## Combating Early Psychosis Stigma

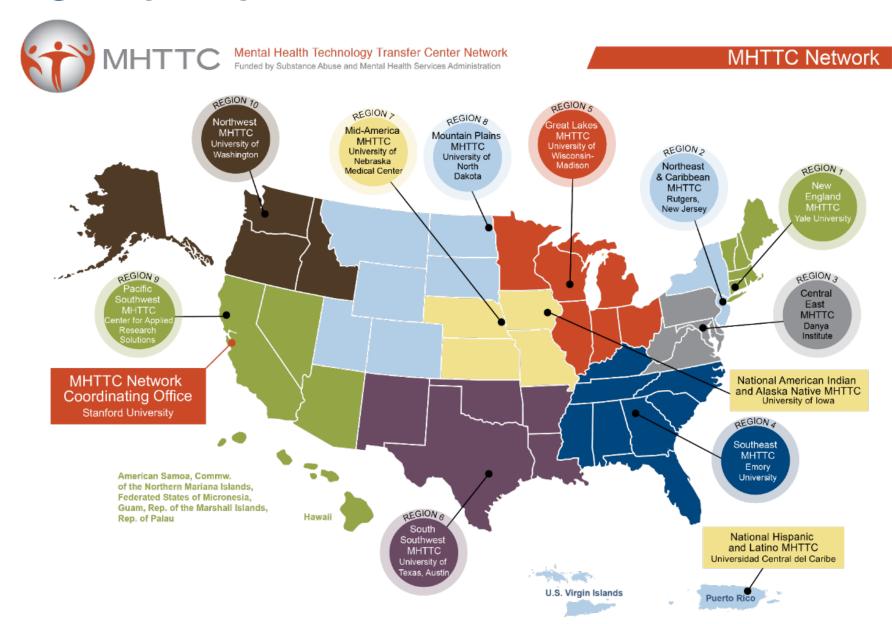
Joseph DeLuca, Ph.D. (he/him/his)

Icahn School of Medicine at Mount Sinai

June 23, 2021, 11:00am-12:30pm ET



#### **MHTTC Network**



#### **MHTTC Purpose**

The MHTTC Network vision is to unify science, education and service to transform lives through evidence-based and promising treatment and recovery practices in a recovery-oriented system of care.



#### **Central East MHTTC Goals**

#### Funded by SAMHSA to:

- Accelerate the adoption and implementation of mental health related evidence-based practices
- Heighten the awareness, knowledge, and skills of the behavioral health workforce
- Foster alliances among culturally diverse practitioners, researchers, policy makers, family members, and consumers
- Ensure the availability and delivery of publicly available, free of charge, training and technical assistance

## **Central East Region 3**



#### **DISCLAIMER**

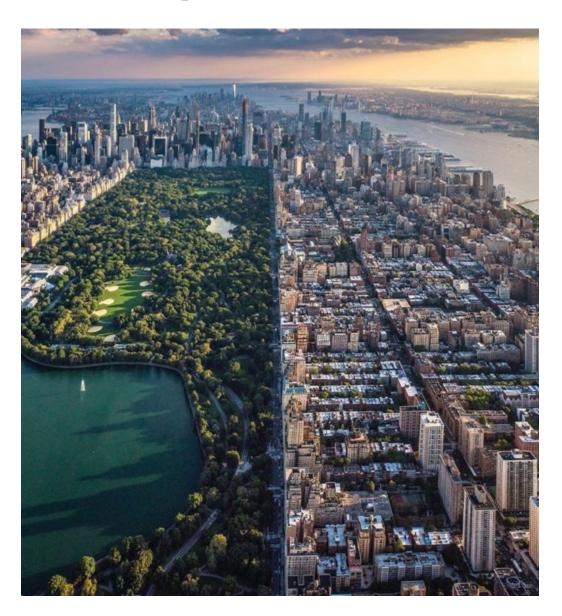
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At the time of this presentation, Tom Coderre served as Acting Assistant Secretary for Mental Health and Substance Use at SAMHSA. The opinions expressed herein are the views of the speakers, and do not reflect the official position of the Department of Health and Human Services (DHHS), or SAMHSA. No official support or endorsement of DHHS, SAMHSA, for the opinions described in this presentation is intended or should be inferred.

#### **Evaluation Information**

As part of receiving funding through SAMHSA to provide this training, the Central East MHTTC is required to submit data related to the quality of this event. At the end of today's presentation, please take a moment to complete a brief survey about today's training.

#### Background



- Clinical psychologist by training and a current NIMH-T32 Postdoctoral Fellow specializing in the early stages of psychosis.
  - 1. see patients at risk for psychosis for individual, group, and family therapy.
  - 2. conduct research on psychosis.
  - 3. help with training and outreach.
- I am passionate about mental health education (particularly psychosis), <u>stigma reduction</u>, and equitable, culturally responsive, evidence-based care.

#### **Agenda**

- 1.Defining the issue
- 2. The unique impact of stigma on psychosis
- 3. What do we do?

