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# **HONEST, OPEN, PROUD**

**to Eliminate the Stigma of Mental Illness**

## *MANUAL*



FOR PROGRAM FACILITATORS AND PARTICIPANTS  
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Honest, Open, Proud was formerly known as Coming Out Proud to Eliminate the Stigma of Mental Illness. For information, contact Patrick Corrigan ([Corrigan@iit.edu](mailto:Corrigan@iit.edu)) or visit the website at [www.hopprogram.org](http://www.hopprogram.org)

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# PREFACE

This is the companion manual to the *HOP* program workbook. The program is meant to be flexible and can be done in different formats based on feedback received from *HOP* facilitators.

- *HOP* might be completed as a daylong seminar of about nine to ten hours with a three-hour booster about one month later.
- It can be done as four, 2-3 hour sessions which includes the booster one month later. Each session corresponds with one of the three lessons and the booster.
- *HOP* can be administered in as nine, 1 hour sessions corresponding with the tasks under each lesson (as outlined in the Table of Contents on the previous page.) This approach would include a three-session booster one month later with each **booster** session corresponding to the follow-ups outlined in the table of contents.

Facilitators should decide among these options based on needed accommodations of program participants.

In this manual, lessons/tasks are laid out with learning points, discussion questions, and group exercises. Individual lessons directly correspond with sections of the program manual. This program is best run with four to eight participants. One or two people should facilitate, preferably people with the lived experience of mental illness. All that is needed to run this program is a private room, manuals for the facilitators, and paper copies of the workbook for each participant. All materials in this manual and in the program workbook can be downloaded for free on the program website.

([www.hopprogram.org](http://www.hopprogram.org)).

## *A Little Bit of History*

*Honest, Open, 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 service 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

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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, Canada, 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 very difficult 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. Consider this example.

*“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.

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## ***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. Still, “*mental illness*” can be a hurtful word too. Hence, one of the first tasks in Lesson 1 is to help participants identify terms -- e.g., mental illness, mental health challenge -- that work for them.

## ***Workbook***

A workbook has been written as a companion to this manual (*Honest, Open, 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 “Manual and Resources” page of [www.hopprogram.org](http://www.hopprogram.org).

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### *Acknowledgements*

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### *About the Authors*

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*Honest, Open, Proud*

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## ***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 *Honest, Open, 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.

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# LESSON 1

## Considering the Pros and Cons of Disclosing

### LESSON OVERVIEW

Honest, Open, 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 two parts:

- Task 1      We discuss the idea of IDENTITY and mental illness so you can decide how you frame your identity.
- Task 2      We help you weigh the costs and benefits of coming out so that you can decide whether or not to disclose.

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### **Task 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. This section helps people understand whether and how they identify themselves.
- Words are central to stigma. Participants consider how they like to label their experiences leading to stigma: mental illness, mental health challenge, or other term.
- Some people agree with stigma and beat themselves up as a result. Program participants might want to consider Appendix 1 when in this situation.

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### IN THE WORKBOOK:

*Worksheet 1.1 helps people to decide whether “I identify as a person with mental illness.”*

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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 discloses 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

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is a complex decision that each person needs to make for him or herself. The purpose of the *Honest, Open, 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. Section 1 of Worksheet 1.1 helps participants consider these options.

### ***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.

### ***What's in a Name?***

The *Honest, Open, Proud* program is subtitled *Eliminating the Stigma of Mental illness*. While terms like *people with mental health* and *people in recovery* might hurt less, it may confuse the public. We believe mental illness is stigmatized by the population. It is mental illness and not mental health that leads to prejudice and discrimination. Still, words can hurt and some people do not like to identify themselves as a person with mental illness. Hence, the second part of *Worksheet 1.1* helps people consider terms that work for them, how they wish to identify themselves. Section 2 of *Worksheet 1.1* directs

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participants through these issues. Words, like identification, are not a one time decision. People might change their mind about how they wish to be referred which is fine.

### *Addressing One's Own Self-Stigma*

*Honest, Open, Proud* is based on assertions that stereotypes and prejudice are not only false but unjust.

- People with mental illness are **violent** and **unpredictable**.
- They **choose** to be mentally ill.
- They are **weak** and **incompetent**.

Stereotypes like these are in the same immoral class as racist, sexist, and ageist comments. Unfortunately, some program participants with mental illness agree with stigmatizing beliefs like these and internalize them.

- I have a mental illness so I must be **violent** and **unpredictable**.
- I have a mental illness so I **choose** to be mentally ill.
- I have a mental illness so I must be **weak** and **incompetent**.

Appendix 1 includes a strategy that helps people control self-stigma, learning to replace false beliefs about danger or incompetence with affirming attitudes of recovery and self-determination.

