thorough outline with specific examples of each point. Extensive preparation also includes dress rehearsals with friends who might provide gentle feedback about the strong points of the story, as well as make suggestions for changing your presentation. Specific advantages to extensive preparation are many: those who choose to extensively prepare will tell a well-organized story, cover the essential elements, make fewer errors, and be better prepared for reactions from the audience. Some speakers might also decide to prepare visual aids to illustrate key points in the worksheet. For example, you might present photographic slides from your childhood illustrating the “*normalcy*” of your life.

On the downside, extensive preparation may lead to a stale presentation as a result of rote practice. Moreover, some speakers might find repeated consideration and critique of their stories to be anxiety producing. Sometimes, it is better to just “*do*” the speech and not spend a lot of time worrying about how it sounds. Finally, extensive planning requires several hours of preparation before the presentation, time that many busy people may not have.

There are several benefits to speaking off-the-cuff. For instance, some speakers are able to provide an engaging summary of their experiences with mental illness and stigma with nothing more than a half-dozen notes. They believe that this approach is fresh and allows the speaker to weave in talking points that address the specific interests of the audience. For example, Clarence noticed his audience was comprised of several homeless people. So, he decided to talk more about his own experiences with living on the streets. There are disadvantages to an extemporaneous style, however. Many people are unable to present an organized story without some up front preparation of their ideas. Without this kind of careful organization, the audience may become confused about the purpose of the presentation. As a result, the effect on stigmatizing attitudes may be muted.

How does telling your story affect you? Putting your experiences with mental illness into a cogent story and sharing it with others will not only benefit the audience, but will benefit you as well. For some, it serves a therapeutic process. It helps you to make sense of the challenges you have endured, and to take stock of your accomplishments. It may also outline areas in your life that need further attention.

Telling your story can also be empowering. Telling helps you to recognize that you are no longer a passive responder to mental illness, nor to a society that looks down on your disabilities. Instead, speaking publicly about your illness is evidence that you are a person who accepts your responsibilities to society (to become a productive citizen and supportive neighbor) and demands the rights that these responsibilities entail.

Making the Experience More Powerful

You are likely to have greater impact when presenting to established groups, rather than trying to assemble a bunch of citizens together for this one issue. Established groups have an organized membership, regular meetings, and a commonplace to rendezvous. The purpose of churches, synagogues, and mosques make them especially appropriate groups to contact; their mission is to promote a moral view of society that should include open-mindedness to groups such as people with mental illness. Several civic groups, service groups, and social groups are also excellent venues for presenting your story on mental illness. Rotary International, for example, inaugurated “*Erasing the Stigma*” in 1997, a campaign designed to educate business leaders about the truths and misconceptions of severe mental illness. The League of Women Voters also has a rich history of inviting disenfranchised groups to its meetings. In some ways, however, seeking out groups like Rotary and the League is like speaking to the already converted. You may also wish to contact other groups in your area.

Adult education provides another place where you may seek out citizens to whom you can tell your story. Growing numbers of adults are returning to community colleges, either to improve career opportunities, or to participate in stimulating courses about areas

of interest. Frequently, instructors in service-related disciplines— nursing, social work, psychology, pastoral ministry, education, and recreational therapy— would find the story of a person with mental illness to be an interesting addition to their curriculum. You may also wish to contact children’s groups. Schools and service groups (like the Scouts) would benefit from your story, and would provide you a stage to present it from.

Your presentation is further enhanced when authorities of these institutions publicly support you and your story. For example, your impact on a church group would be even greater if the pastor welcomed you in front of the congregation and encouraged participants to listen carefully to your message. Similarly, school principals and civic group presidents should endorse the presenter in front of the audience.

Sometimes, group leaders may not be aware of the importance of their public endorsement. You may wish to talk with them before your presentation and encourage them to provide an introduction that supports your message. The leader's introduction should include the following parts:

- you are a person who has successfully met the challenge of mental illness;
- you have come to discuss with the group the fact that mental illness, like most disabilities, can be overcome;
- one unnecessary burden you wish to inform the audience about is society's stigma; and
- everyone in the audience can assume an important role in changing stigma by listening to your speech and supporting your strategies.

Find opportunities for frequent, “real world” contact. Going to various church and civic groups as an invited speaker, and interacting with members after the presentation, are excellent ways to introduce citizens to ideas that contradict stereotypes about mental illness. This beginning can be expanded further when you find opportunities to regularly interact with the public. One way to do this is to become a member of the group and to participate in their activities. Joining alongside citizens in

“everyday, normal” activities communicates a key message in a subtle way: *I'm just like you.*

For this kind of interaction to have a significant impact, you need to interact with fellow group members as equals. This means that you should become a member of and regularly attend church and civic group meetings and activities. Of course, you need to consider what kind of groups in your community coincide with your values and fit into your schedule. You will have the greatest impact on peers in the group when you assume equal status. Equal status is earned when you meet all of the responsibilities of membership; for example, attend meetings, volunteer for tasks, and assume leadership roles. This goal is not achieved quickly. It takes everyone several months or years to be fully accepted into a new group. But, this kind of acceptance is perhaps the best evidence that stereotypes are beginning to be torn down in your community.