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#### **Psychosis: Big picture**

- Approximately 1% -3% develop a psychotic disorder in their lifetime.
- 100,000 adolescents and young adults develop a first episode of psychosis each year in the US.
- Estimated economic burden of \$156 billion in the US.
- Significant individual impact (earlier mortality, lower QoL).
- Although there are negative outcomes associated with psychosis, it is important to note that many individuals who experience psychosis can and do lead full and successful lives.
- Tremendous stigma still unfortunately persists.
- Additionally, many individuals who experience psychosis report positive changes afterwards (e.g., personal strength; spiritual growth).



#### **Psychosis**



- Not a diagnosis
- Diverse set of experiences, including loss of touch from reality (hallucinations, delusions)
- Commonly associated with schizophreniaspectrum disorders, but may be present in mood disorders, trauma, substance use, etc.
- "Early-stage psychosis" = first signs and experiences

#### Early-stage psychosis

## Psychosis-risk (aka Clinical High Risk [CHR] for psychosis, or... ultra-high risk... "prodrome"... etc.)

- warning signs; sub-threshold
- psychosis-like experiences that resemble psychosis, but do not rise to the same level of severity and frequency; doubt is also intact
- ~22% develop a psychotic disorder (Fusar-Poli et al., 2020)

#### First-Episode Psychosis (FEP)

- first signs of a threshold/full episode
  - most have a CHR phase before developing a FEP

## Early-stage psychosis

- Onset generally occurs between the ages of 12-30, during key developmental periods.
  - E.g., think about stigma intersecting with identity development, normative self-consciousness, peer approval, etc...
- Onset may begin in adolescence and continue into young adulthood.



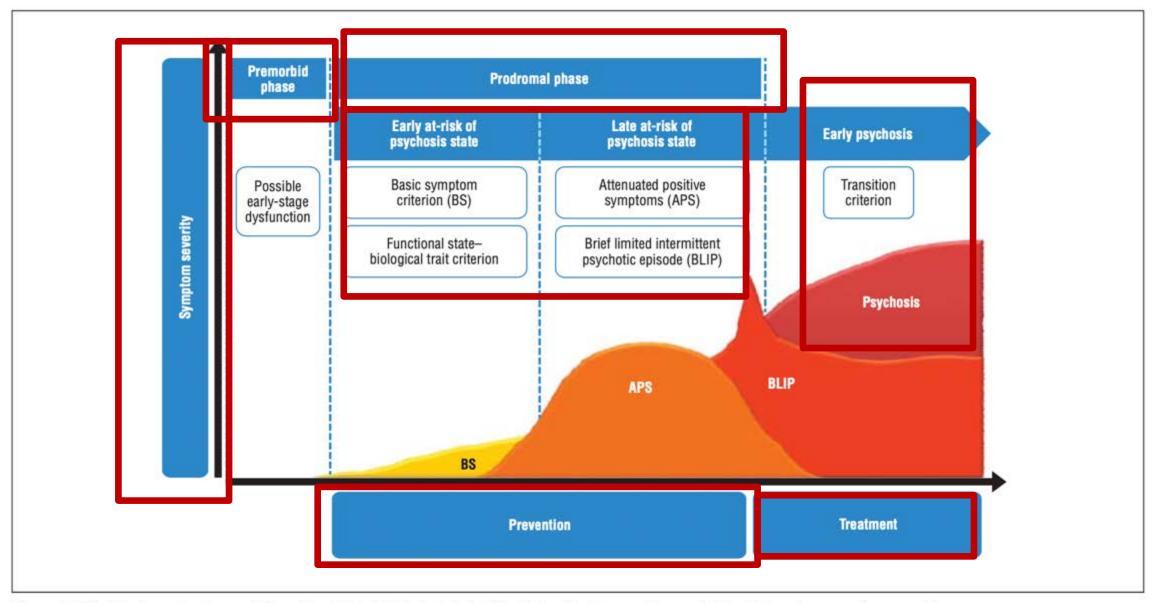


Figure 3. Model of psychosis onset from the clinical high-risk state. The higher the line on the y-axis, the higher the symptom severity.

#### **Psychotic Symptoms: DSM-5**

• Two types of psychotic symptoms (DSM-5 'Criterion A', e.g., for schizophrenia)

1
Positive symptoms
(Behavioral excess)

Negative symptoms (Behavioral deficits)

- Hallucinations
- Delusions
- Disorganized speech
- Disorganized/catatonic behavior

#### **Positive symptoms**

- Hallucinations: perceptual/sensory abnormalities that occur without an external stimulus
  - auditory (most common), visual, tactile, olfactory

- **Delusions:** false and fixed beliefs
  - "I think people are talking about me"
  - "Someone is following me"
  - "People are talking about me to plot against me"
  - "Aliens are sending me messages through the TV"

## Positive symptoms (continued)

Disorganized speech: difficult to follow

- Disjointed monologues
- Idiosyncratic use of words

Disorganized behavior: unpredictability/agitation

- Dressing in unusual manner
- Unpredictable emotional response



**Goal-directed behavior** 

**Functioning** 

**Disorganized movement:** unusual movements

## **Negative symptoms**

 Two types of psychotic symptoms (DSM-5 'Criterion A', e.g., for schizophrenia)

1

Positive symptoms (Behavioral excess)

2

**Negative symptoms** (Behavioral deficits)



- Social withdrawal
- Decreased motivation
- Decreased activity
- Limited facial expression

# Summary: early-stage psychosis and revisiting "prevalence"

- **DSM-5 psychotic disorders** = 1-3% lifetime prevalence
- Psychosis-risk in general population = 3.3% (Woods et al., 2019)
- Psychosis-risk in clinical samples = 20% (Woods et al., 2019)
- In one study, 1 in 4 non-psychotic adolescent inpatients met psychosis-risk criteria (Gerstenberg et al., 2015)

Conclusions = not rare; likely under-detected + highly stigmatized!