The last part of *Worksheet 1.1* includes a brief assessment so participants can determine whether they might benefit from or participate in the self-stigma control strategies in Appendix 1. Facilitators and participants might want to consider an extra, 90-minute session for people scoring above 20 on the scale. Please keep in mind; the scale is meant to encourage discussion. In **NO WAY** must a participant complete Appendix 1 if they choose not to, regardless of their score.

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## Task 2. 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.

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### IN THE WORKBOOK:

*Worksheet 1.2, “Some Reasons Why People Decided to Disclose Their Mental Illness”* gives several example reasons why people might disclose and provides space to write in your own reasons.

Tables are provided to list the costs and benefits of disclosing and of not disclosing your mental illness (see *Table 1.1* and *Table 1.2*).

See a completed table (*Table 1.3*) that shows the short- and long-term costs and benefits of disclosing for Alan.

*Table 1.4* considers a list of advantages and disadvantages for additional ideas about costs and benefits.

*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.

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### *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. *Worksheet 1.2* gives examples of benefits, reasons people decided to disclose their mental illness. After going through the examples, your own reasons for wanting to disclose should be considered and written in the empty spaces. Several more examples of both costs and benefits are summarized in *Table 1.1*. Let us consider the benefits first,

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the reasons why letting other people know about your psychiatric disabilities may help you.

<b>Benefits</b>	<b>Costs</b>
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

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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.

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*“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*

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*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

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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

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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 he 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 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 starred one cost: Alan was concerned that people would talk about him and spread rumors about his mental illness.

<b>Table 1.3: Example for Alan</b>		<b>Setting: at the office.</b>	
<b>Short-Term Benefits</b>		<b>Short-Term Costs</b>	
<ul style="list-style-type: none"> <li>- Others help me deal with our hostile boss.</li> <li>- Don't have to keep it hidden.</li> <li>- May identify co-workers with similar problems.</li> <li>- Make more friends at work. *</li> </ul>		<ul style="list-style-type: none"> <li>- Co-workers won't ask me to lunch.</li> <li>- Worry about others talking about me.</li> <li>- Get left out of work opportunities.</li> </ul>	
<b>Long-Term Benefits</b>		<b>Long-Term Costs</b>	
<ul style="list-style-type: none"> <li>- Boss provides on-the-job help.</li> <li>- With accommodations get better pay.</li> <li>- Stay on job longer. *</li> </ul>		<ul style="list-style-type: none"> <li>- Supervisor passes over my promotion.</li> <li>- Rumors start about me. *</li> <li>- I quit in embarrassment.</li> <li>- I get fired.</li> </ul>	

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

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this by using the extra copies of the *Costs and Benefits Worksheet 1.3* provided in Appendix 4 of the Workbook 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) really 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!”*

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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 1.2 (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

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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.

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Hence, another copy of *Worksheet 1.3* is given to you to do as homework. To complete the homework you want to think of someplace or someone currently important to you whom you might disclose to. This homework is given to you for the purpose of gaining practice with disclosure, you are not expected to turn it in or share it with anyone. You may find yourself filling out the *Costs and Benefits Worksheet* several times in your life and coming up with different conclusions each time; Appendix 4 of the workbook has five blank copies of *Worksheet 1.3* for you to complete in the future.

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# LESSON 2

## There are Different Ways to Disclose

### LESSON OVERVIEW

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

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

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### Task 1. Different Ways to Disclose

#### LEARNING OBJECTIVES

- People might disclose their experiences 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.

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#### IN THE WORKBOOK:

*Table 2.1 “Five Ways to Disclose or Not Disclose” summarizes the five ways people might disclose their experiences with mental illness.*

*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).

<b><i>Table 2.1: Five Ways to Disclose or Not Disclose</i></b>	
<b>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.</b>	
<b>Benefit:</b> You don't encounter people who will unfairly harm you.	<b>Cost:</b> You lose the opportunity to meet new people who may possibly be supportive.
<b>2. SECRECY: Participating in work and community situations, but keeping your mental illness a secret.</b>	
<b>Benefit:</b> 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.	<b>Cost:</b> Some people feel guilty about keeping secrets. You may also receive less support from others because they are unaware of your mental illness.
<b>3. SELECTIVE DISCLOSURE: Disclosing your mental illness to selected individuals, like co-workers or neighbors, but not to everyone.</b>	
<b>Benefit:</b> You find a small group of people who will understand your experiences and provide support.	<b>Cost:</b> 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.
<b>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.</b>	
<b>Benefit:</b> You don't worry who knows about your problems. And you are likely to find people who will be supportive.	<b>Cost:</b> You may tell people who then hurt you with the information.
<b>5. BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people about your experience with mental illness.</b>	
<b>Benefit:</b> 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.	<b>Cost:</b> 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.