Responses from the Audience

Audiences frequently have strong reactions to stories about mental illness. You are presenting an emotionally poignant story that challenges some long-held viewpoints. Their responses may vary from polite acceptance to angry denial. The response you hope for is *“sign me up.”* This response would mean that the individual recognizes their stigmatizing attitudes, and vows to stop them. In addition, the individual hopes to amend past mistakes by joining the stigma-busting effort. Sometimes, the public responds with a *“me too.”* The *“me too”* listeners may be struggling with a psychiatric disability and have experienced, firsthand, the injustice about which you speak. These respondents may be family members who have suffered stigma because of the trials of their loved ones. *“Me too”* respondents may be people who are challenged by physical disabilities, or who are members of another society's out-group (such as ethnic minorities or gay and lesbian groups). Regardless of the source of the stigma, these individuals understand the injustice about which you speak, and want to stand up and support your message in the meeting.

Perhaps the most difficult group to deal with is the “*I don't believe it*” crowd. Their approach may take several forms. They may say they don't believe someone who is functioning as well as you could really be “*mentally ill.*” Or, they may discount your accomplishments altogether: “*getting out of the hospital and overcoming ten years of psychosis is no big deal.*” Or, they may think you that are an oddball who does not represent “*real*” mental patients. They might say you are whining and need to toughen up: “*Aw c'mon. Public opinion isn't that bad against mental patients.*”

Having someone stand up after your presentation and challenge your message can be daunting. However, consider these people— individuals who publicly question your message— as the success stories in the crowd. After all, they represent the important group of listeners who once believed the stereotypes about mental illness. You and your story challenge their beliefs and change the way they view the world. Now, they are trying to set the world back the way they knew it by questioning you. Remember, though, that every question that challenges you yields a response that threatens their stigmatizing attitudes.

***Audience Member:** You tell a great story and obviously have done okay for yourself. But you're not really mentally ill. Not like mental patients we see in the newspaper.*

***Speaker:** What would you consider being really mentally ill?*

***AM:** Well like you lose touch with reality, or hear voices, or, I know, get locked up in state hospitals for a while.*

***S:** But that's me... sometimes. I have an illness called schizophrenia. At times in my life I have heard voices. I have had delusions where I thought the radio was talking to me. I have been hospitalized for up to 3 months at a stretch.*

***AM:** But mental patients don't get jobs.*

***S:** Yes, sir. We do get jobs, frequently good ones. We may still need some help but many of us are able to hold on to them and make an income.*

One of the more difficult responses to your presentations is that of the listeners who *politely accept* your message. They seem to offer no arguments, nor do they seem to want to join the stigma-busting campaign. It is hard to determine whether polite acceptors have heard the message and challenged their stereotypes, or have ignored its meaning and experienced no real change in attitudes. Polite acceptors may need repeated exposure to people with mental illness in order to experience any real change in opinion.

2. Coming Out with Peer Support

LEARNING OBJECTIVES

- Coming out can be easier when you have peer support.
- There are many types and characteristics of consumer-operated services.
- Identify how important different characteristics of consumer-operated services are to you.

IN THE WORKBOOK:

Worksheet 3.3, “Characteristics of Consumer-Operated Service Programs (COSP): Which are Most Important to You?” provides a format for identify characteristics that are most important to you.

Worksheet 3.4, “Finding Consumer-Operated Programs that Meet Your Needs and Interests” provides an opportunity to identify COSPs that meet your needs and interests.

Coming out can be easier when a person decides to join together with others for support. This might be informally, such as joining a group of friends who have shared lived experiences. But, here we talk about a more formal collection of programs, often called consumer-operated services. Consumer-operated services, which include self-help and mutual assistance programs, are perhaps the best kind of programs that promote empowerment. As the name suggests, consumer-operated programs were developed by

consumers for consumers. These kinds of services are by no means another form of clinical care. Clinical treatment reflects a medical model, meaning: people seek out services to resolve symptoms and replace deficits. In a medical model, there is a hierarchy between healer and person in clinical settings; healers have some special power that they use to help patients resolve their problems. The relationship between healer and patient is expected to end when symptoms remit.

Consumer-operated programs have been likened to communities with life long histories or grassroots information and support systems, as opposed to this medical model. Mental illness may be the common experience that draws people to consumer-operated services. But, unlike traditional clinical treatment, this is not where the impact of consumer-operated services ends. These services provide a caring and sharing community where the person can find the necessary understanding and recognition that society at large is not able to give. Nor is there a hierarchy of roles in consumer-operated programs; all members are peers who benefit from interactions with equals. There are no limits placed on the amount of time a person can be involved in a program. Depending on personal needs, some members come and go from consumer-operated programs while others may stay connected throughout their lifetime.