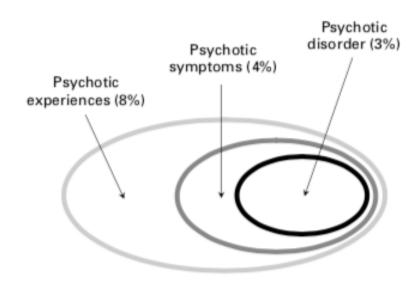


Fig. 4. Psychosis: variation along a continuum.

Van Os et al., 2009

## Conceptualizing Stigma

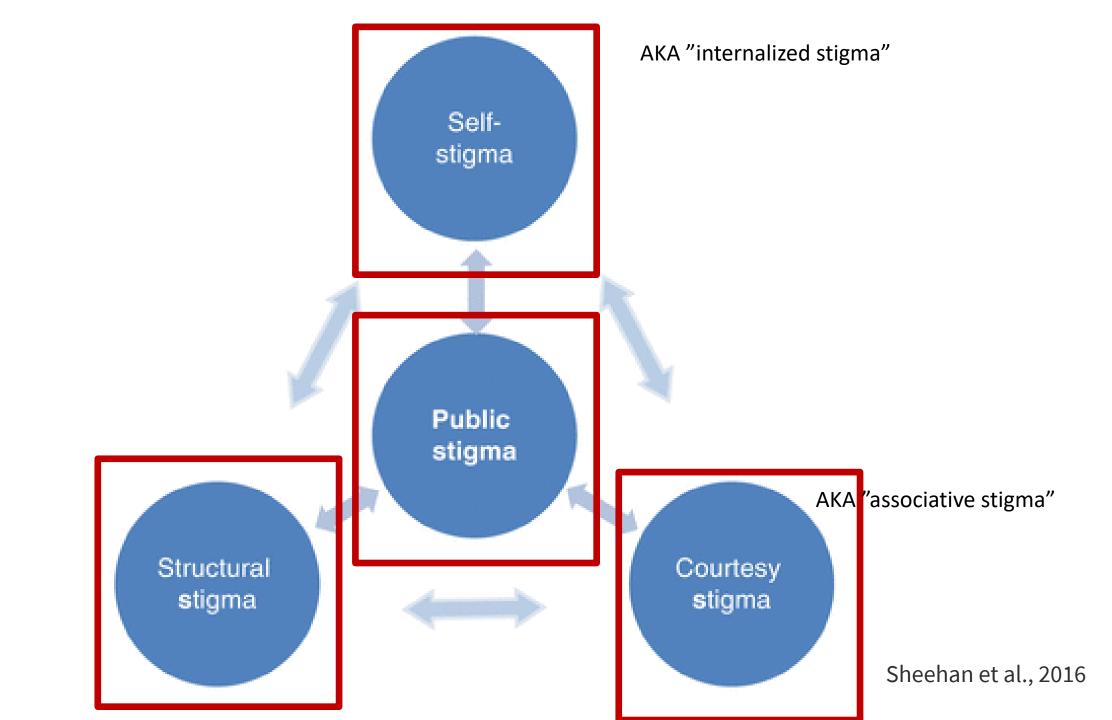
#### **Annual Review of Sociology**

Vol. 27:363-385 (Volume publication date August 2001) https://doi.org/10.1146/annurev.soc.27.1.363

- Interrelated components
- Distinguishing and labeling differences
- Associating human differences with negative attributes
- Separating "us" from "them"
- Status loss and discrimination
- Dependence of stigma on power

Another, more recent guiding theory and conceptualization – the "stigma complex" (see also Pescosolido & Martin, 2015, p. 101):

"the set of interrelated, heterogeneous system structures, from the individual to the society, and processes, from the molecular to the geographic and historical, that constructs, labels, and translates difference into marks"



- At the most basic level, stigma involves labeling (e.g., "mentally ill," "crazy") + stereotyping (e.g., "unemployable," "violent") (Link & Phelan, 2001; Goffman, 1963) (e.g., public stigma)
- Stigma also manifests in power dynamics and institutional policies and laws (*structural stigma*)—which can contribute to status loss and discrimination—as well as internalizations of negative stereotypes by individuals who are thinking about seeking MH treatment/in treatment/diagnosed (e.g., self- or internalized stigma)

- Courtesy or associative stigma extended to people who are close to the person who is stigmatized.
- Most commonly reported by friends and family members