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## 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

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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

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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

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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

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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. 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

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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.”*

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#### 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

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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

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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

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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.

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## Task 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.

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### IN THE WORKBOOK:

*Table 2.2, “Types of Relationships & Important Characteristics of a Good Person to Disclose to”* groups people into categories to summarize the several reasons why you might pick a specific person to disclose to.

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

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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 disclose to?
2. We propose a way in which you might “*test out*” the person before fully disclosing.

**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

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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.

**Table 2.4: Types of Relationships & Important Characteristics of a Good Person to Disclose to**

**1. FUNCTIONAL RELATIONSHIP**

The person provides some function for you where knowing your experiences with mental illness might help accomplish the function.

Sample functional relationships include:

- psychiatrist
- doctor
- minister
- car pool member
- supervisor
- co-workers
- teacher
- team member

**2. SUPPORTIVE RELATIONSHIP**

The person seems to be friendly and will provide support and approval to you when they find out about your experience.

Characteristics of this kind of person include:

- pleasantness
- concern for others
- trustworthiness
- open-mindedness
- loyalty
- helpfulness

**3. EMPATHIC RELATIONSHIP**

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.

Their characteristics include:

- willingness to listen
- kindness
- an understanding nature
- honesty

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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 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. *Worksheet 2.3* offers a space to make a list of positive representations of people with mental illness in the media. After making your list, consider asking the questions given and determine whether the person's responses suggest that they are a good person to disclose to. 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,

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*“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

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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*

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*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*.

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.

**Table 2.5: Some Reasons People Disclose**

**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.”

**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.”

**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.”

**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.”

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.

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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.

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## Task 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.

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### IN THE WORKBOOK:

*Table 2.3, “How People Might Respond to Your Disclosure”* 3 lists a variety of reactions to disclosure that are sorted into groups by positive versus negative emotional response

*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.

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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.”*

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

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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?*”). *Worksheet 2.4* allows you to practice hearing negative responses and rate the reaction you had to hearing these hurtful sentences.

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.

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# 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.

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

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### Task 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.

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#### IN THE WORKBOOK:

*Table 3.1, "Kyle Uphoff-Wasowski's Story" an illustrated example by Kyle Uphoff-Wasowski from Don't Call me Nuts*

*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.*

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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 powerful 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*

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*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*

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*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*

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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

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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.

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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 contribute, 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.

Lets try it out. Using Worksheet 3.1 as your guide, take a few minutes to write down your story. When you are done, partner with someone and tell them your story. Complete Quality of Experience in Worksheet 3.2 to rate your experience.

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## Task 2. How Did It Go?

### LEARNING OBJECTIVES

- Learn how to evaluate a specific instance of disclosure.
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### **IN THE WORKBOOK:**

***Worksheet 3.3, “Details of Your Disclosure- How Did it Go?” provides a format for evaluating a specific act of disclosure.***

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This section provides guidance on how to evaluate a specific instance of disclosure. Worksheet 3.3, reproduced in Table 3.2 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 3.3, 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

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happened. Scores in between 6 and 10 mean that more information may be needed before going forward.

**Table 3.2: 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"> <li>▪</li> <li>▪</li> <li>▪</li> </ul>	<p>What you said</p> <ul style="list-style-type: none"> <li>▪</li> <li>▪</li> <li>▪</li> </ul>
<p>Person's Reaction</p>	

\_\_\_\_\_ How satisfied are you with the exchange?

<b>not at all satisfied</b>		<b>neither</b>		<b>very satisfied</b>
1	2	3	4	5
6	7			

\_\_\_\_\_ How positive was the exchange?

<b>not at all positive</b>	<b>neither</b>	<b>very positive</b>
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<p><b>TOTAL SCORE</b></p>
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<p><b>MORE THAN 10:</b> Good experience; worth doing again.</p> <p><b>LESS THAN 6:</b> Not so good; what went wrong?</p> <p><b>BETWEEN 6 AND 10:</b> Need more information for the future.</p>
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## Task 3. Honest, Open, Proud through Peer Support

### LEARNING OBJECTIVES

- There are many types and characteristics of peer services.

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### IN THE WORKBOOK:

*Worksheet 3.4, “Where do I find peer support groups?”* provides an opportunity for participants to generate a master list of programs they can join.

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### *Peer Run Programs*

Peer-led programs have been likened to communities with life long histories or grassroots information and support systems, as opposed to the 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 peer-led 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 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 peers 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

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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.”*

Peers 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.

Peer support programs often use novel approaches. Some programs use different forms of art: acting, singing, dance, drawing, or sculpture. Story telling is often important here as are writing groups. Others are spiritual with some rooted in Christian traditions while others might reflect Asian or Native American perspectives. Some are wedded to advocacy, organizing to impact the mental health service agenda in their area.