There is a fundamental distinction between self-help groups and mutual assistance programs. Self-help programs are developed by consumers to help them help themselves. As such, benefits from these groups result from learning coping skills and obtaining support from others. Self-help suggests an ethos of rugged individualism where the person takes coping ideas and support from others in order to make it on their own. Mutual-help recognizes an important element provided by these groups: people benefit from helping each other. This kind of assistance extends beyond sharing information about coping skills or ways to manage the mental health system. The experience of both giving and receiving help enhances the person's sense of belonging in the community, as well as their overall well being.

“I had been taking from others for so long that I forgot I had something to give. I can't tell you how important it was for me to realize that my advice can be useful to others. Just last week for example, I helped Sammy with her baby-sitting problems. It was the best pill for depression I could have taken.”

Consumers have also distinguished between mutual help groups and mutual help organizations. Groups are somewhat limited in scope. Members attend regular meetings where individuals benefit from the process, support, and exchange of information. Organizations have a similar structure of meetings and processes. However, the mutual help organization is augmented by regular social events for members. Many mutual help organizations also provide residential, vocational, food and legal assistance, transportation, and temporary housing services so that members can address appropriate role functioning needs.

Characteristics of Peer Run Programs

A peer run program is a group of consumers, convened over two years, and supported by a grant from the U.S. Substance Abuse and Mental Health Services administration to identify the common ingredients of consumer-operated services. These ingredients become a veritable checklist of what makes up peer run services, a list which you might review when trying to find programs like these that meet your needs. They are summarized in *Table 3.3* on the next two pages and in *Worksheet 3.3*.

| Table 3.3: Characteristics of Consumer-Operated Services | |
|---|--|
| Structure | Definitions |
| Consumer-Operated | Consumers constitute the majority (at least 51%) of the board or group that decides all policies and procedures. With limited exceptions, staff consists of consumers who are hired by and who operate the COSP. Consumers have control of the operating budget. Role opportunities for participants may include board and leadership positions, volunteer jobs, and paid staff positions. |
| Participant Responsive | A COSP responds flexibly to the needs of participants. Consumers have ways to indicate dissatisfaction with their program and to have grievances addressed. |
| Linkage to Other Supports | A COSP offers linkage to other supports, with referrals to other community services, and networking with other consumer groups. |
| Accessibility | Consumers can walk to the COSP or get there by public transportation; or the program comes to the consumer. Hours of operation are geared to meet the needs of participants. COSP programs are either free or charge a nominal fee. Program use is not dependent on ability to pay. Efforts are made to ensure that consumers with physical and sensory as well as psychiatric disabilities can participate in programming. |
| Safety | The COSP provides a noncoercive milieu in which fears due to past traumatization are appreciated and assuaged, including trauma induced by the mental health system. There is no threat of commitment, clinical diagnosis, or unwanted treatment except in cases of suicide or physical danger to other participants. Norms/rules to protect the physical safety of participants are developed by consumers for consumers—either by the participants themselves or by consumer staff and they are agreed on by all participants. |
| Informal Setting | Working toward common goals in a comfortable setting creates a sense of belonging and support. Rigid distinctions between “provider” and “client” do not exist. While some program components may be structured, there remains a sense of freedom and self-expression. The COSP provides a sense of fellowship, in which people care about each other and create community together. |
| Reasonable Accommodation | No timeline is attached to participation in the COSP. No pressure to join and no time limit to participation. Schedules and tasks can be flexible and adapted to individual needs. Reasonable accommodation to disabilities of all kinds is advocated and practiced in program and work settings. |
| Belief Systems | Definitions |
| Peer Principle | Relationships are based on shared experiences and values. They are characterized by reciprocity and mutuality. A peer relationship implies equality, along with mutual acceptance and mutual respect. |
| Helper’s Principle | Helping oneself and others is a corollary of the peer principle. Working for the recovery of others facilitates personal recovery. Help or advice is friendly rather than professional and does not demand compliance. All services at COSPs are based on peer-to-peer relationships, as part of the peer principle. |
| Empowerment | Empowerment is honored as a basis of recovery. It is defined as a sense of personal strength and efficacy, with self-direction and control over one’s life. Consumers are expected, but not forced, to be accountable for their actions and to act responsibly. Self-reliance is encouraged. Group empowerment: Belonging to an organized group that is recognized by the larger community contributes to the personal empowerment of the individuals within it. Both personal empowerment and group empowerment can be going on at the same time. As a group, the COSP has the capacity to impact the systems that affect participants’ lives. Consumers participate in systems level activities at their own pace. |
| Choice | Participation is completely voluntary, and all programs are elective and non-coercive. Choice of services includes the right to choose none. Consumers are regarded as experts in defining their own experiences and choosing COSP |

