HONEST, OPEN, PROUD

to Eliminate the Stigma of Mental Illness on College Campuses

MANUAL



FOR PROGRAM FACILITATORS AND PARTICIPANTS
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PREFACE

This is the companion manual to the *HOP on College Campuses* 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 eight 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 workbook. 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.).

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

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

These are all very important issues. The implications are vast. Decisions to disclose one's mental illness will impact one's life in many ways.

The original version of *Honest, Open, Proud* is directed towards people who are working adults. This program started as a chapter on disclosure in Patrick Corrigan and Robert Lundin's *Don't Call Me Nuts: Coping with the Stigma of Mental Illness (DCMN*; published by Recovery Press, Tinley Park, IL, 2001). Maya Al-Khouja and Patrick Corrigan recreated this program to address the stigma of mental illness on college campuses, college age being the age of onset for many mental illnesses. This program was developed by a group of diverse college students at the Illinois Institute of Technology to ensure that the program had the accuracy to apply to all college students. To adapt the program, we created a focus group comprised of both current college students and recent college graduates. We used this group to create an outline of issues uniquely faced by college students who have a mental illness, using this adapted program to address those issues.

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

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

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

Acknowledgements

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About the Authors

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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 health challenges 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,
- Everyone's opinion counts, and
- We respect each other.

The facilitators should also discuss with the group whether other ground rules might be helpful. Consensus should be sought if extra rules are proposed. Introductions and ground rules should be repeated prior to all subsequent lessons. The goal is to create an

open environment where people feel comfortable sharing their opinions and feelings should they choose to do so.	

LESSON 1

Consider 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.

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 while others do. 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 -- *Challenging Personally Hurtful Self-Stigma* -- when in this situation.

IN THE WORKBOOK:

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

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

Marie is 21 years old and has had about five years of struggling with bipolar disorder. Despite this disability, things are working out well: she hasn't been hospitalized in two years, she's working a good job on-campus, she's earning good grades in all of her classes, and she's living with a supportive roommate. By many people's standards, she has beat her mental illness and recovered. 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. Mary speaks out at campus events where she publicly discloses as a person with mental illness who is outraged by the disrespectful images of mental illness that are rampant in our society as well as on campus. Marie is a person who identifies herself as "mentally ill."

John Henry has a very similar history to Marie. He has struggled with bipolar disorder since he was 16. Now, he is 21, involved in a debate team on campus, and working a great internship to complement his business major. He has not been hospitalized in two years and almost no one at his internship or in his social circle on campus 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 <u>should</u> publicly label themselves as mentally ill. Openly disclosing one's experiences with mental illness is a complex decision that each person needs to make for him or herself. The purpose of the *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: "*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 I of *Worksheet 1.1* helps participants consider these options. Hand out *Worksheet 1.1* and give participants 10 minutes to complete Section I. Then, lead a discussion based on participant responses to the questions.

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 limiting wellness center). 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 *erasing the stigma of mental illness*. While terms like *people with mental health* and *people in recovery* might hurt less, they may confuse the public about the stigma issue. We believe it is mental <u>illness</u> and not mental health that is stigmatized by the population. 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. After completing the discussion, participants should state way(s) they wish to be identified in terms of their experience with stigma. Section II of *Worksheet 1.1* directs participants through these issues. Words, like identification, are not a onetime 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.

Task 2. Considering the Pros and Cons of Disclosing

LEARNING OBJECTIVES

- There are both benefits and costs to disclosing.
- Only you can weigh them to decide whether it is worth disclosing.
- Costs and benefits differ depending on the setting; for example, in a classroom versus among your roommates.

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.

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

George never talks about his illness; he never voluntarily discloses it.

George lives with his parents while going to university with frequent episodes of depression. He has never breathed a word of his depression to his parents, siblings, or anyone on campus. Why is George so secretive? He is attending a prestigious university where he believes showing as much as a glimmer of weakness could be fatal to his GPA. His symptoms are tolerable, so he carries on in silence.

Susan, on the other hand, lives in an encouraging home with parents who understand her mental illness. Her mental illness is discussed freely and openly among her family members. Gathering strength from her family, Susan is actively encouraged to disclose her schizophrenia at her college. Susan has made great strides in managing her illness. She is proud and gets praise for sharing her recovery from the depths of psychosis and depression.

Some Costs and Benefits of Disclosure

There are a variety of reasons why you might choose not to disclose your experience with mental illness. These could be considered *costs*, or reasons why you may regret disclosing. On the other hand, *benefits* are reasons why disclosure will help you. Several of these are summarized in *Table 1.1* (*Table 1.4* in the Workbook). Let us consider the benefits first, the reasons why letting other people know about your psychiatric disabilities may help you.

Table 1.1: Some Costs and Benefits of Coming Out with Mental Illness			
Benefits	Costs		
You don't have to worry about hiding your mental illness.	Others may disapprove of your mental illness or your disclosure.		
You can be more open about your day-to-day affairs.	Others may gossip about you.		
Others may express approval.	Others may exclude you from social gatherings.		
Others may have similar experiences.	Others may exclude you from university events, 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 about your secret getting out anymore. 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 the frat finding out that I was leaving early to see my psychiatrist. Now, it doesn't matter."