### ***Where do I Find Peer Groups?***

A great place to start is a discussion among course participants; Worksheet 3.4 is meant to facilitate this discussion. After completing the worksheet, have participants pair off and discuss their lists. Then come together as a whole and make a master list.

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

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**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](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.

**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>.

---

Where do I go to find peer support?

List all peer support programs you know of?

Name of Program	Where and contact info	What I like about it
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

---

## Task 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 3.5, “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 3.5*, questions are provided so that participants can summarize insights and decide on future directions. These questions are summarized in *Table 3.4*, 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 3.4: 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.

---

# BOOSTER

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# FOLLOW-UP 1

## The Decision to Disclose

### FOLLOW-UP OVERVIEW

Coming out is the right decision for some people, but not for everyone. This section is designed to review your decision to disclose since completing the *Honest, Open, Proud* baseline program about one month ago. We approach this follow-up in two parts:

- Task 1. We review previous intentions to disclose your mental illness, including to whom, when, and where you decided to disclose as well as what you expected from the disclosure.
- Task 2. We discuss whether you disclosed and help you evaluate how the experience went and how it may affect future disclosures.

---

## Task 1. Did You Intend to Disclose?

### FOLLOW-UP OBJECTIVES:

- Review your intentions to disclose after you completed the HOP baseline program.

---

### IN THE WORKBOOK:

*Worksheet 1.1* helps participants to review their “*Intension to disclose- Who? When? Where? What?*”

---

One month ago, we identified people that might be suitable for disclosure. The three main types of relationships included: functional (e.g., psychiatrist or supervisor),

---

supportive (e.g., someone who is trustworthy), and empathic (e.g., someone who is understanding). Use *Worksheet 1.1* to review intentions you had for disclosure after you completed the baseline program.

**FACILITATOR INSTRUCTIONS:**

When everyone is finished, have participants pair up to discuss their intentions for disclosure or lack thereof. Those who did not have any intentions to disclose should try to pair up with a peer who did.

---

Worksheet 1.1

**Intension to Disclose- Who? When? Where? What?**

When you completed the *Honest, Open, Proud* baseline program about one month ago, did you intend to disclose?

Yes     No

If yes, please fill out this table.

<b>Who did you decide to disclose to?</b>	
<b>When did you plan on disclosing?</b>	
<b>Where did you plan on disclosing?</b>	
<b>What did you expect from the disclosure?</b>	

**If no, why did you decide against it?**

---

## Task 2. How Did Disclosure Go?

### FOLLOW-UP OBJECTIVES:

- If you disclosed, describe how it went and rate the quality of the exchange.
- Explain how the experience changed your mind about disclosing.

---

### **IN THE WORKBOOK:**

***Worksheet 1.2, “Did You Disclose? How Did It Go?” provides a format for evaluating a specific act of disclosure and gives participants space to discuss whether the experience has changed their mind about disclosing in the future.***

---

During the baseline program, we learned how to evaluate a specific instance of disclosure. *Worksheet 1.2* is the same one you completed before. It lays out steps to assess whether interactions in which you disclosed to others were positive or negative. You may have disclosed. If so, discuss how it went here. If not, we can still learn from others. Fill in the worksheet AS IF you did disclose with a real person in a real setting.

*Worksheet 1.2* is adapted from *Worksheet 3.5* in the *Honest, Open, Proud* baseline program. First indicate to whom you disclosed, the date the conversation took place, and the location. This will help track successful or unsuccessful elements of disclosure, and may help you to alter your strategy the next time you decide to disclose. Second, consider what your goals were for disclosing to this person and note what you said to the person; remember to be specific! Next, 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 their 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.

---

**FACILITATOR INSTRUCTIONS:**

When everyone is finished, please have those who **actually** disclosed pair up with a participant who did not so that they may share their thoughts. Participants who did not disclose should use this opportunity to understand what disclosure might mean for them in the future.

---

Worksheet 1.2

**Did You Disclose? How Did it Go?**

Please fill out this page about a disclosure from the past month.

Name of the person to whom you disclosed: \_\_\_\_\_

Date of disclosure: \_\_\_\_\_ Place of disclosure \_\_\_\_\_

Your Goal(s)	What you said
▪	▪
▪	▪
▪	▪

Person's Reaction:

\_\_\_\_\_ How satisfied were you with the exchange?

not at all <b>satisfied</b>			<b>neither</b>			very <b>satisfied</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

\_\_\_\_\_ How positive was the exchange?

not at all <b>positive</b>			<b>neither</b>			very <b>positive</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

<b>TOTAL SCORE</b>
--------------------

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

---

Has your experience changed your mind about whether or not you will disclose in the future?