| | |
|---|--|
| Recovery | We believe in recovery. The recovery process is different for each individual. It is never defined rigidly or forced on others by a COSP. Recovery describes a positive process that acknowledges strengths and enhances well-being. COSPs regard recovery as a normal human process, which is unique for each individual. And like all human processing, recovery takes time and involves a whole range of experiences. It may include ups and downs and also periods of no apparent change. |
| Acceptance and Respect for Diversity | Empowerment and hope are nourished through acceptance of people as they are, “warts and all.” All behaviors are understood in ordinary human terms, never according to clinical interpretations. Consumers respect each other for the person they are rather than for the person they should be. Every person is afforded acceptance, respect and understanding based on his/her uniqueness and value as a human individual. |
| Spiritual Growth | Spiritual beliefs and subjective experiences are respected, not labeled as symptoms of illness. |
| Peer Support | Definitions |
| Peer Support | Individual COSP participants are available to each other to lend a listening ear, with empathy and compassion based on common experience. Similar support may be provided in formal support groups. |
| Telling Our Stories | Personal accounts of life experiences are embedded in all forms of peer support and education. Open discussion occurs in peer support groups or among individuals. Sharing these life experiences may also be a tool for public education, thus becoming an effective means of eliminating stigma and making consumers more accepted within their community. |
| Consciousness Raising | Small support or conversation groups allow participants to “tell our stories” or share common experiences. These groups may be formal peer support groups or casual, ad hoc, conversations. Participants receive information about the consumer movement. New participants discover commonality with others, and this often produces the first dramatic change in perspective from despair to hope and empowerment. |
| Crisis Prevention | Involuntary commitment is minimized through individual or group peer support, or by peer counselors, or by education and advocacy, and by addressing problems before they escalate. |
| Peer Mentoring and Teaching | Consumer staff or leaders serve as positive role models to other consumers and to each other. Individual participants act as mentors to others. Consumers teach skills and strategies to other consumers, either formally or informally. |
| Self-Management/ Problem Solving | COSP programs or individuals teach and model practical skills and promote strategies related to personal issues, treatment, and support needs. The focus is on practical solutions to human concerns. |
| Education | Definitions |
| Education | Consumers teach and are taught skills that will equip them for full participation in the community, such as daily living skills, vocational skills, job readiness, communication skills, relationship skills, goal-setting and assertiveness skills. Consumers develop and improve social skills in a natural social environment. This is often a first step toward creating or re-establishing valued roles in the community and reintegrating into community life. |
| Self-Advocacy | Participants learn to identify their own needs and to advocate for themselves when there are gaps in services. Participants learn to become active partners in developing their own service plans with traditional services to meet their needs. Consumers learn to deal effectively with entitlement agencies and other services. |
| Peer Advocacy | Participants assist other consumers in resolving problems that they may encounter on a daily basis in hospitals and in the community, such as problems with treatment providers, community service agencies, family members, neighbors, landlords, other peers, etc. |
| Systems Advocacy | The COSP uses a number of tools to bring about changes at the systems and legislative level. These tools may include testifying before legislature, participating on boards, committees, and task forces, and communicating directly with policy and lawmakers. |
| Community Education | The COSP uses public education or public relations to bring about positive changes in public attitude. |

Where do I Find Consumer-Operated Programs?

Consumer-operated programs are slowly emerging around the world. We list resources here for how such programs might be found in different locales.

The European Union. The European Network of (ex-) Users and Survivors of Psychiatry lists organizations in individual countries in the language of each country: <http://www.enusp.org>.

The United States of America. The National Mental Health Consumer's Self-Help Clearinghouse has an amazing online directory of consumer-driven services: <http://www.cdsdirectory.org>. The directory lists services by state or by zip code and may search among programs by a variety of categories including advocacy, peer support, or recovery education. Consumer-operated services are changing quickly in America. Each state now has the equivalent of an Office of Consumer Affairs; contact information for these offices can be found at http://www.nasmhpd.org/general_files/Rosters/NAC-SMHA%2010-7-11.pdf. We have encouraged consumer and other advocacy groups to put together similar websites to help readers find consumer-operated services in their country.

Use the website information listed above to finish *Worksheet 3.4* and to find consumer-operated services that might meet your needs.

3. How Did It Go?

LEARNING OBJECTIVES

- Learn how to evaluate a specific instance of disclosure.

IN THE WORKBOOK:

Worksheet 3.5, “Details of Your Disclosure- How Did it Go?” provides a format for evaluating a specific act of disclosure.

This section provides guidance on how to evaluate a specific instance of disclosure. *Worksheet 3.5*, reproduced in *Table 3.4* on the next page, lays out the steps to assess whether an interaction in which you disclosed to another was positive or negative. To complete *Worksheet 3.5*, first indicate to whom you disclosed, the date the conversation took place, and the location. This will be helpful for keeping track of successful or unsuccessful characteristics of the disclosure, and may help you to alter your strategy the next time you decide to disclose. Next, consider what your goals were for disclosing to this person. In the next box, note what you said to the person; remember to be specific! Again, this will help you keep track of key words that were successful or unsuccessful at getting your point across. In the box in the middle of the page, write down how the person reacted to your disclosure. It might also be important for you to note the tone of their voice and their body language, especially if it does not seem to match with verbal content. Finally, rate how satisfied you were with the exchange, and how positive you thought the exchange was on the seven-point scale provided. Add up the two ratings into a total score. Totals greater than 10 suggest that the experience was a success and worth doing again. Totals less than 6 mean that it did not go so well and you might want to further evaluate what happened. Scores in between 6 and 10 mean that more information may be needed before going forward.

