Serving All Veterans Equally (SAVE)

Intervention to Reduce Disparities in Healthcare for Persons with Serious Mental Illnesses

VA | U.S. Department of Veterans Affairs

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Intervention to Reduce Disparities in Healthcare for Persons with Serious Mental Illnesses (e.g. Schizophrenia, bipolar disorder and major depression)

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Purpose of the worksheet:

The SAVE manual is step-by-step programs meant to guide providers with lived experience of mental illness narrate their story in a way to influence the attitudes and behaviors of other providers towards persons with serious mental illnesses.

The content of this manual guides the providers who are also consumers of mental health treatment, in developing and delivering an impactful presentation that integrates information about disparities in care for persons with serious mental illnesses (SMI) and a 10-15 minute long personal story of recovery a from mental health condition.

The research team will provide you the necessary information you need to develop and narrate your lived experience of mental illness in your own words.

Background:

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

Personal Introduction

My name is _____. I am a _____ (state healthcare provider title) and have been a consumer of mental health treatments since age _____. I have a serious mental illness called _____. I grew up in _____ (City, State) with my _____ (#) siblings in a family with_____ (describe resources: professions, quality of childhood, or anything else that you deem important). I have been married for _____ (#) years and have _____ (#) children.

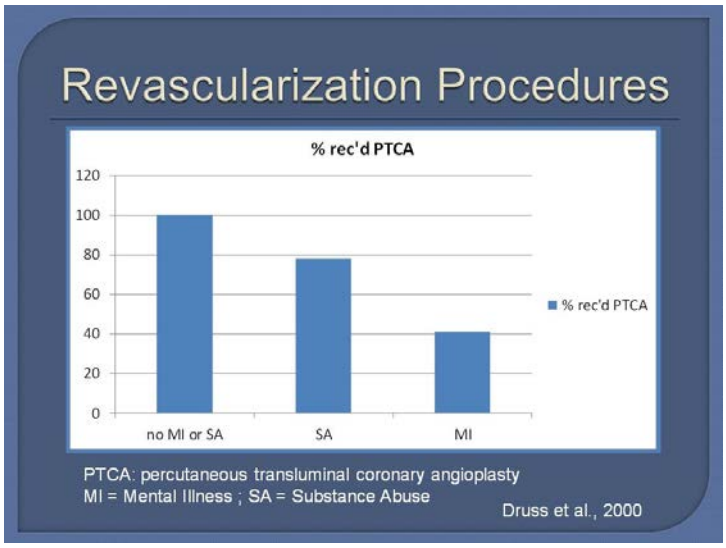
Say in your own words why to chose to narrate your "lived experience."

Overview of Health Care Disparities Among People with SMI

People with SMI receive adequate preventive services and clinically indicated treatments much less often than people who do not have this kind of illness. Below, you will find many examples of such health disparities among people with SMI in the VA and the general population. When discussing these issues with your audience, try to spend no more than two minutes on all of these slides. For example, explain one disparity (preventive care) and then quickly move through the other slides to highlight the other disparities by saying something like, “there are similar disparities in other areas including, likelihood of mammography; referral to weight reduction programs; revascularization procedures following presentation with heart attack; referral for surgery in cancer patients; referral for procedures like hip replacement, breast reconstruction, pacemaker insertion, marrow transplant; and inpatient admission for diabetics with mental illness following evaluation in the emergency room.”

Referral for cardiovascular procedures after myocardial infarction

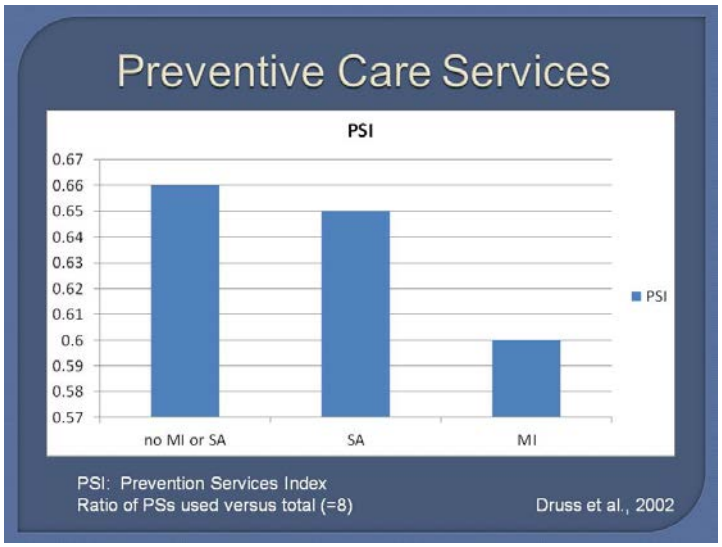
Patients with substance abuse and psychiatric disorder were approximately 20% and 40% less likely to receive revascularization procedures compared to those who did not have substance abuse or any psychiatric illness.[1]