- Prevalent, mostly stable and, in some ways, increasing
- Social distance + stereotypes have been relatively stagnant (Pescosolido, Medina, Martin, & Long, 2013). Perceived relationship between psychosis and violence is increasing in the US (Pescosolido et al., 2010; Pescosolido et al., 2019)
- Perceptions of stigma for seeking help and self-stigma linked to decreased help-seeking and poor recovery outcomes (Vogel et al., 2013; Yanos et al., 2008)
- "Backbone" of stigma worldwide = rejecting the individual as a child care provider, perceiving violence toward self and general unpredictability, rejecting the individual's marriage into the respondent's family, and excluding the individual from teaching children (Pescosolido et al., 2013)

#### **Child stigma**

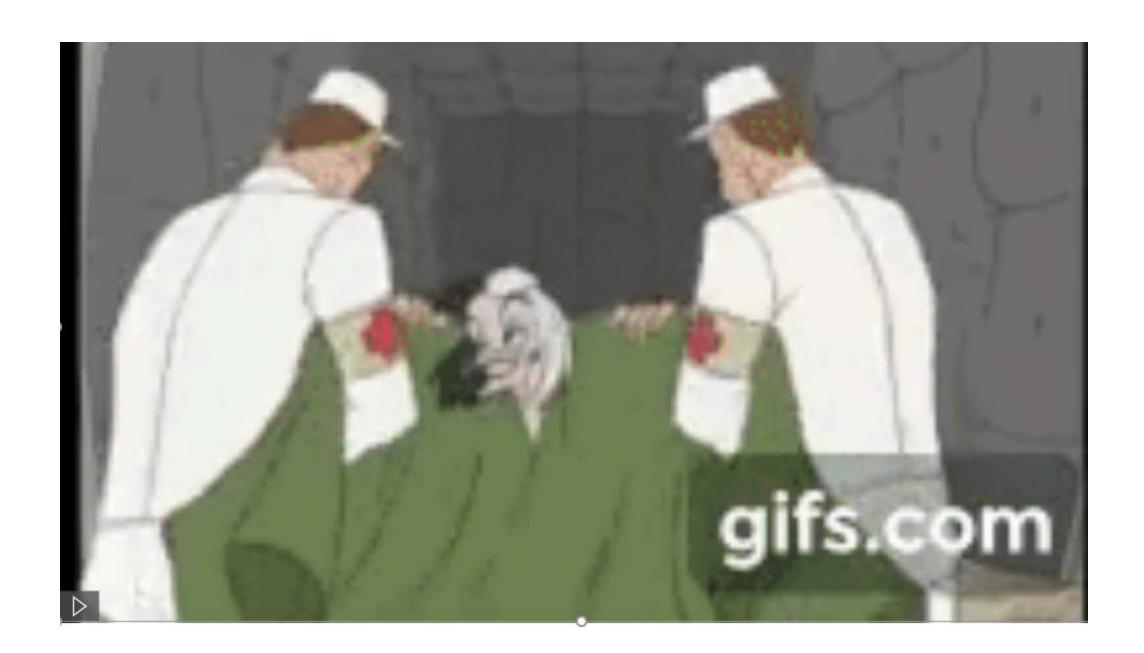
#### Less is known about youth stigma

#### Brief review:

Prejudice, stereotypes, knowledge: As young as seven-years-old, US children are able to define words like "weird" and "crazy" and apply these labels to vignettes of adults manifesting psychiatric symptoms (Spitzer & Cameron, 1995). | 52% of US middle schoolers unsure if someone with SMI can recover with treatment, 72% unsure if SZ means multiple personalities (Wahl et al., 2012)

**Social distance:** US K-8 students want more social distance (as measured by the distance in inches from the heads of each stick figure) from persons labeled as "crazy" or "mentally ill," as compared to persons labeled as "normal" or "physically handicapped" (Weiss, 1986)





#### Youth stigma

- Less researched than adults < 4% of mental health stigma research used samples of children/adolescents (Link et al. 2004)
- To some degree, research limited by the nature of MH stigma (i.e., generally a "hidden" stigma and must be inferred through cues or labels)
- No research had unified adolescent MH stigma research using a theoretical model and considering developmental influences (e.g., identity formation) on the stigma process and outcomes (e.g., help-seeking) (DeLuca, 2020)

Adolescent Research Review (2020) 5:153–171 https://doi.org/10.1007/s40894-018-0106-3

#### **NARRATIVE REVIEW**

## Conceptualizing Adolescent Mental Illness Stigma: Youth Stigma Development and Stigma Reduction Programs

Joseph S. DeLuca<sup>1</sup>

#### Adolescent stigma

Brief review (DeLuca, 2020):

- Most adolescents who live with mental health issues do not receive treatment
- A major barrier to help-seeking among adolescents is stigma, and it appears that the dimensions outlined in Pescosolido and Martin's (2015) *stigma complex* also apply to adolescents
- Stigma among adolescents ranges from public stigma, which can foster unwelcoming and noninclusive environments, to treatment carryover and self-stigmas, which can reduce self esteem and help-seeking intentions
- The roots of this stigma appear to start with a labeling process, which is then combined with negative stereotypes and negative affect
- Foundations for stigma toward persons with mental illness are set in childhood (Wahl, 2002) and children often learn to reject persons with mental illness at young ages. These views extend into later childhood and adolescence—particularly as adolescents enter middle school and high school
- Models of adolescent stigma are growing, but (1) few studies use validated instruments or assess multiple dimensions of stigma (especially help-seeking stigma) and (2) none have used measures of adolescent development