Table 3.4: Details of Your Disclosure- How Did it Go?

Name of the person to whom you disclosed: _____

Date of disclosure: _____ Place of disclosure _____

| | |
|---|--|
| <p>Your Goal(s)</p> <ul style="list-style-type: none"> ▪ ▪ ▪ | <p>What you said</p> <ul style="list-style-type: none"> ▪ ▪ ▪ |
| <p>Person's Reaction</p> | |

_____ How satisfied are you with the exchange?

| | | | | | | | |
|--------------------------------|----------|----------|----------------|----------|----------|----------|-----------------------|
| not at all satisfied | | | neither | | | | very satisfied |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |

_____ How positive was the exchange?

| | | | | | | | |
|-------------------------------|----------|----------|----------------|----------|----------|----------|----------------------|
| not at all positive | | | neither | | | | very positive |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |

| |
|---------------------------------------|
| <p>TOTAL SCORE</p> |
|---------------------------------------|

| |
|--|
| <p>MORE THAN 10: Good experience; worth doing again.</p> <p>LESS THAN 6: Not so good; what went wrong?</p> <p>BETWEEN 6 AND 10: Need more information for the future.</p> |
|--|

4. Putting it All Together

LEARNING OBJECTIVES

- Summarize insights from the worksheets provided in this workbook.
 - Decide how you would like to move forward with the issue of disclosure.
-

IN THE WORKBOOK:

Worksheet 3.6, “Insights and Future Directions” provides discussion questions to encourage reflection on what you have learned from the program.

We end the program with a pause for insight and direction. In *Worksheet 3.6*, questions are provided so that participants can summarize insights and decide on future directions. These questions are summarized in *Table 3.5*, below. Complete these and then share your responses with a partner. After finishing your discussion with a partner, come back to the group as a whole and discuss one or two decisions that you have made about coming out in going forward.

Table 3.5: Insights and Future Directions

- What did you learn about stigma and coming out from this program?
- What are the costs and benefits of you coming out? Might you come out in some places? Where? (*Worksheet 1.3*)
- What ways might work for you in terms of coming out? (*Worksheet 2.2*)
- To whom might you disclose? (*Worksheet 2.3*)
- How do you feel about stigmatizing responses from others? (*Worksheet 2.4*)
- What do you think of your story? How might you improve it? (*Worksheets 3.1 and 3.2*)
- Are there consumer-operated programs that might work for you? (*Worksheet 3.4*)
- List three things you might do in terms of coming out in the future.

Appendix I. Did This Program Help?

IN THE WORKBOOK:

Worksheet 3.7, “Personal Empowerment Self-Assessment Scale,” provides a way to evaluate your sense of personal and community empowerment from BEFORE and AFTER participating in the program.

Worksheet 3.8, “Comparing Your Scores on Self and Community Empowerment-Did Your Scores Improve?” provides a way to visually compare your scores.

One way we believe the *Coming Out Proud* program might be shown to help is by increasing a person’s sense of personal empowerment. In this last lesson, we provide a scale for assessing personal empowerment, a measure that might be used to assess program impact. The scale is thoroughly described in the workbook, as well as at the end of this lesson. First, however, we briefly define personal empowerment.

Personal empowerment is the opposite of self-stigma. People who feel positively about themselves and stand up to their community are not victimized by self-stigma. Hence, one way of defining empowerment is the absence of self-stigma. Unfortunately, this kind of definition suggests that personal empowerment represents the absence of pathology. Personal empowerment is much more than the absence of self-stigma. Personal empowerment is also a positive approach to one's life and to his or her community. Consistent with the discussion in the Personal Empowerment Self-Assessment Scale, we describe empowerment in two positive ways: the affirmative way in which individuals view themselves, and the affirmative way in which people interact with their community.

Empowerment and One's Sense of Self

People who have a strong sense of personal empowerment have good self-esteem. They view themselves positively; self-statements include beliefs that they are dependable individuals.

“I am a good person. Sure, I might have a mental illness. But, I’m also a son; a brother; a husband, friend, and lover; a student, a co-worker, a member of a church congregation. These things together add up to an important person in this world who has much to offer.”

This perspective exceeds the absence-of-disease view of self-esteem.

“I’m not all bad even though I have a mental illness.”

The absence-of-disease view is almost defensive; people define themselves by denying their disease. Empowered people also deny negative self-statements about themselves. But, more importantly, empowered people recognize their countless positive attributes rather than obsessing over their flaws. They affirm why they are an important person in the world. Sure, they recognize the occasional errors that haunt us all. But, they acknowledge these mistakes and still value their role in the world.

