

DEPARTMENT OF VETERANS AFFAIRS

Support And Family Education



Session Eighteen – Dealing with the Stigma Surrounding Mental Illness

Materials Needed

Handout GG: [Coping with Stigma](#)

I. Introduction: Experiential exercise

Invite participants to participate in an experiential exercise. Ask the following questions sequentially:

Raise your hand if:

1. You went to a doctor's appointment in the past year.
2. You were admitted to a hospital for any reason over the past year.
3. You took any medication over the past year.

How did it feel to answer these questions in this group setting?

Now if we were to ask you to raise your hand (no need to raise your hand) if...

1. You saw a mental health professional over the past year.
2. You took any psychiatric medications over the past year.

... how would you feel?

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Discussion Questions:

- How are these questions different from the previous ones? What makes them different?
- How does this activity relate to your loved one's experience of having a mental illness?

II. Impact of stigma on family experience of mental illness

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Discussion Questions:

- What is the biggest consequence for your family of your loved one's having a mental illness?
 - How long did it take your loved one to seek mental health treatment once the need became apparent?
 - What kept him/her from seeking treatment earlier?
 - What motivated him/her to seek treatment?
- A. *Stigma* has been defined as a mark, blemish or defect; a symbol of disgrace, shame, or reproach. Stigma is often used to differentiate people. It often involves fear of that which is different.
1. What does *stigma* mean to you?
 2. How has stigma affected your family?

Possible answers may include:

- Embarrassment/social discomfort
- Feeling "different"
- Decreased self-esteem in loved one
- Isolation
- Problems in loved one's getting/maintaining employment
- Challenges in getting housing
- Insurance issues
- Others?

- B. Stigma can deter individuals from seeking treatment. For example,
1. According to the National Institute on Mental Health, about one in four or five adults has a diagnosable mental disorder in a given year. That's over 58 million people in the United States.
 2. Yet only about half of all Americans with a serious mental illness seek treatment (Kessler et al., 2001).

Although failure to seek mental health treatment can be attributed to a variety of factors (e.g., lack of money/insurance, availability of providers), mental health stigma is also a significant deterrent.

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Discussion Questions: How do you think stigma is perpetuated?

Possible answers may include:

- Portrayals of individuals with mental illness in the media as violent and unable to contribute to society
- Fear of that which is different
- Avoidance of individuals with mental illness
- Messages given to young people about mental illness

III. Understanding the history of stigma in mental health

- A. Unfortunately, the mental health profession contributes to the stigma surrounding mental illness. For example, as recently as the 1960s and 70s, mental health professionals were taught that schizophrenia was caused by being raised by a cold, unavailable, critical “schizophrenogenic mother” and living in a family marked by high expressed emotion, which involves much criticism, hostility, and emotional over-involvement. Families were held responsible for the loved one’s mental illness.
- B. These theories guided our understanding of mental illness and psychiatric care, and the mental health profession harshly judged many families. Unfortunately, this viewpoint contributed to the stigma and sense of responsibility that many families experienced.
- C. Since that time, science has reformulated our theories regarding the cause of mental illness, resulting in a fairly widespread acceptance of the vulnerability-stress model (as explained in session one) of etiology.
1. As a review, the vulnerability-stress model involves understanding mental illness as being caused by a combination of “nature” (genes, heredity, etc.) and “nurture” (family upbringing, life events, social environment, etc.).