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 school."

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

You might be pleasantly surprised to find out that *others have similar problems*. Frequently, people discover that when they admit to psychiatric problems, others respond "*me too*." Given that more than 20% of the population are struggling with some kind of mental illness (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 after class, I dropped by Betty's dorm room 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. Peer-support groups provide a place where you can let your secrets out. They are places where people with mental illness can 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 my friends about my experiences with manic depression. I didn't feel like the meek lamb anymore. I had something to say, I looked them in the eyes, and I said it."

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

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

"It was so educational sitting next to Jim in class. I thought "mental patients" were all dangerous and could never go to college. Jim was the best student in our class and 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 reason 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. 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 classrooms and dorms. 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 on-campus organization opportunities. An organization president might keep you away from the group because of hostility: I'm not having that crazy in my sorority."

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, "We 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 my football team and they were patronizing. 'Don't stress yourself, pal. Don't work too hard, buddy.' I would have rather had their scorn."

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 office are ribbing me about my 'psycho' son."

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

Weighing the Costs and Benefits of Disclosing

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

The impact of costs and benefits are sometimes relatively immediate; at other times, the impact is delayed. For example, Alan identified short-term costs ("If I tell my classmates that I have been hospitalized for major depression they may not want to meet me for lunch on Wednesday.") and short-term benefits ("Perhaps other people in my class could help me deal with our intimidating professor if they knew about my mental illness.") related to telling classmates. He also identified long-term costs ("If I tell my classmates I have regular bouts of depression, they might not invite me to join their study group.") and benefits ("If I tell, my professor he may provide me some extra help on assignments and exams."). Generally, people tend to be more influenced by short-term costs and benefits because they happen sooner. But, 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 hang out 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 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. In *Table 1.2* (*Table 1.3* in the Workbook) two benefits stood out for Alan. First, he thinks that he will be able to make more friends in class. In the past, he has avoided socializing and studying with classmates because he worried that they were going to find out his secret. Second, opening up to his professor will help him to avoid dropping or failing the class. He also starred one cost: Alan was concerned that people would talk about him and spread rumors about his mental illness.

Table 1.2: Example for Alan	Setting: Classroom
Short-Term Benefits	Short-Term Costs
 Others help me deal with our intimidating professor. Don't have to keep it hidden. May identify classmates with similar problems. Make more friends in class. * 	Classmates won't ask me to lunch.Worry about others talking about me.Get left out of group study sessions.
Long-Term Benefits	Long-Term Costs
 Professor provides extra help. I get help through class accommodations. Avoid dropping or failing the class. * 	Classmates won't study with me.Rumors start about me. *I drop the class in embarrassment.

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 classmates rumors might start about me."). Or, you may mark items that suggest a lot of hope ("Maybe if I tell my classmates I will make more friends."). Some people consider the list of advantages and disadvantages in Table 1.1 on page 12 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 not in the list that is especially relevant to you.

Your decision depends on the setting. Costs and benefits of disclosing your experience vary by the situation you are in. The example for Alan concerned his classes. Telling people your history with psychiatric experience is a lot different in your classes than in your fraternity or with your rugby teammates. You could conceivably decide to tell people on your sports team but not those in your classes, or tell your close friends but not your roommates. Hence, you need to list costs and benefits of disclosing your lived experience with mental illness separately for each setting that is important to you. You can do this by making copies of *Costs and Benefits Worksheet 1.3* and enter the name of each setting and the person to whom you might disclose on the first line at the top of the form: fraternity(e.g. president), classroom (e.g. professor), social groups (your girlfriend), synagogue (your rabbi), or family (your cousin). Then write down costs and benefits of disclosing to that person in each setting.

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

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

<u>What is your decision</u>? The purpose of *Worksheet 1.3* is to yield a decision about whether or not 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 the worksheet. 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 to my fraternity!"

Some people may not be able to make a decision about disclosing after reviewing costs and benefits; you may need to decide to postpone your 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 seek advice, you are going to have to disclose your illness to the people from whom you seek advice.

Family members may be good sources of advice. That being said, don't forget that your decision may impact them and their image 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 friends, might tell you to keep your lips sealed.

<u>Disclosure is a journey</u>. 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.

Disclosing your experiences with mental illness is a *journey*, just like any important life decision. Hence, there are five extra copies of *Worksheet 1.3* in Appendix 4 of the Workbook. You may find yourself filling out the *Costs and Benefits Worksheet* several times in your life and coming up with different conclusions each time.

LESSON 2

There are Different Ways to Disclose

LESSON OVERVIEW

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

- Task 1 We describe five ways here, and then guide you through considering the costs and benefits associated with each strategy.
 - a. We clarify the differences in disclosing face to face versus over social media.
- 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.

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.
- Discuss using social media to disclose to someone versus disclosing face to face.

IN THE WORKBOOK:

Table 2.1 "Five Ways to Disclose of 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 organization.

