Definitions of Stigma

- Historically: a mark with which others try to shame or disgrace a person
- Goffman (1963): “spoiled identity” via societal prejudice
- **Societal Stigma re Mental illness:** The negative regard that people with mental health problems face because of negative stereotypes and biases that others believe.
What is *Internalized* Stigma?

- when a person absorbs stigmatizing messages about people with mental health problems
- from strangers, staff, family, peers, media of all kinds, health care programs, societal leaders & institutions,
- And comes to believe they are true of one’s self.

= stigmatizing yourself

**Effects of Societal Stigma & Internalized Stigma**

Experiences: rejection or distancing by others, disrespect, disregard, blocked opportunity, discrimination

Emotions: sad, angry, frustrated, dejected, demoralization, depressed, worthless, resolved, helpless

Behaviors: shrink inside, isolate or withdraw, rebel, silence, not try new things, avoid help/people/services, give up goals

**Self Stigma and Recovery**

- Greater social avoidance, avoidant coping and fewer social contacts (Lysaker et al, 2007, Vercoulen et al, 2008)
- Less recovery oriented attitudes (self-direction, empowerment, hope, etc.) (Ritchie et al., 2003)
- Impedes treatment seeking, treatment engagement, and participation (Inserra et al, 2007; Leaf, 1997; Drey, 2002)
Alienation
Withdrawal
Avoidance

ESS

- Stigma research & theory
- Mental Health recovery & empowerment work
- Cognitive-Behavioral Therapy practices
- First person life experiences
- Clinical care experiences
- Participant input during pilot

- Weekly 90min classes
- Peer &/or Staff led
- Manualized
- Interactive format
- Very personalized
- Class & home practice
- Each session offers different strategy, emphasizing choice & practical approaches
Brief description of ESS

Each session follows a basic structure:
1) review of home practice from previous session,
2) review of the material presented in previous session,
3) introduction and discussion of a new skill / strategy
4) in-class practice of the new skill / strategy
5) discussion of home practice for the next week based on this class

Focus is on what participants want to do, what would be rewarding, enjoyable – no shoulds.

All classes include discussion, personal experiences, reflection and interaction among group members.

ESS Sessions

1. Recognizing That Stereotypes are Not True
2. Cognitive-Behavioral Strategies for Dealing with Stigma, Pt 1
4. Strengthening and Diversifying One’s Own Self-Concept
5. Increasing Belonging in the Community
6. Increasing Belonging with Family/Friends
7. Effectively Responding to Stigma and Discrimination
8. Review of Strategies/Tools
9. Planning Next Steps
What are some stereotypes?

Most common?

Most hurtful or harmful?

Strategy:
Remind yourself these are FALSE myths

Strategy #1: Myth / Fact

Public / Societal Stigma
People with MI are...
- Frightening, dangerous
- Slow, unintelligent
- Unreliable, incapable
- Unable to contribute to society, family, etc
- Permanently Disabled
- Less important than "normal" people
- Unable to get better

Internalized / Self Stigma
Therefore, I am...
- Violent, dangerous, scary
- Stupid, unable to learn
- Always going to mess up
- Worthless to society, family, myself, etc
- Unable to reach any of my goals
- Not worthy of resources, respect, not a full person
- Hopeless, broken

Stigma is Social Pollution
Strategy #4: Strengthening Your Self Concept

Mental Illness

Strengthening Parts of Your Self

• Ask yourself these questions:
  – What do I like about myself, past or present, that I haven’t thought about lately?
  – What interests do I love / value but am not currently pursuing?
  – What dreams / skills / hobbies have I put on the back burner or given up because of having a mental illness?

• Choose one you want to strengthen.

• Decide one modest step you want to take to strengthen this one a bit or get closer to it.

– What do I like about myself, past or present, that I haven’t thought about lately?
– What interests do I love / value but am not currently pursuing?
– What dreams / skills / hobbies have I put on the back burner or given up because of having a mental illness?

Choose one you want to strengthen.
Decide one modest step you want to take to strengthen this one a bit or get closer to it.
Pilot Study

• Significant in internalized stigma and in recovery orientation and social support, but small study with no control group. (Lucksted et al, 2011)

• Participants liked it, found it useful.

I learned what stigma is...about the myths of mental illness...how to protect myself mentally.

Now: Two Randomized Trials

NIH / Community: Alicia Lucksted, PI

• 5 psychosocial rehabilitation settings in Maryland
• Randomized to ESS or minimally enhanced TAU

VA HSR&D Merit: Amy Drapalski, PI

• Outpatient mental health clinics/programs at 3 VA Medical Centers
• Randomized to ESS or “health & wellness” control group

Both: psychological and behavioral outcomes via social cognition models of self stigma (Corrigan, et al)

Study Aims, for both

• To see if a 9 week ESS group will reduce participants’ levels of internalized stigma

• To see if the 9 week ESS group will help promote other psychosocial outcomes (i.e., recovery orientation, self-efficacy, self esteem, engagement in treatment services)
Study Procedures

3 Interviews:
- Baseline, Post, 6 month follow-up
- Participants randomized to ESS or control at end of first interview
- Objective measures: sense of belongingness, self esteem, self efficacy, experiences with discrimination, self stigma

Possible 4th Interview
- Some participants invited for 4th interview after 6 month follow-up
- Randomly chosen + drop outs + champions
- Qualitative interview re their experiences with stigma and their involvement in the ESS group