2. Individuals may inherit a predisposition to mental illness and then experience a stressor that results in the emergence of an illness. On the other hand, an individual may be born with a predisposition but have excellent coping strategies and/or social support and never experience the illness.
 3. Research continues to explore the relative contributions of genetics and life experiences to various mental illnesses. For example, some illnesses (e.g., schizophrenia) are believed to be highly influenced by genetics; while others (e.g., PTSD) are more a response to life events/situations.
- D. In spite of science's shift away from a "family-blaming" mentality, many families continue to feel responsible for their loved ones' illnesses. Perhaps in response to this experience and in an attempt to relieve years of guilt, many families and advocacy organizations have adopted an extreme "nature" viewpoint; this perspective conceptualizes mental illnesses as "neurobiological disorders" and minimizes the role of any social/family contribution.
 - E. Similarly, there is growing attention to means of overcoming stigma evidenced by research, practice recommendations, and reports urging the profession to tackle this challenging topic. For example, the President's New Freedom Commission on Mental Health report, *Achieving the Promise: Transforming Mental Health Care in America*, includes a recommendation to "Advance and implement a national campaign to reduce the stigma of seeking care" (Recommendation 1.1). In a parallel vein, mental health providers have recognized the role that stigma places in deterring service members from seeking mental health help (both while on active duty and thereafter) (Hoge, Castro, Messer et al., 2004), and many new programs are attempting to make our services more accessible.

IV. The role of diagnosis in stigma

- A. Psychiatry has devoted years of research and clinical study to identifying and naming clusters of behaviors/problems as specific disorders. When classification systems emerge, researchers can study the clinical phenomena and develop effective treatments. The *Diagnostic and Statistical Manual of Mental Disorders* (currently in its 4th revision) contains specific criteria sets for many psychiatric diagnoses.
- B. Labels can also provide a useful, normalizing function for the consumer and family. Individuals often feel reassured when diagnosed with a condition because they know they're not alone and feel more understood.
- C. However, labels/diagnoses can have negative consequences as well:

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Discussion Question: How can diagnoses or labels reinforce stigma?

Possible answers may include:

1. Diagnoses are sometimes misused when a unique individual is placed into a general category (e.g., “He’s just a schizophrenic”), and his/her experience is oversimplified. Further, expectations are sometimes lowered because of the label (“...he wouldn’t be able to hold a job”).
2. Diagnoses (even if inaccurate) often stay with a person for a long time. For example, documentation in medical records of psychiatric and/or substance-abuse problems can interfere with consumers’ abilities to get insurance coverage and other treatments in the future.
3. Diagnoses can serve as a rationalization for behavior (e.g., “Don’t hold me responsible because I am sick”).

Optional: Share a video clip depicting issues surrounding stigma.

Suggested videos (most contain discussion questions as part of the videotape package):

The Stigma of Mental Illness. (1997). Kenneth Duckworth, MD, Massachusetts Mental Health Center. (15 minutes). Curriculum contains a pre-test quiz and suggested discussion questions for after the video.

Imagining Robert: My Brother, Madness and Survival. (2002). Films for the Humanities and Sciences. 56 minutes. Study guide and other resources available on-line at: www.imaginingrobert.org

Myths About Madness: Challenging Stigma and Changing Attitudes. (1999). Films for the Humanities and Sciences. 30 minutes.

In Our Own Voice. (2001). Idaho Public Television. 60 minutes.

A Beautiful Mind (2001). Depicts the true story of John Nash (a brilliant mathematician who has schizophrenia) and debunks some negative public stereotypes of mental illness.

V. Coping with stigma

Stigma can seem overwhelming at times, and changing societal attitudes may feel like a daunting task. However, families can take specific steps to help cope with the stigma in their specific situations/communities.

- A. Remember that you and your loved ones have choices.
1. You can decide whom to tell about the mental illness and what to tell them. Your choice may range from telling no one at all to telling anyone (e.g., via public action).
 2. Your decisions may change over time and likely depend on the specific relationship.
 3. You and your loved one may disagree on whom and what to tell. In general, families are well served by respecting the consumer's decisions about sharing this information. However, family members need places where they can be honest and receive support, either professionally (e.g., support groups) or personally (through family and friends). When differences among families emerge, you may use the problem-solving strategies outlined in session 7.
 4. You and your loved ones may choose to do a cost-benefit analysis surrounding these decisions:

Group Activity: *Invite participants to create a list of pros and cons of disclosing the mental illness (adapted from Corrigan and Lundin, 2001). List them in a chart or worksheet, and facilitate discussion surrounding benefits and costs of disclosure.*

Potential Benefits of Disclosing

Possible answers may include:

- You don't have to worry about hiding the mental illness and/or explaining confusing behavior to others.
- You don't have to spend as much energy keeping a secret.
- You can release some shame about the illness in the family.
- Others may be able to provide additional support.
- Others may be coping with similar situations, and you can provide mutual support. You could feel less alone.