#### Adolescent stigma (continued)

Brief review (DeLuca, 2020):

- Compared to adults:
  - tend to be less aware of MH problems and treatments
  - tend to be more concerned about anticipated stigma (e.g., peer, family, school staff beliefs about them)
  - May experience greater impact from internalized stigma (e.g., buying into negative stereotypes about mental illness)
- Developmental factors are very important

Clement et al., 2015; Nam et al., 2013

#### **Agenda**

1.Defining the issue

# 2. The unique impact of stigma on psychosis

3. What do we do?

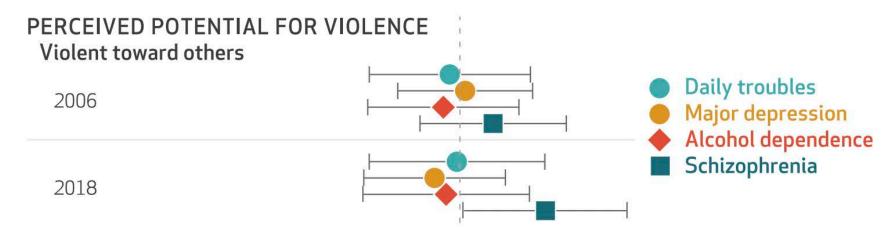
#### Stigma and psychosis

 Like most mental health problems, the onset of psychosis is during adolescence and young adulthood

&

 Stigma toward psychosis is significantly higher than stigma toward depression and most other MH problems

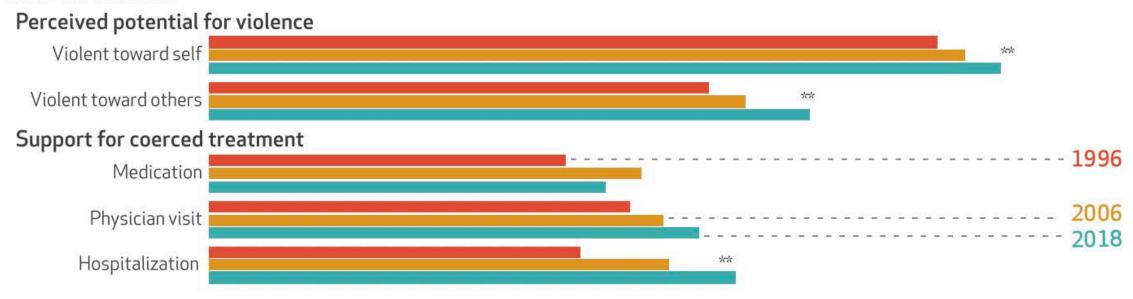
> Percent of respondents to the 2006 and 2018 National Stigma Studies who rated the potential for violence of, and their support for coerced treatment for, people with mental illness in study vignettes, compared to 1996



#### EXHIBIT 1

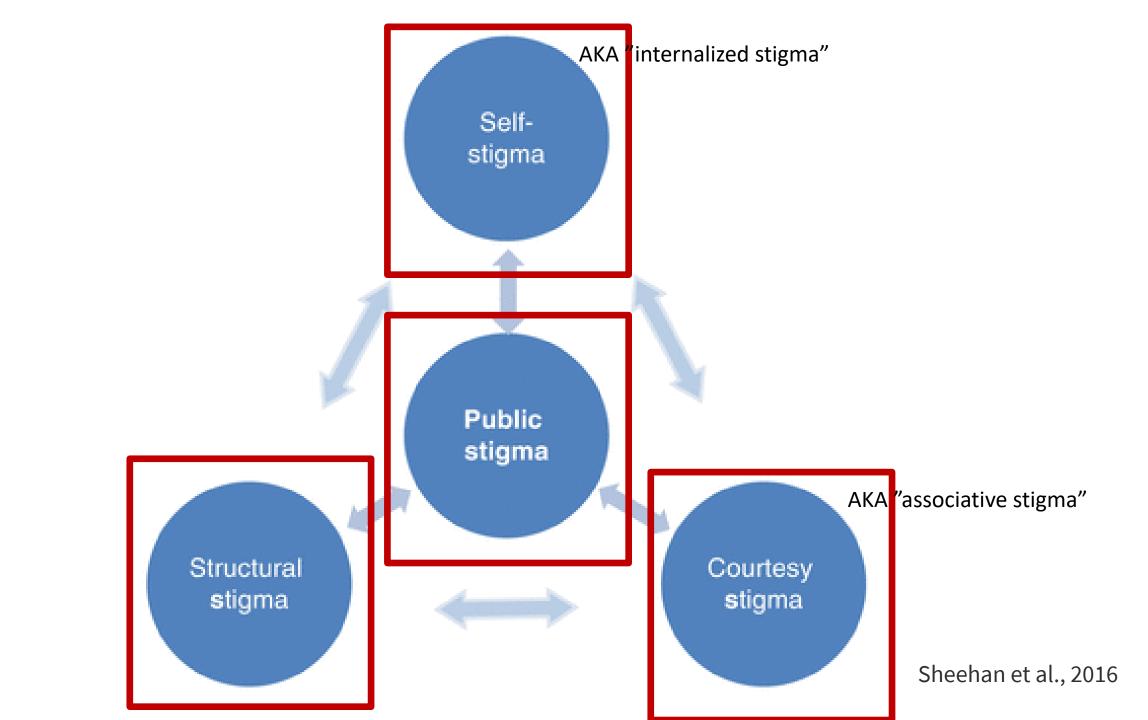
Unadjusted percent of respondents to the 1996, 2006, and 2018 National Stigma Studies who rated the potential for violence of, and their support for coerced treatment for, people with mental illness in study vignettes