[1] Druss, B. G., Bradford, D. W., Rosenheck, R. A., Radford, M. J., & Krumholz, H. M. (2000). Mental disorders and use of cardiovascular procedures after myocardial infarction. *Journal of the American Medical Association, 283*(4), 506-511.

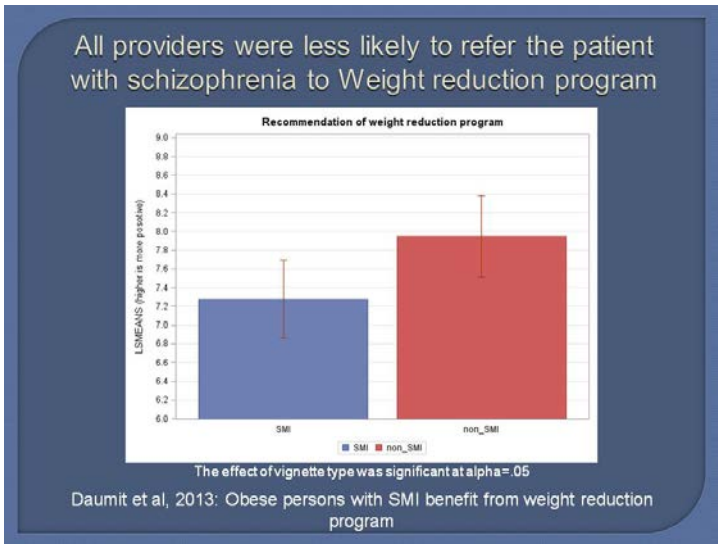
Receipt of preventive care services within VA

Preventive services index is defined as proportion of the preventive interventions an individual received divided by the interventions that the individual was s eligible. Compared to Veterans without either substance abuse or psychiatric illness (66%), Veterans with substance abuse (60%) and psychiatric disorders (65%) were significantly less likely to receive preventive services.[2]



Referral for weight management

In a vignette-based study, patients with schizophrenia were 9% less likely to be referred by VA providers to a weight management program.[3]



[2] Druss, B. G., Rosenheck, R. A., Desai, M. M., & Perlin, J. B. (2002). Quality of preventive medical care for patients with mental disorders. *Medical Care, 40*(2), 129-136.

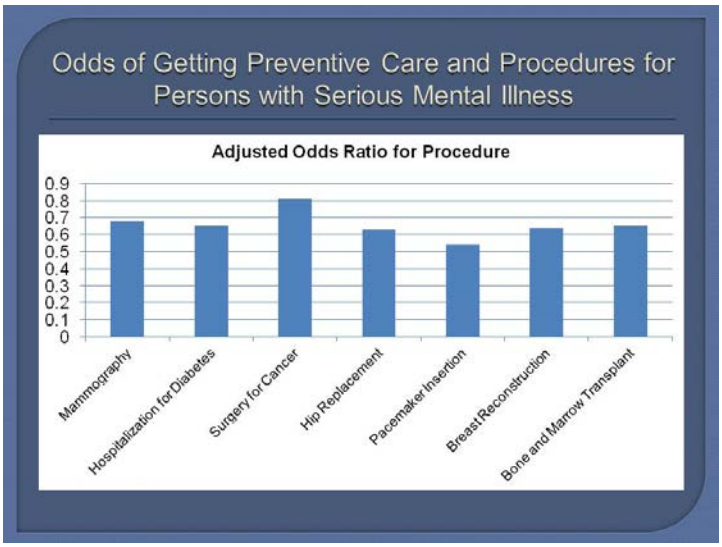
[3] Sullivan, G., Mittal, D., Reaves, C. M., Haynes, T. F., Han, X., Mukherjee, S., Morris, S, & Corrigan, P. W. (2013). *Influence of patient's schizophrenia on the clinical practices of physicians and nurses: A vignette study*. Manuscript submitted for publication.