Potential Drawbacks of Disclosing

Possible answers may include:

- You take the risk of being vulnerable. Others can say unkind things to or about your loved one/family.
- Your loved one and/or family might be excluded from social activities.
- Your loved one may experience discrimination (housing, work, etc.).

- Having shared the information, you may worry more about what others think of your family.

Distribute [Handout GG: Dealing with Stigma](#). Although we did this activity today as a group, you may wish to sit down with your loved one and create a list of pros and cons for your unique situation.

B. Remember that you are not alone.

1. Many people struggle with depression, anxiety, substance abuse, and other mental illnesses. In fact, research has revealed that one in four Americans will experience a serious mental illness at some point during the course of his or her life.
2. Many famous individuals have disclosed their mental health struggles, and some celebrities have used their status to educate the public about mental illness:
 - a. Individuals who have disclosed depression: Robert Boorstin (White House aide, bipolar disorder), Mariah Carey, Charles Dickens, Tipper Gore (after son's car accident), Amy Grant, Abraham Lincoln, Rosie O'Donnell, Oprah Winfrey, Rod Steiger, Mike Wallace, Tennessee Williams, Monica Seles, Elton John, James Taylor, Robin Williams
 - b. Individuals who have disclosed substance abuse: AJ McLean (Backstreet Boys); Ben Affleck; Aaron Sorkin (creator of "West Wing"); Matthew Perry ("Friends"); Robert Downey, Jr.; and Martin Sheen

C. Remain hopeful and remember that treatment works.

1. Science has made tremendous progress in the past few decades in understanding mental illness and discovering effective treatments. New medications and psychosocial treatments are being created, and many individuals enjoy productive lives.
2. You can play an active role in your loved one's treatment plan by communicating regularly with providers, encouraging your loved one to take medications and participate in therapies, maintaining a low-stress family environment, and watching for relapse warning signs.

D. Praise your loved one for seeking help.

1. Mental health treatment can be difficult, as individuals often need to be patient in trying new medications, coping with side-effects, and learning new behaviors. Therefore, helping your loved one to feel good about him/herself is important.

2. Your praise can do wonders to lift your loved one's spirits, so remember to tell him/her often that you are proud of him/her.
3. The times that you feel least motivated to give praise are the times when your loved one probably needs your support the most! Be honest, but look for something to praise in your loved one.

E. Stay active and surround yourself with people who are supportive.

1. One potential negative consequence of stigma can be social isolation. When you fear others' judgment and ridicule, you understandably want to avoid them.
2. However, isolating and discontinuing enjoyable activities put you at high risk for depression and burnout. So take a risk and try new activities in your community. You may choose to investigate the local chapter of NAMI (www.nami.org) or a volunteer organization.
3. Sometimes other people don't know what to say or how to support you. Therefore, telling your friends/family members how they can be helpful to your family can be important. Expressing your requests specifically and directly (e.g., "I would really appreciate if you would...") is most effective.
4. Consider advocacy efforts and speaking out against stigma. You can advocate either on a small or large scale.
 - a. In your daily interactions with others, you can address misconceptions by gently sharing accurate information and/or your personal experiences.
 - b. If you prefer larger-scale action, you may consider lobbying for mental health parity, writing editorials for the newspaper, responding to stigmatizing material in the media, writing your state representative about specific mental health bills, and/or participating in NAMI advocacy activities.

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Discussion Question:

- If there was one message you could give the public about mental illness, what would it be