#### **SCHIZOPHRENIA**



## Stigma and psychosis

- Stigma toward psychosis is increasing in the United States (Pescosolido et al., 2019). Conclusion:
  - "It appears that scientific evidence cannot correct the public and political rhetoric surrounding mass shootings that links violence and mental illness...
  - "...Emboldened by political arguments, daily reports of impersonal violence, and media mentions linking mental illness and crime, members of the public may be expected to continue to support the stigma of dangerousness and call for the return of mental asylums as suggested recently by politicians"



## Public stigma & psychosis

- As noted, highly stigmatizing attitudes from the public regarding violence, ability to recover, willingness to interact with, etc.
- This public stigma can worsen symptoms, impact treatment engagement, etc. (Colizzi et al., 2020; Mueser et al., 2020)
- Can lead to status loss and discrimination (devaluation, leading to unfair treatment) (Yang et al., 2013)
  - Applies to schizophrenia labels and psychosis-risk labels

# Should we be concerned about stigma and discrimination in people at risk for psychosis? A systematic review

Published online by Cambridge University Press: 17 February 2020

Marco Colizzi (D), Mirella Ruggeri and Antonio Lasalvia

Show author details >

## Public stigma & psychosis: what do we do?

**Brief Reports** 



## Public Stigma Associated With Psychosis Risk Syndrome in a College Population: Implications for Peer Intervention

Lawrence H. Yang, Ph.D., Deidre M. Anglin, Ph.D., Ahtoy J. Wonpat-Borja, M.P.H., Mark G. Opler, Ph.D., Michelle Greenspoon, M.A., and Cheryl M. Corcoran, M.D.

"The psychiatrist explained that being at high risk of psychosis means that the person has not yet developed a full psychotic disorder but has some symptoms that might lead to a future psychotic disorder. However, the psychiatrist said only 35% of these individuals will go on to exhibit psychosis within 2.5 years of identification."

**EDUCATION** 

## Public stigma & psychosis: what do we do?

### Reducing Stigma Toward Individuals With Schizophrenia Using a Brief Video: A Randomized Controlled Trial of Young Adults

Doron Amsalem ⋈, Lawrence H Yang, Samantha Jankowski, Sarah A Lieff, John C Markowitz, Lisa B Dixon

Schizophrenia Bulletin, Volume 47, Issue 1, January 2021, Pages 7–14, https://doi.org/10.1093/schbul/sbaa114

Published: 15 August 2020

Sustained Effect of a Brief Video in Reducing Public Stigma Toward Individuals With Psychosis: A Randomized Controlled Trial of Young Adults

Doron Amsalem , M.D., John C. Markowitz, M.D., Samantha E. Jankowski, M.A., Lawrence H. Yang, Ph.D., Linda Valeri, Ph.D., Sarah A. Lieff, M.P.H., Yuval Neria, Ph.D., Lisa B. Dixon, M.D., M.P.H.

Published Online: 26 Apr 2021 https://doi.org/10.1176/appi.ajp.2020.20091293

**Check out recovery videos here** 

"CONTACT"

# Public stigma & psychosis: what do we do?

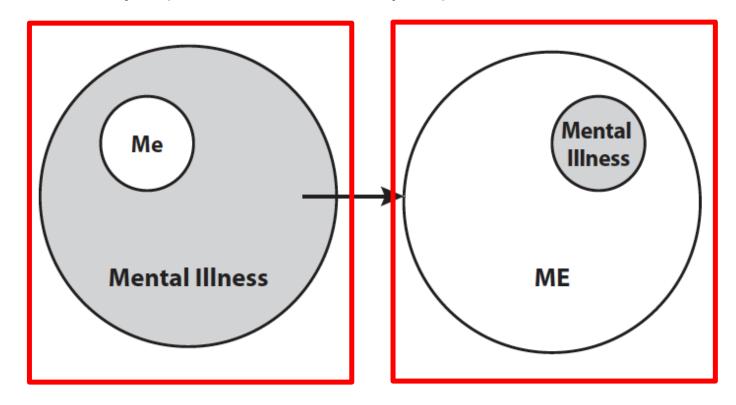
# Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies

Patrick W. Corrigan, Psy.D. Scott B. Morris, Ph.D. Patrick J. Michaels, M.S. Jennifer D. Rafacz, Ph.D. Nicolas Rüsch, M.D.