Mammography

Compared to women without mental illness, women with mental illness had lower odds of receiving mammography.[4]

Inpatient Hospitalization after Emergency Department Visit

Compared with persons without mental illness, persons with diabetes and co-occurring mental illness had lower odds to be hospitalized after an emergency department visit.[5]



Cancer-Related Mortality

Compared to patients without psychiatric problems, psychiatric patients had a reduced odds of surgery for cancers (colorectal, breast, and cervical cancers).[6]

Referral Sensitive Surgical Procedures

Compared to patients without psychiatric problems, patients with mental illness had lower odds for receiving joint replacement, breast reconstruction, pacemaker insertion, coronary artery bypass graft, coronary angioplasty, organ or bone marrow transplant.[7]

The Bottom Line – People with SMI are not getting the same level of care and therefore are more likely to experience greater physical health problems and die earlier than patients without SMI.

You may choose to use some or all of these slides.

Please contact Dinesh Mittal for the slide set: Dinesh.Mittal@va.gov

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[4] Koroukian, S. M., Bakaki, P. M., Golchin, N., Tyler, C., & Loue, S. (2012). Mental illness and use of screening mammography among Medicaid beneficiaries. *American Journal of Preventive Medicine, 42*(6), 606-609.

[5] Sullivan, G., Han, X., Moore, S., & Kotrla, K. (2006). Disparities in hospitalization for diabetes among persons with and without co-occurring mental disorders. *Psychiatric Services, 57*(8), 1126-1131.

[6] Kisley, S., Crowe, E., & Lawrence, D. (2013). Cancer-related mortality in people with mental illness. *JAMA Psychiatry, 70*(2), 209-217.

[7] Li, Y., Cai, X., Du, H., Glance, L. G., Lyness, J. M., Cram, P., & Mukamel, D. (2011). Mentally ill Medicare patients less like than others to receive certain types of surgery. *Health Affairs, 30*(7), 1307-1315.

Why do these disparities happen?

There are a myriad of reasons for existing health disparities. Physicians and nurses are not to blame for these disparities. Understanding what contributes to this problem can improve the quality of our services and our patients' health. For example:

- Some persons with SMI may have difficulty making appointments, traveling to appointments, communicating their needs or asking questions about available treatments/medications
- Some providers feel uncomfortable caring for people SMI
- Other providers hold negative personal beliefs about SMI. They may have developed such beliefs as a result of their clinical experiences of seeing very sick patients who are chronically ill or have frequent relapses or what they have learned from textbooks, newspapers, and maybe even horror movies.

The Bottom Line – While there may be patient and system related factors, there are clearly some provider related factors that certainly calls for promoting affirmative attitudes and actions by the doctors and nurses.

Leading a Discussion of Lived Experience with SMI

This guidebook is for persons who have previously disclosed their lived experience of mental illness publicly. However, we would like for you to read the following paragraph to ascertain your comfort of disclosure for this research study. There are risks of any disclosure that may affect your work and social relationships.

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

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

These are all very important issues. The implications are vast. Decisions to disclose one's mental illness—to COME OUT—to other providers, leadership and other colleagues will impact one's life in many ways. Finding a

job or keeping a job may be at stake. For example, some providers and supervisors may think less of you as a provider or as a person if they know about your history of mental illness. Feelings of self-esteem and self-worth may be hurt.

- Do you want to share the story – only out ; decided that you are out
- Who are you asking to share the story
- Audience: knowing about phenomenology and cognitive though process –from normal to disabled

Our objective is to focus on the positive aspects of treating patients with SMI. You can decrease healthcare disparities for persons with SMI by describing your experiences as both a health care provider and as a patient who receives mental health care. This experience allows you to see service delivery areas to improve upon. This is not a blame-game lecture, but rather a conversation. Please feel free to share your thoughts and reactions. The following tips will help you lead this discussion with your audience.

Share a Credible Message

Research shows that people often find stories more compelling/grounded when people may have or had:

- A diagnosable mental illness (e.g., schizophrenia, bipolar disorder, major depression) with significant symptoms (e.g., distress, hearing voices, strange beliefs, unclear thinking, trauma) that led to disability (periods where the person was unable to meet education, work, or independent living goals);
- Been hospitalized for this illness;
- Been receiving psychotropic medication for long periods of time;
- Attempted suicide;
- Abuse alcohol and other drugs; or
- Seen a mental health professional (most notably a psychiatrist).

Share your Story of Lived Experience with Mental Illness

Discussing your lived experience with mental illness may be difficult. The following tips are tools for framing the conversation, which will hopefully make you and your audience more comfortable and generate deep, thoughtful discussion. Often, stories of recovery have two components, *on the way down* and *on the way up*.