Worksheet 2.3, "Social Media Disclosure" discusses the costs and benefits of in person disclosure versus disclosure over social media

Depending on your decision, there are a variety of ways in which you might 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 sports team and immediate family), keep it a secret in other situations (e.g., not tell any of my classmates), and avoid a third set of situations altogether (e.g., not go out with my roommate after class—they would make fun of me if they found out).

Table 2.1: Five Ways to Disclose or Not Disclose

1. SOCIAL AVOIDANCE: Not telling anyone about your mental illness and avoiding situations where people may find out about it.

Benefit: You don't encounter people who will unfairly harm you.

Cost: You lose the opportunity to meet new people who may possibly be supportive.

2. SECRECY: Participating in campus activities and school organizations, but keeping your mental illness a secret.

Benefit: Like social avoidance, you withhold information about your mental illness from others. But, you don't avoid important settings like the campus community in the process.

Cost: Some people feel guilty about keeping secrets. You may also receive less support from others because they are unaware of your mental illness.

3. SELECTIVE DISCLOSURE: Disclosing your mental illness to selected individuals, like professor, significant others or family members, but not to everyone.

Benefit: You find a small group of people who will understand your experiences and provide support.

Cost: You may disclose to some people who then hurt you with the information. You may have difficulty keeping track of who knows and who doesn't.

4. INDISCRIMINANT DISCLOSURE: Making the decision to no longer conceal your mental illness; this does not mean, however, that you are telling everyone your story.

Benefit: You don't worry who knows about your problems. And you are likely to find people who will be supportive.

Cost: You may tell people who then hurt you with the information.

5. BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people about your experience with mental illness.

Benefit: You don't have to worry who knows about your history of mental illness. You are promoting a personal sense of empowerment in yourself. You are striking a blow against stigma.

Cost: You are going to encounter people who may try to hurt you with this information. You are also going to meet people who disapprove of your political statement.

1. Social Avoidance

Ironically, the first way to handle disclosure may be to not tell anyone. This means avoiding situations where people may find out about one's mental illness. People who are victimized by stigma may choose not to socialize with or work alongside people without disabilities. Instead, they only associate with other people who have mental illness. This may include interacting only 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.

Unfortunately, there are major negatives to social avoidance. People who choose

to avoid the "normal" world lose out on all the benefits that it brings, such as free access to a broader set of opportunities and citizens who support your experience with mental illness. Moreover, in some ways, social avoidance promotes stigma and discrimination. It endorses the idea that people with mental illness need to be locked away from the rest of the world. People who choose to avoid social situations may be putting off a challenge that they must eventually face. Social avoidance may be a useful strategy during times when symptoms are intense and the person needs a respite from the demands of society. But, avoiding the normal world altogether will likely prevent most people from achieving the breadth of their life goals.

2. Secrecy

There is no need to avoid university 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 is a popular student in his third year of college and none of his classmates suspect that he has been struggling with anxiety disorders. Cynthia lives with her parents while commuting to school every day. She never let them know about her depression. Tarik went to mosque weekly and never let others know his history with ADHD. It wasn't too hard for each of these individuals to hide their psychiatric history.

<u>But can't they tell I'm mentally ill?</u> 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. Roommates may think you're depression is temporary blues. Professors 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 miss 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. If you dress within customary bounds, you'll be overlooked.

<u>How do I keep it private?</u> There is a process to keeping your mental health history secret. The first step is *don't tell anyone*. Don't share your history of hospitalizations, doctors, medications, and symptoms.

The next step is to clue in any friends or family members who are familiar with your experiences and may need to be included in the secret. At a minimum, you cannot permit your parents to tell their co-workers or friends your psychiatric history if you are trying to maintain your privacy: let them know you have secrets from others.

"Dad, I told everyone at the fraternity 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 my friend comes over today."

For some, these acts of deceit are a disadvantage of secrecy: "Why do I have to lie about my mental illness?" It can be even harder when they ask family members or friends to participate in the secret. Other individuals like to think of this secrecy as more of a process of telling one's life experiences in a manner that is palatable to 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 individuals such as friends or to their significant other. These people are taking a risk, however, as those who find out may shun them.

- "I don't want to be friends with a mental patient."
- "I don't want to be with someone who had to be hospitalized."

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 Annie knew, it was such a freeing feeling to open up to her. She is really supportive."

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 is 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 family, guys on my football 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 2.2* on page 36) are still relevant for selecting people to tell. The difference is that you no longer worry about hiding your history from the world.

Reframe your experience. Most people have to change the way they view their mental illness if they are to opt for indiscriminant disclosure. This may mean adjusting a lifelong attitude about the place of mental illness in society. In the past, you probably viewed mental illness as something that is disparaged by others and, therefore, should be kept secret. The desire to keep mental illness a secret needs to change radically for you to partake in indiscriminant disclosure.

This redefinition may require accepting mental illness as part of *who you are*. Mental illness is not a bad part of you that needs to be rejected. It is one of many qualities that describe you: right-handed, brown haired, skilled in math, fair-skinned, blue eyed, tall, poor at sports, and bi-polar. 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, 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 saying things like:

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

<u>Can you handle disclosure?</u> 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.