**National Alliance on Mental Illness** 

## Self/internalized stigma & psychosis

- "the incorporation of others' prejudices and stereotypes about people with mental illnesses into beliefs about oneself" (Lucksted & Drapalski, 2015, p. 99)
- "...spoiled identity" (Goffman, 1963, p. 3)



## Self/internalized stigma & psychosis

- Adults with schizophrenia: ~40% may internalize (e.g., Brohan et al., 2011)
  - E.g., "I am embarrassed and ashamed that I have a mental illness"; "People with mental illness cannot live a good or rewarding life"; "I can't contribute anything to society because I have a mental illness"
  - ISMI scale available here
  - Empowerment, perceived discrimination, social contact all play roles
- Approximately 20% to 30% of adolescents in general U.S. help-seeking samples report frequently experiencing internalized stigma owing to having psychiatric diagnoses, including shame, embarrassment, and fear of peer rejection (Moses, 2009, 2010)
  - Youth experiencing psychosis-spectrum symptoms tend to have more internalized stigma (Colizzi et al., 2020; Firmin et al., 2019)

## Self/internalized stigma & psychosis



Journal of Abnormal Psychology

© 2021 American Psychological Association ISSN: 0021-843X

https://doi.org/10.1037/abn0000679

Predictors of Internalized Mental Health Stigma in a Help-Seeking Sample of Youth: The Roles of Psychosis-Spectrum Symptoms and Family Functioning

#### Longitudinal predictors of stigma in first-episode psychosis: Mediating effects of depression

Lindsay A. Bornheimer ⋈, Nicholas Tarrier, Aaron P. Brinen, Juliann Li, Meredith Dwyer, Joseph A. Himle

First published: 12 February 2020 | https://doi.org/10.1111/eip.12935

## Clinical and demographic correlates of stigma in first-episode psychosis: the impact of duration of untreated psychosis

K. T. Mueser X, N. R. DeTore, M. A. Kredlow, M. L. Bourgeois, D. L. Penn, K. Hintz

First published: 26 September 2019 | https://doi.org/10.1111/acps.13102 | Citations: 9

# Self/internalized stigma & psychosis: what do we do?

Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries

Published online by Cambridge University Press: 16 November 2011

S. Evans-Lacko, E. Brohan, R. Mojtabai and G. Thornicroft

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# Self/internalized stigma & psychosis: what do we do?

- Interventions for adults (see Yanos et al., 2015 for a review). Core components:
  - Generally group-based
  - Psychoeducation
  - CBT-based (e.g., cognitive restructuring) and other coping skills
  - Narration/meaning-making and autonomy-building
  - Behavioral decision-making (increase/elicit hope, empowerment, motivation)

#### **Examples:**

- Narrative Enhancement and Cognitive Therapy (NECT)
- Ending Self-Stigma
- Honest, Open, Proud

# Self/internalized stigma & psychosis: what do we do?

- Interventions for youth are less common, but emerging:
  - Healthy Self-Concept (McCay et al., 2007)
  - NECT recent NIMH R34 grant to study this
  - Be Outspoken and Overcome Stigmatizing Thoughts (Best et al., 2018)

Table 1. Outline of BOOST session content.

Internalized Stigma	Session 1	Psychoeducation: Psychosis and Stigma
		Group Introductions
		Activity 1: Identify Myths and Facts About Psychosis
		Activity 2: Perceptions of Psychosis
		Mission: Stigma in Everyday Life
	Session 2	Psychoeducation: Internalized Stigma
		Activity 1: Stigma Video
		Self-Labelling and the Self-Fulfilling Prophecy
		Activity 2: Experiences of Internalized Stigma
		Mission: Fighting the Self-Fulfilling Prophecy
	Session 3	Evaluating Negative Thoughts
		Activity 1: 5-Part Model
		Automatic Thoughts and Thinking Traps
		Activity 2: Evaluating Negative Thoughts
		Mission: Evaluating Negative Thoughts
	Session 4	Normalizing Experiences
		What is Normal?
		Activity 1: Video of Famous Person with Schizophrenia
		Activity 2: Identifying Famous Voice Hearers
		Mission: Evaluate Negative Thoughts - Normalizing Information
Assertive Communication Skills	Session 5	Changing our Behaviour and Being Assertive
		Introduction to Assertiveness Skills
		Activity 1: Characteristics of Communication
		Activity 2: Role-Play Communication Styles
		Mission: Practice Assertive Communication
	Session 6	Assertiveness Skills I
		DEAR Technique
		Activity 1: Role-Play DEAR Technique
		Mission: Plan out Assertive Interaction using DEAR
	Session 7	Assertiveness Skills II
		Activity: Assertiveness Role-Play Practice
		Mission: Assertiveness Bucket List
Review	Session 8	Review and Goal Setting
	5555011 0	Review Sessions
		Introduction to SMART Goals
		Activity: Develop SMART Goals

## Courtesy/associative stigma & psychosis:

Matthias C. Angermeyer · Beate Schulze · Sandra Dietrich

### **Courtesy stigma**

### A focus group study of relatives of schizophrenia patients

 "The structure of mental health care is experienced as extremely confusing. Often relatives "encounter walls", "feel left alone"," are pushed from fire brigade to hospital to doctor and back again"..."