On the way down discussions include your struggles with and challenges of mental illness

When discussing your experience with mental illness before you started receiving treatment, you might:

- Describe your family, school, and work relationships before mental illness struck.
- Describe your struggles with the lived experience of mental illness, in your own words.
- Describe what the mental illness did to your life.
  - Besides the symptoms you experienced from the mental illness, the members of audience may also be interested in your cognitive process when you first developed symptoms of mental illness.

You may find examples for these points by reflecting on the following items:

- Distressing symptoms (major depression or anxiety attacks; experiences with psychosis, trauma)
- Significant disabilities (dropping out of school, can't keep a job or residence, homelessness)
- Relationship stress (estrangement from loved ones, friends, colleagues)

- Dark days (substance abuse, suicide thoughts/attempts, criminal justice encounters)
- Challenging treatments (hospitalization, drug side effects, commitment)

On the way up discussions reflect recovery as a rule and not as an exception.

When discussing you experience with mental illness after receiving treatment, you might:

- Discuss your strengths, resilience and recovery in managing your mental illness and associated physical illnesses (e.g. weight gain, asking for help etc.)
- Illustrate with your lived experience how your providers and system helped you with your efforts to recover
- Describe your human qualities and needs as a person with mental illness, such as need for respect, care and physical health needs similar to those who do not have SMI.

You may find examples for these points by reflecting on the following items:

- Managing symptoms (total remission, less distress)
- Achieving goals (education, work, independent living)
- Helpful treatments (professional, peer, faith-based)
- Regaining hope and self-esteem
- (re)Establishing relationships
- Asserting personal power and self-determination
- I HAVE RECOVERED!

Describe yourself as an empowered person who attains goals as a person and a provider.

Discuss personal, community and professional successes about which you are proud.

- Emphasize how providers helped you achieve recovery and success in your life pursuits with examples.
- Bring out examples of your resilience in managing mental illness (people with SMI have the same goals – work, mature relationships, education, make money).
- Highlight how providers helped your recovery
- Stress how your experience with mental illness made you a better provider and what you want to share with/ask the providers today to have an impact in addressing disparities.

Take Home Message for Health Care Professionals – When you evaluate a person with serious mental illness, do not let the deficits you see prevent you from making referrals and offering preventive care services.

General Pointers for the provider and consumer of mental illness

Make It Personal

First, your story needs to be personal. It needs to reflect your experiences and impressions. This is accomplished by using first person words like “me”, “I”, and “my”. Don't talk about your experience in the third person, for example: “The experiences of people like yours truly, the speaker, are ……”

Bring Your Story to Life

Bring it home by telling good stories illustrated with concrete experiences.

Tell the Truth

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.

It’s Okay to Keep Things Private

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.

Discussion points following face-to-face presentation:

You have many options for creating a dialogue with your audience after the presentation, including:

- Soliciting comments, questions, and facilitating discussion.
- Asking the audience about what terms they know to describe patients with schizophrenia and other serious mental illnesses to open discussion and then go into how the use of pejorative terms for people with serious mental illness is prevalent but we have made progress in not using racial slurs.

How to overcome challenges in developing your story of lived experience

Developing and presenting one’s story can be challenging. Consider the following in becoming an effective speaker.

- Prepare a story: The next pages include a worksheet to develop a first draft.
- Learn speaker’s skills: Getting up in front of a group can be daunting. There are effective ways to be comfortable in front of a group as well as master public speaking.
- Practice, Practice, Practice

STORIES OF RECOVERY WORKSHEET

Let me tell you about the time before the mental illness struck me.

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

1. _____
2. _____
3. _____
4. _____

My mental illness started when I was about _____ years old.

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

1. _____
2. _____
3. _____
4. _____

Unfortunately, my mental illness did not go away quickly.

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

1. _____
2. _____
3. _____
4. _____

Despite these problems, I have achieved several accomplishments.

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

Emphasize how providers helped you achieve recovery and success in your life pursuits with examples.

Emphasize how your experience with mental illness made you a better provider

1. _____
2. _____
3. _____
4. _____

Despite my accomplishments, I have experienced some stigma and unfair responses to my illness.

List some of the unfair experiences and harsh reactions you have experienced from society.

1. _____
2. _____
3. _____
4. _____

Therefore, I would like to see these changes from all of you.

1. _____
2. _____

[1] This worksheet was adapted from the materials provided by the Center on Adherence and Self-Determination (WWW.CASD1.ORG)