5. Broadcast Your Experience

Indiscriminant disclosure means no longer trying to hide your mental illness. On the other hand, you are not likely to go out of your way to inform people about it.

Broadcasting your experience means educating people about mental illness. It's similar to coming out of the closet in the gay community; the goal is to actively let people know your experience with mental illness. This kind of disclosure is much more than dropping your guard and throwing away any notion of secrecy. Your goal is to seek out many people with whom to share your past history and current experiences with mental illness.

Broadcasting your experience has the same benefits as indiscriminant disclosure. You no longer need to worry about keeping a secret. You will also find people who may provide understanding, support, and assistance to you because of your message. However, people who choose to broadcast their experience seem to derive an additional

benefit. Namely, it seems to foster their sense of power over the experience of mental illness and stigma. No longer must they cower because of feelings of inferiority.

"I'm equal to everyone else. I have nothing to hide."

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

"I'm angry; every time I question my meds, my doctor thinks I'm acting out and puts me back in the hospital. I'm unable 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, like indiscriminate disclosure, and more. Citizens who hear someone's story about mental illness frequently battle the message and the messenger. Like the person choosing indiscriminate disclosure, broadcasters get hostile reactions to their messages.

"Why do I have to dorm with a crazy guy like you? You're dangerous to my well-being. 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 try to treat everyone the same. Why do you have to go and make trouble? Just go through your

college years 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 try a role-play exercise to find out if you can handle this. Determine whether your emotional response is excessive.

Instruct participants to work through *Worksheets 2.1 and 2.2: Costs and Benefits* of the Five Ways to Disclose. Worksheet 2.1 has participants consider the five ways to disclose for Allison Miller, a student with bipolar disorder who is president of her sorority. Worksheet 2.2 has participants consider the five ways to disclose with their own chosen setting: an organization they either attend currently, attended in the past, or would wish to attend in the future.

a. Social Media Disclosure

If you decide to disclose, you might choose to do so face to face or using various social media. *Worksheet 2.3* describes three different categories of social media that can be used to disclose your mental illness and some examples of costs and benefits of each category. The first category of social media you can use is online video chat, in which you talk to someone face-to-face without needing to meet in person. Popular types of online video chat include programs like Skype or FaceTime. There are benefits to using online video chat, such as the ability to express emotion, and to see his or her reaction. You will also be able to have a full conversation with someone who is living far away, such as a friend from home or a family member.

"I couldn't wait until going back home for Christmas to tell my mom about my mental illness, so I told her over Skype. She was very supportive and said she would come visit me on campus soon."

The drawbacks to this kind of disclosure is that conversation will not be as personal as disclosing to someone in person. You will also be speaking in real time to the person you are disclosing to, so it might be a good idea to plan what you want to say.

The second kind of social media is private messages. Including text messages, emails, and private Facebook messages. One benefit for this kind of disclosure is that you can plan and write what you want to say completely before sending the message. This makes disclosure less stressful: you don't have to look the person in the eye and disclose but instead can tell the person privately over a carefully thought-out message. Costs of using this form of disclosure may be great. Sending the message privately does not mean it will stay private. Unlike online video chat, written messages can be shared with others whether you want them to be or not.

"I cannot believe Sarah shared my text with Tabatha. I wasn't ready for other people to know about my bipolar disorder but now everyone on my residence floor will know."

People can be insensitive to your personal issues and think of them as juicy gossip to be shared with others. When using this method, people must be wary of who they are sharing the message with, making sure they are trustworthy people who are empathic. Another cost is that writing out a message conveys no emotion to the person you are disclosing to. This can lead to misunderstandings in what you are trying to say or even cause the person to not take you seriously.

The final category of social media that can be used for disclosure is public messages. This type of disclosure should only be used if you are trying to broadcast your experience to anyone and are not fazed by who knows about your mental illness. Examples of media like this include Twitter, Instagram, blog posts, and public Facebook statuses. Benefits of this include finally being "out" to everyone all at once, freeing yourself from keeping secrets from others, and having an opportunity to educate the public about your mental illness.

"I tweeted that I was on my way to the psychiatrist for my depression and a bunch of people retweeted my message with supportive comments about mental health!" Although you might receive some support, you may also get negative comments from people who are not educated on the topic. Everyone can see what you post in a public message and everyone has opinions that they like to voice anonymously online.

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.

In the previous section, we showed that people might disclose their experiences 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.

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 2.4, "Testing a Person For Disclosure" provides a way to test whether a person might be a good person to disclose to.

Who is a good person to disclose to? Selective disclosure does not mean sharing your experiences with everyone. You need to identify people who are likely to respond positively to your message. There are several reasons why you might pick a specific person to disclose to. *Table 2.2* on the page 35 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. He or she sees you in order to diagnose and treat your mental illness. Thus, addressing the mental illness is the grounds for developing the relationship. The same type of relationship might be true with your family doctor or a school counselor.

You might consider disclosing to a person with whom you have developed a **supportive** relationship. Friendly and kind people may be more likely to 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 others take interest in you and seem 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.

This demonstrates one facet of 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.