Yes    No

**How has it changed?**

---

# FOLLOW-UP 2

## Peer Support Programs

### FOLLOW-UP OVERVIEW

Some people find it helpful to seek a peer support group to share experiences and struggles of mental illness and to overcome the fear of disclosure. As a reminder, peer support services, which can include self-help and mutual assistance programs, may make coming out easier because a person is joining together with others for support. This includes those who have already come out and those who are still thinking about coming out. This section assesses your experiences with peer support programs since completing the *Honest, Open, Proud* baseline program.

Task 1. We discuss the meaning of peer support and identify pros and cons of peer support programs. At the same time, we help you rate the quality of your peer support experience.

---

### **Task 1. Did You Pursue Any Peer Support Programs?**

#### FOLLOW-UP OBJECTIVES:

- Discuss what peer support means to you.
- Identify pros and cons of peer support programs.
- Evaluate your peer support experience and discuss the future of peer support in your life.

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#### **IN THE WORKBOOK:**

*Worksheet 2.1, “Did You Pursue Any Peer Support Programs?”* helps participants to list the pros and cons of peer support programs and provides them with a format to rate any programs that they may have attended.

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One month ago, everyone in the group brainstormed a list of peer support programs they might attend. In **Section I** of *Worksheet 2.1*, write down what peer support means to you and make a list of the pros and cons of attending a peer support program. **Section II** will help you to evaluate any peer support experience you may have had since completing the baseline program. When you are finished filling out **Section I**, please discuss your ideas with the group before moving on to **Section II**.

**FACILITATOR INSTRUCTIONS:**

Lead participants in a group discussion of the meaning of peer support and its advantages and disadvantages before they rate any peer support programs they may have attended. When they are finished rating their peer support experiences, ask if anyone would like to share their experience with the group.

---

Worksheet 2.1

**Did You Pursue Any Peer Support Programs?**

**SECTION I.**

Please provide a brief description of what peer support means to you.

Use the table below to list the pros and cons of attending a peer support program.

Pros	Cons

**SECTION II.** Since completing the HOP baseline program, did you attend a peer support program?

Yes     No

If yes, what was the program called? \_\_\_\_\_

When was the meeting? \_\_\_\_\_

Where was the meeting? \_\_\_\_\_

---

Please complete the following scales about the peer support program you attended.

**I liked the peer support program.**

Disagree greatly			Neither agree nor disagree			Agree greatly
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

**I will go back to the peer support program.**

Disagree greatly			Neither agree nor disagree			Agree greatly
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

**I would recommend this peer support program to others.**

Disagree greatly			Neither agree nor disagree			Agree greatly
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

**Will you return to this peer support program? Why or why not?**

**Will you find another peer support program? Why or why not?**

---

# FOLLOW-UP 3

## What Has Changed?

### FOLLOW-UP OVERVIEW

Experiences since completing the *Honest, Open, Proud* baseline program may have reshaped your thoughts about coming out. In this section we:

- Task 1. Reassess the costs and benefits for disclosure and compare them to what you brainstormed one month ago.
- Task 2. Evaluate what worked and did not work when telling your story and decide how you might change the story.

---

## Task 1. Revisiting the Costs and Benefits of Disclosure

### FOLLOW-UP OBJECTIVES:

- List the costs and benefits of disclosure as you see them now.
- Compare them to costs and benefits you brainstormed before.

---

### **IN THE WORKBOOK:**

***Worksheet 3.1, “Revisiting the Costs and Benefits for Disclosing My Mental Illness”* helps participants to brainstorm the costs and benefits of disclosure for the second time and compare them to what they listed before.**

---

In *Worksheet 3.1* we provide you a table to list the short-term and long-term costs and benefits to disclosing that you can think of now. Note that we do NOT want you to list only the new costs and benefits that you have. Rather, we want you to include EVERYTHING that you can think of, even if you remember that you included it before. As a reminder, benefits represent why you would disclose, or what you expect to happen

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that is positive as a result of disclosing to others. Costs are why you wouldn't do it, or the negatives or harm that could result from disclosing.

**Just like before, don't dismiss any costs or benefits no matter how silly they may seem.** Put them 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 it. After listing all the costs and benefits, put a star (\*) next to one or two that are especially important. When you are finished, you will be given your old cost and benefits worksheet to compare and answer the follow-up questions.

**FACILITATOR INSTRUCTIONS:**

When participants are finished filling out the costs and benefits table at the beginning of *Worksheet 3.1*, please hand back *Worksheet 1.3* from the *HOP* workbook at baseline—The Costs and Benefits Worksheet for Disclosing My Mental Illness— so that they can make comparisons and answer the questions on the second half of the worksheet. When everyone is finished, participants can volunteer to share any new costs and benefits with the group.