People with a sense of personal power have confidence in their ability to be successful. Psychologists call this self-efficacy. They believe that they can competently attain their goals and deal with problems that may arise in the future.

“I used to think that because I have a mental illness I couldn’t handle real work. Why bother trying for the good job? I’m not up to an employer’s demands. But now I realize that I have the same mix of strengths and weaknesses as everyone. I can call on these strengths to help me excel at my new job as a billing clerk.”

This kind of perspective helps people gain control over their future. Rather than being a victim to their disabilities, they are able to make decisions about how to attain personal goals. People who are self-empowered are optimistic. Instead of being overwhelmed by their symptoms and by a sometimes coercive treatment system, they believe that they will be successful. Those readers who have not experienced the loss of hope that is fostered by a paternalistic treatment system may not realize how important regaining optimism and control over one’s future can be.

“My doctors always meant well. But they robbed me of control over my life. They said I wouldn't get married, I can't live on my own, I'd never handle a job, forget about earning real money. I felt like a spectator watching my life go by. And it was a horrendous feeling. Now I have a different outlook. I can accomplish my goals. I don't need to wait for others. And the return of personal power has made me super human.”

Self-empowerment does not mean hiding from one's disabilities. People with optimism and a sense of control over their life do not deny that they have suffered psychiatric symptoms in the past. Nor do they think that they will never experience symptoms in the future. Instead, these people replace being overwhelmed by symptoms with acceptance of their disability.

“Having a psychiatric disability is who I am just like being female, white or left-handed. There are disadvantages to these other qualities, too. My second grade teacher used to punish me when I picked up my pen with the wrong hand.”

With acceptance also comes the realization that the person is more than just a diagnosis. Much more! Self-empowered people accept their problems. But, they also recognize that “*who they are*” goes beyond a set of symptoms. The total of one's sense of self includes the various roles and goals that make up life. Self-empowerment and positive self-esteem represent the appreciation of the breadth and depth of these goals and roles.

Empowerment and One's Community

People with a sense of personal empowerment are not intimidated by a sometimes hostile society. Rather, they are confident that they can fight the ignorance of their community and beat stigma.

“Other groups have done it. The civil rights actions of the 50's and 60's turned around attitudes about race. We can do the same thing with mental illness.”

People who are empowered may feel righteous anger: anger towards the disrespectful images of people with mental illness on TV, in magazines and on the internet; towards landlords and employers who won't hire them because they have been hospitalized; and towards mental health professionals who said they will never make it beyond the walls of an institution. Empowered people have given up their sense of powerlessness in the face of an oppressive majority. In its place, they face the stigmatizing ways in which society responds to people with mental illness.

Empowered people are not overcome by anger. Instead, they are able to channel this anger into activities that diminish stigma, and further opportunities. Empowered people may affect change by becoming active in anti-stigma programs that protest hurtful images of mental illness, by joining mutual-help programs that foster empowerment among peers, or by earning the appropriate credentials and trying to change the mental health system from within as a provider. The point here is that righteous anger can energize people, enabling them to take control of their lives rather than be victimized by stigma and discrimination.

The Personal Empowerment Self-Assessment Scale

One way to assess empowerment is to complete the Personal Empowerment Self-Assessment Scale in *Table A.1*. Readers should answer the questions in this scale in order to determine if they beat themselves up with stigma, or if they have some sense of personal empowerment. Alternatively, readers might share this test with peers who have questions about their level of empowerment. The key for the scale as well as the interpretation guidelines can be found at the bottom of the next page. Complete the scale fully before reviewing the key.

Table A.1: Personal Empowerment Self-Assessment Scale

Rate how much you agree with the following statements using this scale:

| Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |
| _____ | | | | |

Scoring:

Add up the scores of all the ODD numbered items and enter the total in Box 1. **Box 1**

Then add up all the EVEN numbered items and enter the total in Box 2. **Box 2**

KEY & INTERPRETATION GUIDELINES TO TABLE A.1

The total in Box 1 represents views about empowerment towards yourself: self-esteem, future optimism, and self- effectiveness. Scores in Box 1 that are less than 8 suggest that you do not have much empowerment towards yourself. In this case, you will benefit from many of the suggestions to improve empowerment that are listed in this lesson.

The total in Box 2 represents views about empowerment towards your community: righteous anger and willingness to take action. Scores in Box 2 that are less than 8 suggest that you are unsure about challenging your community and its stigmatizing ways. You will benefit from the empowerment strategies as well as the anti-stigma approaches reviewed in this lesson.

The Self-Assessment Scale provides two scores for people who complete the test: self-empowerment and community-empowerment. They represent the two ways in which empowerment impacts the person with mental illness. People who feel empowered have good self-esteem, believe they are effective in life, and are optimistic about their future. Low scores on this scale (below 8) suggest that the person does not feel empowered about him or herself. Alternatively, empowerment can affect a person's view of his or her community. Empowered people may show righteous anger against prejudice and actually participate in civil actions that target stigma. Low scores on this scale (below 8) mean that the person is intimidated by public stigma and does little to counter it.