Table 2.2: 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

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

"Hey Mary. Did you see the movie The Perks of Being a Wallflower? Logan Lerman was in it. He portrayed a boy who had Post Traumatic Stress Disorder, although he himself did not know until the end. I was really impressed by the movie; 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 to the followup questions in *Worksheet 2.4* if she said:

"Yeah... I saw that. I have a friend with PTSD and movies like that one 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, as a person to whom you might disclose. What if Mary had said:

"You know, I am sick and tired of these kinds of cry baby movies 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, 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.

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

"No, I'm not still mentally ill in the sense that I need to be hospitalized.

Sometimes I get a little depressed. But I can handle it."

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

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

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

"As I got to know Miguel, I told him more and more about my experience with depression. He had never been diagnosed as depressed but he still knew what I was talking about; everyone has off-days"

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 Renee. 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 still friendly 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 in my sorority know. I wanted Marie to understand why I had to leave chapter meetings early on Wednesdays for my therapist's appointment. More importantly, I just didn't want to have to keep my illness a secret from her any longer. Her reaction was a pleasant surprise: Marie told me that sometimes she suffers from depression too. 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 2.3* (*Worksheet 1.2* in the workbook).

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. 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 2.3: Some Reasons People Disclose

To tell the secret

- "I just wanted someone else to know that I get help 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

"I can go to the University Disabilities Office to get accommodations for class assignments."

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 doctor. It might be emotional assistance, such as gaining someone to talk with about his or her illness. Finally, there can be legal reasons for disclosing a mental illness.

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.

IN THE WORKBOOK:

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

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 2.4 (Table 2.3* in the workbook) on the next page lists a variety of reactions to disclosure, which are sorted into groups by two factors.

Factor 1. <u>Emotional Response</u>: Peoples' emotional responses to you may be positive or negative.

Factor 2. <u>Behavioral Reaction</u>: 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 feeling blue."

Table 2.4: How People Might Respond to Your Disclosure





EMOTIONAL RESPONSE					
Positive Negative					
Understanding "It must be hard living with your illness and the secret."	Disrespect "I don't want some dangerous loony like you around."				
Interpersonal Support "I'm here for you if you need someone to talk to."	Denial "I'm not giving you any special breaks because of your mental illness."				
Assistance "Let me know if you need extra help to complete the class assignment."	Retribution "I'll get you kicked off the team. I don't have to practice with a crazy guy like you."				
	Fear/Avoidance "You're dangerous. I'm staying away."				
	Gossip "Hey, did you hear about Joe? He was hospitalized for depression."				
	Blame "I have the same kind of problems as Gayle but I don't go around and blab about it."				

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 frat know about your psych problems. I've 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 lunch. 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 students 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 on our soccer team hear about this. You're out of the game 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. And even though they avoid you, you may become the target 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 cause a commotion with talk about your mental illness?").

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

LESSON 3Telling 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 tasks:

- Task 1 Learn a way to tell your story in a personally meaningful way.
- Task 2 Review how telling your story felt.
- Task 3 Put together all you've learned in order to move forward.

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 telling your story.

IN THE WORKBOOK:

Table 3.1, "David Goldberg's Story presents you with an example story of a college student living with mental illness.

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

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

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

As an example, we include a story developed and presented by David Goldberg in the workbook (see *Table 3.1* on the next page). David has struggled with depression since he was 12 years old. As of the 2015, he is 24 years old and has many accomplishments including earning a master's degree from the Illinois Institute of Technology.

Elements of a good story. David'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 <u>your</u> 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 David did this: he illustrates his story with specific people, places, and times. People learn much better by explicit example ("My self-loathing and suicidal ideation was worse than ever"), as opposed to heady abstraction ("Self-loathing is like a dark cloth causing utter sadness."). Listeners can clearly imagine having feelings of depression to the point of self-loathing, whereas the dark cloth metaphor is vague and more difficult to make sense of.



Table 3.1: David Goldberg's Story

My name is David Goldberg and I have a mental illness. I'm sure many of you have heard of depression. This is a serious mental illness that has caused major problems in my life. I was born in Delaware, to a loving family. I lived there for about 6 years, attended Montessori when I was age 4 and 5. Shortly before we moved from Delaware, my sister was born. My family and I moved to Minnesota when my dad was transferred to work in Minneapolis. You might be thinking if you've moved before, that moving can be a traumatic experience. Believe me, it can be, but not at this point in my life. I remember being excited to start elementary school (and a bit nervous).

Elementary school was mostly uneventful. I was enrolled in primarily accelerated/gifted classes. I spent most of my time hanging out with the neighborhood kids and a couple good friends down the street. The only negative thing I can really think of is being picked on for being nerdy and overweight. That upset me, but it wasn't until middle school where I started experiencing some more serious problems.

In the middle of sixth grade, things started to change. I was invited to join the International Baccalaureate program because I performed very well academically in elementary school. Unfortunately, this meant a lot more work. I wouldn't really call it a "program for smart kids". It was more that the amount of homework we received sucked the life out of us. Academically, I wasn't doing so great. There was a ton of competitive pressure and my dad was laid off from his job.