---

Worksheet 3.1

**Revisiting the Costs and Benefits for Disclosing My Mental Illness**

Setting: \_\_\_\_\_ To Whom: \_\_\_\_\_

**Since completing the HOP baseline program:**

- I have decided **to disclose** my mental illness.
- I have decided **NOT to disclose** my mental illness.
- I have decided **to put off** my decision.

Please use the tables below to list the costs and benefits of disclosure that you have now, about one month after completing the HOP baseline program.

Just like before, don't censor any ideas. Write them all down.

Put a star (\*) next to costs and benefits that are especially important.

Make sure to specify the setting and audience to which each cost and benefit applies (e.g., work, family, etc.), if more than one is included.

<b>Short-Term Benefits</b>	<b>Short-Term Costs</b>
<b>Long-Term Benefits</b>	<b>Long-Term Costs</b>

---

Please review your copy of *Worksheet 1.3* from the HOP workbook at baseline—**The Costs and Benefits Worksheet for Disclosing My Mental Illness**—and put a circle around items that are the same in both worksheets. When you are finished, please answer the following questions:

**Were there any differences in starred items on the two worksheets?**

**Did you star any of the NEW ITEMS as especially important? If so, which ones?**

**Why do you think you made these changes, if any?**

---

## Task 2. How Will You Tell Your Story Now?

### FOLLOW-UP OBJECTIVES:

- Describe what worked and what did not work when telling your story.
- Brainstorm things to add and things to eliminate from your story.
- Receive feedback from peers.
- Determine whether goals in disclosing have changed.
- Rewrite your story and review how you felt telling it.

---

### IN THE WORKBOOK:

This section includes three worksheets. *Worksheet 3.2 “How Has Your Story Changed?”* helps participants to evaluate their coming out story and decide on any changes. Next, *Worksheet 3.3* provides them with “a guide to setting up a story about [their] experiences with mental illness.” Finally, *Worksheet 3.4* allows them to rate the “quality of experience” after telling their story.

---

One month ago, you were provided with a template on how you might formulate your coming out story. It included the following parts:

1. Your name and what you call your mental illness;
2. Some events in your youth that are typical of most people’s lives and/or that might reflect the beginnings of your mental illness;
3. Ways in which your mental illness emerged, and the age that this occurred;
4. How your mental illness did not go away and your ensuing struggles;
5. Your achievements and accomplishments despite your mental illness;
6. The purpose of your story and struggles with stigma;
7. And the moral of your story:

***I, LIKE ALL PEOPLE WITH MENTAL ILLNESS, LIVE, CONTRIBUTE,  
AND PLAY JUST LIKE YOU.  
SO PLEASE TREAT ME THE SAME. DO NOT VIEW ME OR RESPOND TO  
ME BASED ON ANY UNFAIR STEREOTYPES.***

---

You will be given the story template that you completed one month ago, and you will have the opportunity to use it in order to complete the next worksheet. *Worksheet 3.2* has two parts. **Section I** should only be completed if you have already disclosed. This will give you the opportunity to reflect on parts of your story that did and did not work. **Section II** will then ask you to determine whether there are things that you would like to add or eliminate in your story. If you have not yet disclosed, you should only complete **Section II**. When you are finished brainstorming, please pair up and discuss your ideas with a peer. The last part of the worksheet will ask you to explain whether or not your goal in disclosing has changed as a result of rewriting your story. Once you have finished, *Worksheet 3.3* serves as a fresh copy of the story template so that you can apply any changes that you decided to make in *Worksheet 3.2*.

**FACILITATOR INSTRUCTIONS:**

Before participants start *Worksheet 3.2*, hand back *Worksheet 3.1* from the *HOP Workbook at baseline—A Guide to Setting Up a Story About Your Experiences With Mental Illness*—so that participants can decide what they might change about their story. *Worksheet 3.3* in the booster workbook serves as a fresh copy of the story template so that they can rewrite their story and apply any changes that they decided to make in *Worksheet 3.2*.





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Worksheet 3.3

**A Guide to Setting Up a Story About Your Experiences**  
**With Mental Illness**

Hi, my name is \_\_\_\_\_  
and I have a mental illness called \_\_\_\_\_.