The *Personal Empowerment Self-Assessment Scale* is provided to help the person understand him or herself better. Sometimes, both test-takers and professionals make the “grand error of truth” in using assessment information. They assume that, if a test says so, then it must be true.

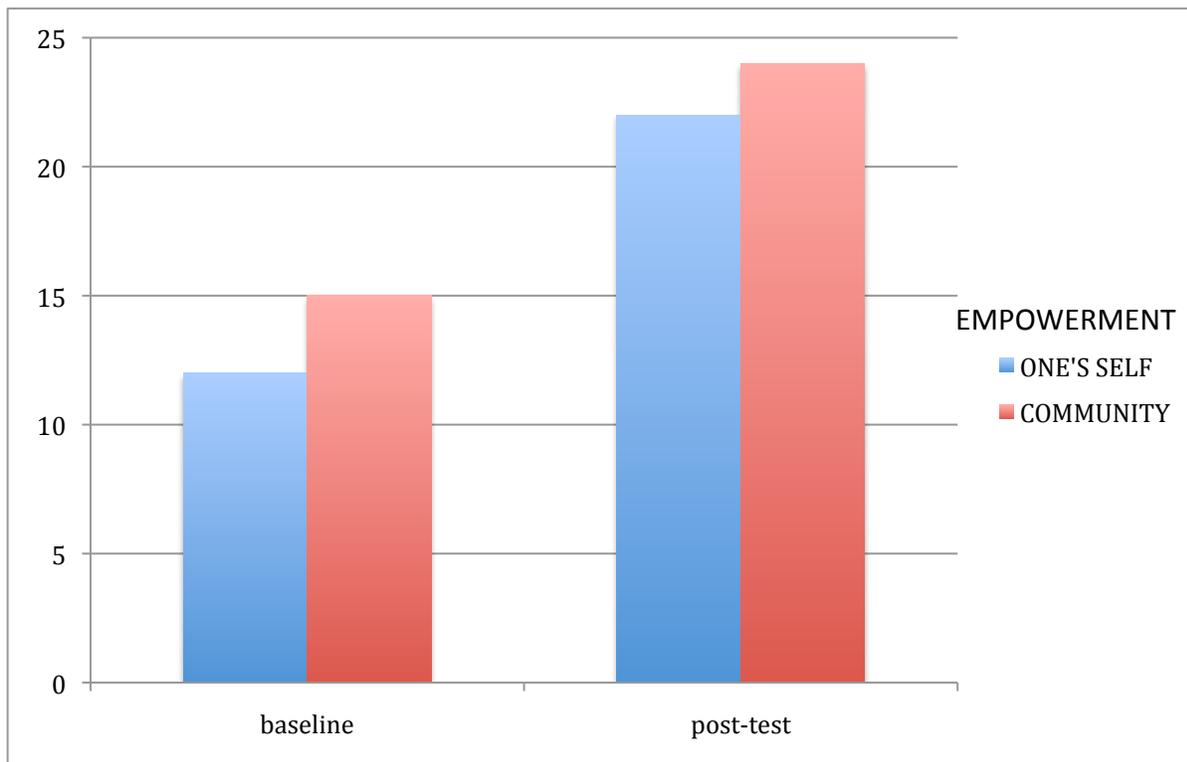
“I didn't think I had low empowerment. But I scored less than 8 so I must disapprove of myself.”

Information in these tests is meant to help people consider issues of self-stigma and empowerment. The final gauge of whether test information is right or wrong is the person taking the test. If the information makes sense or helps the person to stop and think over an issue, then it is probably useful feedback that the person may wish to heed. But, if test results seem to come out of left field and do not reflect the person's experience, then the information may be incorrect. Some tests just don't work right for some people. In these cases, it may be best to ignore the test findings/results altogether.

Program Evaluation

The *Personal Empowerment Self-Assessment Scale* can also be used to evaluate the effectiveness of a specific trial of the *Coming Out Proud* program. To do this, all participants in the program should complete the scale twice: before starting any part of the program (called the baseline), and upon completion (called the post-test). Baseline is

usually administered at the same time as the first meeting and Lesson 1, immediately before starting any aspect of the program. All program participants are given paper copies of the measure and asked to complete it. Post-test is given upon completion of the last meeting, Lesson 3. Group facilitators should then determine the group average of pre-test scores separately for Box 1 [*Empowerment and One's Self*] and Box 2 [*Empowerment and One's Community*]. These should then be plotted on a simple bar graph such as the graph shown below:



As can be seen in this example, empowerment for one's self has increased from about 12 to more than 22 from baseline to post-test. Empowerment for one's community has grown from 15 to 24 from baseline to post-test. Researchers and statisticians struggle to understand how much of an increase represents a significant, or meaningful, increase, a debate that is beyond the scope of this manual. Simply put, we propose any increase of five points might be considered a success.