When my dad lost his job, I knew that it meant we would have to move again. I had plenty of friends and I liked Minnesota, but that would all soon change. When my mom told me the news, we both cried. It's still clear in my mind. We were driving home from school in the old minivan. She said we'd have to make some changes, which basically meant less spending, but that didn't bother me. I was just concerned about moving. My mental illness started when I was about 12 years old.

My dad found a new job in Des Plaines, IL. This the first time I remember feeling "depressed". Nothing else seemed to matter anymore. I struggled with telling my friends that I was leaving. My mom called several of them and told them the news. I was not the same

happy kid that I used to be. My personality became much darker. I found solace in heavy metal and violent games and movies. I felt down and sad a lot more than I ever had before. School now became a challenge. I didn't really care. My grades turned from A's and B's to B's and C's. My mediocre grades placed me into the "slow" classes. I continued to be on the slow track throughout high school and I really do blame my mental illness for this. I really started to self-handicap myself by never studying, but this isn't just about school. I began to have trouble committing to friends and family obligations for fear of having to leave them behind. Regret was common for me. I tended to dwell on the past, believing life would be so much better if we never moved. Minnesota was great for me and suddenly I'm dragged down to shitty Illinois. There's certainly more to this part, but I'm afraid I don't remember a lot from 12 years ago. Freud might say that I'm repressing those memories.

I continued to suffer in school. My parents took me to see a psychologist, Dr. Hayes, whom I met with on a regular basis until I graduated high school. It was nice having a neutral party to talk to. My family and I fought a lot at this time in my life. If I even brought up an idea, I felt like my parents would just shoot it down. It's like they had to approve of anything I thought of. This was very disheartening for me.

I began to develop a fascination with swords, knives and axes, which led to me buying my first katana at age 13. Whenever I became upset or angry, I'd always find comfort in my weapons. I'd walk around the room, holding one, admiring its blade. This was a type of suicidal ideation. Although I never injured myself, I thought about it quite often. Hurting myself seemed like a wonderful idea, but at the same time, I never liked the sight of blood and I knew this would negatively impact my future. I had some friends who cut, but I had the discipline to stop myself. As for my friends who did, I can't blame them.

Fast forward a few years. High school was the worst. I felt like I was in prison. One wrong move and the teachers would bust you for anything. But it wasn't just the teachers, it was my friends, too. I got harassed many times for being Jewish. I never even knew what a "kike" was until someone called me by the word. This happened on a semi-regular basis, but there was one time that was exceptionally bad. I was surrounded by a group of students in a circle, who chanted hurtful things like "stupid Jew" and "kike" and "Christ killer". I managed to break out of the circle. Once I got home, I cried to my parents. They tried to comfort me and together we went to the dean. The good news was that no one bothered me for my religion anymore, but now I'd been labeled as a tattle-tale. This happened when I was a junior. My junior year was easily the worst year in high school. It got so bad, I considered dropping out. My parents convinced me that education was the path to freedom and instead I graduated a semester early.

How does this relate to my depression? I was incredibly disturbed by this event and my self-loathing and suicidal ideation was worse than ever. Had I not had a supportive family and a great therapist, I don't think I'd be alive today. This event kept coming up in my counseling sessions. It took me quite some time to get over this and I'm a pretty resilient person. I'm not trying to say that my life was any harder than anyone else's. I know a lot of people who struggled during high school, but this bullying really made me struggle on top of

my chronic depression. Bullying someone for being different is such a terrible thing and I'm afraid I just don't understand the motive.

When I went away to college, my relationship with my family improved greatly. I had that freedom I had always wanted. The first year away was great! I was happy to be four hours away. I may have partied a bit too much my first semester, but I straightened up my act. This was the first time in my life I really didn't experience depression. I had a strong group of friends. My dorm roommate and I got along great!

However, depression is a chronic condition. The next year, I began to hate Springfield. I realized that such a small school wasn't for me. I ended up transferring to University of Illinois at Chicago. Life improved greatly. I loved living in the city. I no longer had to deal with bullying (from high school). I still suffered from anxiety and depression in this new environment. However, I was consistently happier than I ever had been. Depression was something I could shove under the rug and not worry about it. I joined a fraternity and am still active with my chapter today. My support group was like a tree with many, many branches.

After college, life got bad. I was a poor college graduate. I needed money, so I found a job completely unrelated to my field, shipping John Deere tractors all over the world. It was alright at first, but I quickly discovered the hypocrisy of the corporate workplace. The money was good, but the authoritarian style environment was just awful. I called in sick many times just to get a break from the terrible office. Because I was so depressed, I decided I needed to get out of there. I applied to Illinois Institute of Technology, and they accepted me!

I was working 25 hours/week at the same company during my first semester there. It was rough. I quit after a few months. Several colleagues commented on how much happier I seemed. I was finally working toward a field I had gone to college for. I started taking anti-depressants about a year ago. That and a healthy lifestyle have really improved my quality of life. I still get depressed once in a while, but life's not perfect. I'm proud to say that my mental illness is manageable.