**Let me tell you about my childhood.**

List some events in your youth that are typical of most people's lives and/or that might reflect the beginnings of your mental illness.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**My mental illness started when I was about \_\_\_\_\_ years old.**

List some of the difficult things that happened to you when you first noticed your mental illness beginning.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**Unfortunately, my mental illness did not go away quickly.**

List some of the things that you have struggled with the past several years due to your mental illness.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**I have found my path of recovery living with my illness. What has worked (works) for me includes:**

1. \_\_\_\_\_
2. \_\_\_\_\_

- 
3. \_\_\_\_\_
  4. \_\_\_\_\_

**Along the way, I have experienced some stigma and unfair responses to my illness.** List some of the unfair experiences and harsh reactions you have experienced from society.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**Despite my challenges and sometimes because of them, I have achieved several accomplishments.**

List some of the things that you have accomplished in terms of your work, relationships, and other personal goals.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**I want to end with these two key points:**

1. **I, like all people with mental illness, live, work, and play just like you.**
2. **So, please treat me the same. Do not view me based on any unfair stereotypes.**

### **WHAT DO YOU WANT TO SAY?**

You probably do not want to communicate **EVERYTHING** in the worksheet. Remember your **GOAL** (from *Worksheet 3.2*).

1. **CIRCLE** the information in the sheet you think is important for the person to hear.
2. **PUT A LINE** through any information:
  - a. you believe is too personal (I was assaulted when I was six years old) or
  - b. the person might not understand (Sometimes I hear God's voice).

---

## LET'S TRY IT OUT

Writing your story and saying it out loud are two very different experiences. Now you have a chance to say your rewritten story out loud. First review the points you made in *Worksheet 3.3*. This is going to be your new story. Take five minutes, find a quiet space and one through it in your head. Maybe you want to write out the story on a separate sheet of paper. Now is a time to do so.

Then find a partner and say your story to him or her. When done, complete *Worksheet 3.4, Quality of the Experience*. Try to write in the box anything not captured in the four questions. When done, listen to the story of your partner. Then join the group and share the experience.

**FACILITATOR INSTRUCTIONS:**

When participants are finished rating the quality of their story-telling experience, invite them to communicate any overall questions, comments, or concerns. Ask how they thought the follow-ups went and thank them for their contribution to the booster. Then proceed with a final discussion about disclosure with the group. Allow participants to voice their thoughts and fears and discuss the possibilities of disclosure in the future. Remind participants of contact information in case they feel distressed.

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Worksheet 3.4

**Quality of Experience**

Use the following 7-point scales to rate the quality of your experience telling your story about mental illness. If there were other feelings that you experienced while telling your story, please write them in at the bottom of the page. Don't discount any feelings you had, even if you think others may think they are silly; these are important in developing your strategy for disclosure.

**How empowered do you feel after telling your story?**

not at all empowered			moderately empowered			very empowered
1	2	3	4	5	6	7

**Was it therapeutic to tell your story?**

not at all therapeutic			moderately therapeutic			very therapeutic
1	2	3	4	5	6	7

**How anxious did you feel while telling your story?**

not at all anxious			moderately anxious			very anxious
1	2	3	4	5	6	7

**How positive was your experience telling your story?**

not at all positive			moderately positive			very positive
1	2	3	4	5	6	7

Please note anything else not already discussed about the quality of your experience telling your story.

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# Appendices

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## Appendix 1. Challenging Personally Hurtful Self-Stigma

### LEARNING OBJECTIVES

- Some people internalize stigma and feel shame as a result.
- This lesson teaches ways to manage thoughts related to internalized or self-stigma.

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### IN THE WORKBOOK:

*Table A.1: Change Our Attitudes Exercise* gives Alan’s example to completing *Worksheet A.1*. *Worksheet A.1* 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.

---

Stigmas are hurtful attitudes about people.

- People with mental illness are **violent** and **unpredictable**.
- They **choose** to be mentally ill.
- They are **weak** and **incompetent**.

Some people with mental illness may agree with stigmatizing beliefs like these and internalize them.

- I have a mental illness so I must be **violent** and **unpredictable**.
- I have a mental illness so I **choose** to be mentally ill.
- I have a mental illness so I must be **weak** and **incompetent**.

There are five steps for changing personal hurtful attitudes like these.

Step 1. Begin with a clear statement of the hurtful attitude using the formula:

*I must be \_\_\_\_\_ because \_\_\_\_\_.*

*“I must be a bad person because I am weak due to 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 never feel weak due to life challenges 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 their underlying assumptions are actually false. So, let’s start by challenging the first assumption: *believing that “normal” people never feel weak due to life challenges*. To do this, seek out a circle of trusted people for feedback; for example, a bible study group. In this example, you might also decide to check with your pastor, who you think is reliable and a “*straight shooter*.” From your bible study group you learn that six out of seven people admitted to “*feeling weak*” at times. Then, your pastor tells you that she is sometimes overwhelmed by church work and feels weak. Both your pastor and the people in the bible group said there are many reasons why people feel weak but it does not necessarily mean MENTAL ILLNESS. After speaking with them, you understand that your hurtful belief (*that “normal” people never feel weak due to life challenges*) 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 feeling weak. Everyone does.”*

You may wish to write the counter down on a card so that you remember it better. Then, the next time that you’re feeling bad for weakness, pull out the card. Remind yourself that everyone feels weak once in a while and that there is nothing wrong with it. Use the workbook, specifically *Worksheet A.1* and the example provided by Alan (*Table A.1*) to see how the second assumption: *it is shameful to have a mental illness*, was challenged and countered.