Appendix II. Protections Against Unwanted Disclosure

In making decisions about disclosing your experiences with mental illness, you first need to consider how your right to privacy is protected. Most governmental bodies have passed laws guaranteeing that interactions with mental health professionals remain confidential. Things may vary a bit from country to country. A fact sheet summarizing the key points of these laws is provided in *Table A.2*.

Table A.2: A Fact Sheet About Confidentiality Laws

All states in the Union have legislation that requires mental health workers to NOT disclose any information about you without your permission. Depending on the State, this generally means the following for adults.

- Every interaction you have with a mental health organization is considered confidential and may not be disclosed without your permission.

This includes obvious issues like individual and group psychotherapy, meetings with a psychiatrist, participation in community meetings, and medical examinations by a nurse practitioner.

Moreover, this literally means every interaction. Talking to the receptionist, waiting in the lounge, riding on the agency van, bumping into the janitor are all interactions that are confidential. No one has a right to know about anything you do in a mental health organization without your prior written permission.

In fact, no one has the right to know that you ATTEND a mental health organization without your permission.

- Confidentiality laws also apply to all mental health-related records: written charts, videotapes, or computer files. They may not be disclosed without your permission.
- Confidentiality applies to everyone who works for an organization: from the medical director to the gardener to even volunteers.
- No one - including your employer, landlord, or family members - may obtain confidential information about you without your written permission.
- Your confidentiality is protected forever, even after you die. Employees of a mental health organization have to respect your confidentiality forever, even after they leave the organization.

Table A.2 continues on the next page.

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-
- You may choose to disclose any part of your record or interactions with a mental health organization. You can only do this when you sign a written release of information that specifies what materials are to be released (John Doe's history in the Opportunities Vocational Program from October 1 to December 1, 1998) and where they are being sent (to Dr. Jones at Blackhawk Mental Health Center).
 - The only authority that can order a mental health professional to violate your confidentiality is a judge in a court of law when you are involved in civil or criminal proceedings.

Confidentiality Laws

Very few governmental bodies allow mental health professionals to disclose information about your history without your permission. This includes clinical interactions with the mental health system such as psychotherapy, group therapy, and participation in community meetings. But, it usually also means every interaction you have in a mental health setting, such as a conversation with a receptionist or while riding in the hospital van to an outing. No one has the right to know that you have ever been in a hospital or attended a community mental health center, without your prior written permission.

After you leave a hospital or community program, confidentiality applies to all of your records. These records cannot be released without your explicit permission. These include written charts, videotapes, and computer files. Similarly, anyone seeking your medical charts will be rebuffed unless they have your permission, such as landlords, your employer, or even your family members. Your records are kept from everyone, even after you die. You may release your records to another mental health organization or person, but only with a prior, written release. Consider the two stipulations here. First, permission must be obtained prior to the release of information; it is rarely legal to do so after information has been shared. Mental health agencies cannot ask you to sign a release when they have already given material about you to someone else. In addition, this permission must be written and must specify what information is to be released,

where it is being sent, who will receive it, and when the release will no longer apply. By the way, you are entitled to a copy of that release and may revoke it later if you change your mind. Also, an agency cannot pressure you in any way to sign a release of information.

A judge presiding over a civil or criminal case in which you are involved is the only person who may override this system of confidentiality, in some situations. He or she can order your mental health agency to provide information about you in matters before the court. You can decide to appeal this decision (usually with the help of an attorney representing your interest). Nevertheless, the final decision in these cases usually lies with the court.

Who the laws do and don't apply to. Confidentiality laws clearly apply to psychiatrists, psychologists, social workers, nurses, and other staff providing mental health services. In fact, these laws apply to all paid employees of an agency including receptionists, bus drivers, food service workers, and housekeeping staff. In addition, these laws apply to unpaid workers associated with the mental health program: recreation volunteers, therapy students, outside advocates, and members of the board of directors. Note, however, that laws do not apply to one group of people who you regularly encounter at a mental health program: the other people receiving services. Confidentiality laws do not apply to fellow consumers who you meet in a psychiatric unit of a hospital, or who you meet in group therapy at a community program. Nor must family members attending therapy sessions protect your confidentiality. It is certainly the case that staff will request that fellow group members respect your confidentiality -- they probably wish the same protections for themselves -- but there are no laws requiring that be so.

Other government laws may protect your privacy outside of mental health institutions. Defamation, slander, and libel are statutes that prevent falsehoods about you from being published or otherwise disseminated. For example, Title 18 of the U.S. Code prevents people from learning about you by reading your mail. Hence, correspondence from your psychiatrist, for example, is protected by law.

There are clearly many legal protections to ensure your privacy. Unfortunately, these protections are not absolute; gossip may always spread. For example, there are no laws that prevent co-workers from telling stories, and neighbors and friends may pass out information about you in a spiteful manner. Hence, you will need to make an explicit decision about whether or not you wish to disclose your experiences with mental illness.