- "Several respondents state having encountered accusations of "wrong or bad upbringing of their children" or "having made their children's decisions for them"."
- "...parents are exposed to especially hurtful statements like "you are the cause of the illness"," it's all your fault" or "it's all because of sexual abuse". Grandmothers, brothers and sisters of the ill, friends, and the ill blame parents and believe that the illness originates from within the family"

## Courtesy/associative stigma & psychosis:

## Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis

Celine Wong, Larry Davidson, Deirdre Anglin, Bruce Link, Ruth Gerson, Dolores Malaspina, Thomas McGlashan, Cheryl Corcoran 

✓

Experience of associative stigma in parents of adolescents at risk for psychosis

Julia Baron, Melina Salvador, Rachel Loewy ⋈

"Only ethnic minority families of individuals with recent-onset psychosis endorsed a sense of shame and need to conceal the patient's illness."

"...increased experience of stigma associated with psychotic-like symptoms as compared to other psychiatric symptoms, attempts to balance fighting against stigma with the privacy needs of adolescents... Stigma impacted treatment-seeking and participation in family groups that were seen as both potentially supportive and threatening"

## Courtesy/associative stigma & psychosis: what do we do?

- Family support and psychoeducation groups (peer- and provider-run)
- "Survival guides" for families (navigating systems, other problem-solving etc.)
- Potential inclusion of families in internalized stigma programs

**National Alliance on Mental Illness** 

### Structural stigma & psychosis

- Access to effective, affordable, culturally-responsive treatment (Cheng et al., 2015)
  - Insurance, transportation, language barriers
- State/federal legislation and mental health parity
- Research funding
- Law enforcement/systems training

#### **Structural Stigma in State Legislation**

Patrick W. Corrigan, Ph.D., Amy C. Watson, Ph.D., Mark L. Heyrman, J.D., Amy Warpinski, B.A., Gabriela Gracia, B.A., B.S., Natalie Slopen, A.M., and Laura L. Hall, Ph.D.

Structural stigma: Research evidence and implications for psychological science.

#### © Request Permissions

Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *American Psychologist*, *71*(8), 742–751. https://doi.org/10.1037/amp0000068

## Structural stigma & psychosis: what do we do?

FIGURE 1. Hypothesized model of systemic racism and psychosis in the United States

#### **Going Upstream to Advance Psychosis Prevention** and Improve Public Health

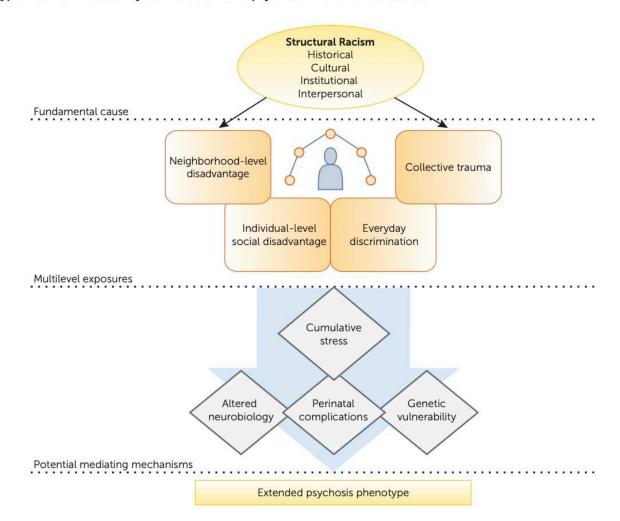
Deidre M. Anglin, PhD1; Sandro Galea, MD, MPH, DrPH2; Peter Bachman, PhD3

#### Structural Disadvantage and Culture, Race, and **Ethnicity in Early Psychosis Services: International Provider Survey**

Nev Jones, Ph.D., Sarah Kamens, Ph.D., Oladunni Oluwoye, Ph.D., Franco Mascayano, M.P.H., Chris Perry, L.F.M.T., Marc Manseau, M.D., M.P.H., Michael T. Compton, M.D., M.P.H.

#### From Womb to Neighborhood: A Racial Analysis of Social Determinants of Psychosis in the United States

Deidre M. Anglin, Ph.D., Sabrina Ereshefsky, Ph.D., Mallory J. Klaunig, Ph.D., Miranda A. Bridgwater, B.S., Tara A. Niendam, Ph.D., Lauren M. Ellman, Ph.D., Jordan DeVylder, Ph.D., Griffin Thayer, M.A., Khalima Bolden, Ph.D., Christie W. Musket, M.S., Rebecca E. Grattan, Ph.D., Sarah Hope Lincoln, Ph.D., Jason Schiffman, Ph.D., Emily Lipner, M.A., Peter Bachman, Ph.D., Cheryl M. Corcoran, M.D., Natália B. Mota, M.D., Els van der Ven, Ph.D.



## Summary

- Early-stage psychosis is under-detected and undertreated, and stigma is a significant barrier to service use treatment engagement
- Stigma operates on many levels: public... internalized/self... courtesy/associative... structural.... Etc.
- It affects patients and families, and may be perpetuated by media, the general public, and even providers
- Education + contact can help on a public level! We have programs that work
- Internalized/self stigma treatments are being developed for this group, and may help families cope with stigma too, in addition to other resources
- Structural changes are also needed

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## Questions



## **Appreciation**



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