---

## Appendix 2. 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.

- 
- 
- 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,

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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.

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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.

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## Appendix 3. Did This Program Help?

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### IN THE WORKBOOK:

*Worksheet A.2, “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 A.3, “Comparing Your Scores on Self and Community Empowerment-Did Your Scores Improve?”* provides a way to visually compare your scores.

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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.

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*“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.

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*“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.”*

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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.3*. 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.3: 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

\_\_\_\_\_ 1. I am able to accomplish my personal goals.  
 \_\_\_\_\_ 2. I want to change my community’s view of mental illness.  
 \_\_\_\_\_ 3. I have control over my treatment.  
 \_\_\_\_\_ 4. It is okay for me to get mad at people who stigmatize mental illness.  
 \_\_\_\_\_ 5. I am not a bad person because of mental illness.  
 \_\_\_\_\_ 6. We can beat stigma if we work together.  
 \_\_\_\_\_ 7. Things will work out in my future.  
 \_\_\_\_\_ 8. I’m going to make waves about stigma.  
 \_\_\_\_\_ 9. I am okay even if I have a mental illness.  
 \_\_\_\_\_ 10. I get mad at the way mental illness is portrayed on TV.

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.

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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.”*

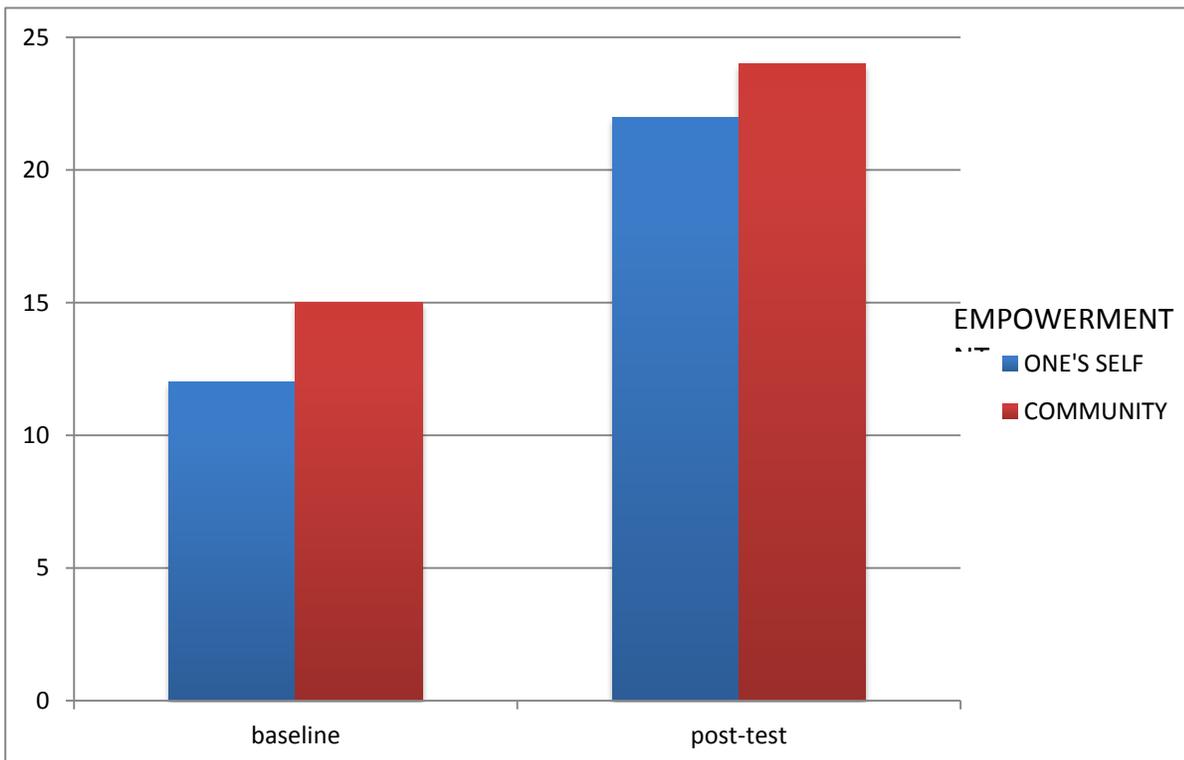
Information in these tests is meant to help people consider issues of self-stigma and empowerment. The final gauge of whether test information is right or wrong is the person taking the test. If the information makes sense or helps the person to stop and think over an issue, then it is probably useful 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

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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.