Full Sample Demographics at Baseline
Mean ± std or Percentage N
Age (range 18-70)  44.7 ± 12.3 268
Highest Education (in years; range 5-18)  11.9 ± 2.1 267
Age 1st Tx for Emot or MH Prob (range 4-62)  22.1 ± 11.6 264
Gender  61% Men, 39% Women  268
Racial Identity
- White / Caucasian  43.7% 117
- African American / Black  46.3% 128
- Am Indian / Alaska Native  1.1% 3
- Asian  3.1% 3
- Multi-Racial  7.1% 19
- Declined to say  0.7% 2
- Hispanic, Latino, or Spanish  6.5% 11
- Ever Married or in LT relationship  27.6% 74
- Have one or more children  41.8% 112
- Veteran  5.2% 14
Psychiatric Diagnosis
- Bipolar  27.1% 70
- Depression  8.9% 23
- Schizophrenia  30.6% 79
- Schizoaffective  21.7% 56
- Other Psychosis (NOS & Dep)  9.7% 26
- Other Dx  1.6% 4

Community Study Results
Did ESS reduce people’s self ratings of internalized stigma?
YES, a modest amount

Source #1: ISMI

<table>
<thead>
<tr>
<th>ISMI</th>
<th>ESS Grp post ave</th>
<th>Ctrl Grp post ave</th>
<th>ESS Grp post ave</th>
<th>Ctrl Grp post ave</th>
<th>p</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alienation</td>
<td>2.3 ± 0.6</td>
<td>2.5 ± 0.6</td>
<td>2.3 ± 0.6</td>
<td>2.5 ± 0.6</td>
<td>.044</td>
<td>-.184</td>
</tr>
<tr>
<td>S. Endorsement</td>
<td>2.2 ± 0.6</td>
<td>2.3 ± 0.6</td>
<td>2.2 ± 0.6</td>
<td>2.3 ± 0.6</td>
<td>.580</td>
<td>-.056</td>
</tr>
<tr>
<td>Discrimination</td>
<td>2.3 ± 0.6</td>
<td>2.4 ± 0.6</td>
<td>2.2 ± 0.6</td>
<td>2.3 ± 0.6</td>
<td>.054</td>
<td>-.050</td>
</tr>
<tr>
<td>Soc Withdrawl</td>
<td>2.4 ± 0.6</td>
<td>2.5 ± 0.6</td>
<td>2.3 ± 0.6</td>
<td>2.4 ± 0.6</td>
<td>.019</td>
<td>-.268</td>
</tr>
</tbody>
</table>

(scores range from 1 – 4)
Community Study Results

Did ESS reduce people’s self ratings of internalized stigma?

YES, a modest amount

**Source #2: SSMI**

<table>
<thead>
<tr>
<th></th>
<th>SSMIS</th>
<th>ESS Grp</th>
<th>Cntrl Grp</th>
<th>ESS Grp post ave</th>
<th>Cntrl Grp post ave</th>
<th>p</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>58.6 ± 19.4</td>
<td>56.0 ± 20.6</td>
<td>57.6 ± 19.9</td>
<td>55.8 ± 21.5</td>
<td>726</td>
<td>0.038</td>
<td></td>
</tr>
<tr>
<td>Agreement</td>
<td>32.8 ± 16.1</td>
<td>30.4 ± 15.8</td>
<td>28.4 ± 14.5</td>
<td>32.6 ± 17.4</td>
<td>201</td>
<td>-0.339</td>
<td></td>
</tr>
<tr>
<td>Apply to Self</td>
<td>24.1 ± 14.6</td>
<td>23.2 ± 13.2</td>
<td>20.5 ± 12.9</td>
<td>23.5 ± 12.9</td>
<td>019</td>
<td>-0.220</td>
<td></td>
</tr>
<tr>
<td>Judge Self</td>
<td>20.7 ± 13.8</td>
<td>18.2 ± 14.8</td>
<td>18.2 ± 12.7</td>
<td>20.0 ± 13.6</td>
<td>003</td>
<td>-0.081</td>
<td></td>
</tr>
</tbody>
</table>

(each scale can range from 10-90)

Community Study Results

Recovery Orientation (MARS) also showed significant, modest sized increase compared to controls.

"I think it’s good to address it, the internalized stigma. I see myself as having learned from the other people in the group and also sharing things."

"I noticed, ‘Hey, yeah; I do this already.’ So I learned, re-learned actually, how to deal with my inner stigma."

"being stereotyped is not cool…. I wanna help myself, my family, my friends and my children understand stigma so that I won’t go back out there again."

Considerations for Delivering ESS

- Designed for small-ish, interactive, closed groups
- Anyone with good group skills can facilitate
- Designed for nine 90 minute weekly sessions, but can adapt to other
- Works well in various kinds of programs
- People who are not at least curious about stigma’s effects are usually bored
- Attendance is important to get the best benefit
- We are working on individual and online formats
- And on tailored curriculum for people with PTSD : others in future
Yes, you can use ESS in your program!

1. Email Alicia at aluckste@psych.umd.edu
2. She’ll send you two things to read: summary of classes & agreement letter
3. Quick phone call to discuss plans, questions, etc.
4. You return the signed letter, then we send you the Manual and Tips for Facilitators
5. AND we’ll send you new things as we develop them: catalogue of supplemental exercises in July + more polished & streamlined manual in the Fall
6. All we ask is occasional informal feedback; You are NOT part of any research study, or are any participants.

Questions & Discussion

[ESS] made me stop and think that, well, you’ve internalized this, so you put it into your mind so much that you believe what other people believe....

And for the longest time I just didn’t care:
But then the more I started learning the information... this is stigma, this is what it is.... It’s just the wrong outlook on people.

And I had to come to grips with it.
I had the wrong outlook about me!

VA study results in about 6 months!