Despite these problems, I have achieved several accomplishments. I graduated from UIC in 2011 and will be graduating from IIT in May 2014. I have a 4.0 grade point average. I've discovered that I belong in academia and intend to pursue a PhD in the future. I have traveled to over 40 states as well as several foreign countries. I was awarded a Black Belt in Karate and Tae Kwon Do when I was 16. I still actively practice. I am financially independent and now have a great relationship with my family.

Despite my accomplishments, I have experienced some stigma and unfair responses to my illness. The first thing that comes to mind is my family "dumbing me down", rejecting my ideas while I was depressed. If they could have just listened more, I think our relationship would've improved while I was living at home.

I "came out" to a few people in 2011 and got some surprisingly negative responses. "Why don't you just be happy?" "Get over it!" "You have no reason to be sad. You have a loving family. Unlike you, I've seen some REAL shit in my life." If you're thinking about coming out, that's great, but you should really weigh the pros and cons before you actually do. A couple friends have been amazed that mental illness runs in my family. When I told

them, they didn't understand. "It's genetic? But how? You're not always depressed." I explained that Bipolar disorder and depression are common throughout my mother's side of the family. There were a couple distant relatives who had schizophrenia. Another relative committed suicide before I was born. He would have been diagnosed with PTSD.

The group should now consider the following discussion questions.

- What are some of the things you liked about his story?
- How does it reflect a story of recovery?
- What parts of it might have been hard to tell?
- What parts might you have said differently?

Presentations need to be truthful; don't try to embellish them. You shouldn't tell your story in an overly positive light: "Mental illness isn't that bad. I survived my three suicide attempts easily." Listeners might get the idea that your depression was not really challenging or that you did not have a "real" mental illness. Nor should you try to paint too bad a picture: "Being in a psych hospital is like living in a rat-infested slum."

Although it is true that losing the liberty to come and go from an inpatient ward is demoralizing, some people are likely to think that you have a political agenda and are misrepresenting experiences when you use extreme examples. Moreover, when you stray from the facts, you are likely to say something that is not truthful—"Were you really in restraints and not fed for an entire week?"—and lose your credibility as a result. Be reassured that your story of struggles with mental illness is compelling enough to get most listeners' attention.

There may be some aspects of mental illness that you are still struggling with and do not want to talk about publicly. *Don't feel that you have to discuss everything*. Respect your own sense of privacy. If, for example, you feel uncertain or embarrassed about an unrealistic fear of riding in elevators, there is no need to air this problem with

others. Only share those concerns that you have already resolved in your life. Don't get pushed into telling your story in public until you are ready. Talking to others 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.

David'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. David, for example, noted that he had a normal childhood with loving parents supporting him. 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 and I had never failed at anything I put my mind to. But things were very different and I needed to take time off from college."

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

The take-home message in David'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.* David talks about his achievements that show recovery.

"I graduated from UIC in 2011 and IIT in 2014. I have a 4.0 grade point average. I've discovered that I belong in academia and intend to pursue a PhD in the future."

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. 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 live, go to class, and study 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.

How much should I prepare my presentation ahead of time? The workbook includes *Worksheet 3.1* that will help you to write out a biography that reflects the key parts of your story. Some of you may want to use this exercise to carefully plan all of the details of your presentations. Others may wish to use it as a loose outline for an extemporaneous, off-the-cuff speech.

Task 2. How Did It Go?

LEARNING OBJECTIVES

Learn how to evaluate a specific instance of disclosure.

IN THE WORKBOOK:

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

This section provides guidance on how to evaluate a specific instance of disclosure. Worksheet 3.3, 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 happened. Scores in between 6 and 10 mean that more information may be needed before going forward.

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Task 3. 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 3.4, "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 3.4*, questions are provided so that participants can summarize insights and decide on future directions. These questions are summarized in *Table 3.3*, 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 3.3: 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)
- How do you want to 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)
- List three things you might do in terms of coming out in the future.

BOOSTER MANUAL

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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 on College Campuses* 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 intensions to disclose after you completed the *HOP on college campuses* 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., professor or classmate),

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

FACILITATOR INSTRUCTIONS:

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

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 3.4 in the Honest, Open, Proud on College Campuses 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.

FOLLOW-UP 2

Social Media Disclosure

FOLLOW-UP OVERVIEW

In this day and age, people are becoming very comfortable with social media. In fact, you may have decided to disclose through social media. This section assesses your experiences with social media outlets since completing the *Honest, Open, Proud* baseline program.

Task 1 We discuss which social media outlet you used to disclose and list the costs and benefits. If you did not decide to disclose through social media, we discuss that decision.

Task 1. Did You Disclose Through Social Media?

FOLLOW-UP OBJECTIVES:

- Discuss which social media outlet you used.
- Identify costs and benefits of disclosing through social media.
- Determine why you may not have used social media.

IN THE WORKBOOK:

Worksheet 2.1, "Did You Disclose Through Social Media?" helps participants to list the pros and cons of disclosing through social media.

One month ago, everyone in the group brainstormed the costs and benefits of using different forms of social media. In *Worksheet 2.1*, indicate whether or not you decided to use social media to disclose, discuss which outlet you used, and list the costs and benefits of the experience. If you did not use social media to disclose, please skip to the last question of the worksheet and discuss that decision.

FACILITATOR INSTRUCTIONS:

After participants are finished filling out *Worksheet 2.1*, lead a group discussion of the costs and benefits of their experiences of disclosure through social media. If they did not disclose, encourage them to discuss their reasons for making that decision with the group.

FOLLOW-UP 3

What Has Changed?

FOLLOW-UP OVERVIEW

Experiences since completing the *Honest, Open, Proud on college campuses* 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

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.

<u>May seem.</u> 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

FACILITATOR INSTRUCTIONS:

follow-up questions.

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.

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 AND CONTRIBUTE 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.

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*.

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.

IN THE WORKBOOK:

Table A.1: Change Our Attitudes Exercise shows Alan's example of redefining the attitudes you hold about your mental illness

Worksheet A.1 provides a way to challenge stigmatizing attitudes in the "Change Our Attitudes Exercise."

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	a clear	statement	of the	hurtful	attitude	using	the	formu	la:
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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 basketball team you are a part of. In this example, you might also decide to check with your coach, who you think is reliable and a "straight shooter." From your basketball team you learn that six out of seven people admitted to "feeling weak" at times. Then, your coach tells you that he is sometimes overwhelmed by his work and feels weak. Both your coach and the people in the basketball team 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 feels weak sometimes."

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 college students have a right to privacy but the laws in this area are pretty complex.

- ➤ All mental health professionals, whether on or off campus, are ethically bound to keep what you say during therapy confidential from everyone (including your parents and professors) unless you specifically authorize the release of information about your diagnosis and treatment.
- School counseling centers and outside providers generally will not release your medical information—including to family, parents/legal guardians or faculty—without your written authorization.
 - O However, there are practical issues. If your parents get insurance statements or bills related to your care, they will know you are seeing a therapist. Also, as noted above, disclosure without your consent is permitted to protect your safety and the safety of others.
- School administrators, faculty, disability services coordinators, resident advisors and other staff are bound by different confidentiality restrictions. The interested reader should consult a knowledgeable attorney about those complex issues. One might start with the general counsel's office present at most universities

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. However, it usually also includes 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.

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.

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 classmates 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.

Appendix 3. Did This Program Help?

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.

One way we believe the *Honest, Open, 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 <u>personal empowerment</u>.

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 <u>absence</u> 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 <u>positive</u> ways: the affirmative way in which individuals view themselves, and the affirmative way in which people interact with their community.

Empowerment and One's Sense of Self

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

"I am a good person. Sure, I might have a mental illness. But, I'm also a son; a brother; a boyfriend, friend; a good student, a member of a fraternity that does a lot of charity work. 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 a hard science major. Why bother trying for something that will cause me a lot of stress? I'm not up for a challenging major. 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 being an engineering major."

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

"My doctors always meant well. But they robbed me of control over my life. They said I wouldn't have serious relationships, I couldn't live on my own, and that I'd never handle college well. I felt like a spectator watching my life go by. And it was a horrendous feeling. Now I have a different outlook. I can accomplish my goals. I don't need to wait for others. And the return of personal power has made me super human."

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

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

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

Empowerment and One's Community

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

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

People who are empowered may feel righteous anger: anger towards the disrespectful images of people with mental illness on TV, in magazines and on the internet; towards friends and family who didn't find them to be a capable human being; 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 *Worksheet A.2*. 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 <u>fully</u> before reviewing the key.

Worksheet A.2: 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	
2. I want to 2. I want to 3. I have co 4. It is okay 5. I am not 6. We can be 7. Things was 8. I'm goin 9. I am okay	o change my compontrol over my tray for me to get many a bad person because the stigma if we will work out in range to make waves any even if I have and at the way means of all editems	and at people who streams of mental illness work together. Then add ut the stream of	igmatize ment ess. yed on TV. up all the EVE	Box 2	

KEY & INTERPRETATION GUIDELINES TO WORKSHEET A.2

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

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

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

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

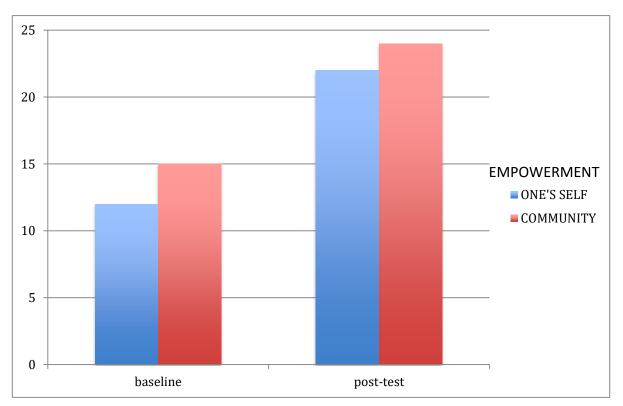
"I didn't think I had low empowerment. But I scored less than 8 so I must disapprove of myself."

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

Program Evaluation

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

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



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