

Stigma In Mental Health:

Breaking Down Barriers & Uncovering Opportunities

Allen Doederlein

President of the Depression and Bipolar Support Alliance (DBSA) Chicago, Illinois

Paul Gionfriddo

President and CEO of Mental Health America Alexandria, Virginia

Otsuka Pharmaceutical Development & Commercialization, Inc.

© 2016 Otsuka Pharmaceutical Development & Commercialization, Inc., Rockville, MD

Lundbeck, LLC.

October 2016 MRC2.CORP.D.00185

The information provided by PsychU is intended for your educational benefit only. It is not intended as, nor is it a substitute for medical care or advice or professional diagnosis. Users seeking medical advice should consult with their physician or other healthcare professional.

1

Allen Doederlein

Position: Mr. Doederlein is the President of the Depression and Bipolar Support Alliance (DBSA), a national mental health advocacy, education, and peer support organization led by and serving people who have depression and bipolar disorder. Through more than 700 support groups and 250 chapters, DBSA reaches millions of people each year with in-person and online peer support; current, readily understandable information about depression and bipolar disorder; and empowering tools focused on an integrated approach to wellness.

Education: Mr. Doederlein earned his Bachelor of Arts from Knox College in Galesburg, Illinois.

Paul Gionfriddo

Position: Paul Gionfriddo has been the President and CEO of Mental Health America since May 1, 2014. He also serves on the 12-member National Advisory Council to the Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services. He is currently a member of the Board of the Jerome Golden Center for Behavioral Health in West Palm Beach, Florida and the Golden Center Foundation. Mr. Gionfriddo is the author of the book, *Losing Tim: How Our Health and Education Systems Failed My Son with Schizophrenia*.

Education: Mr. Gionfriddo earned his Bachelor of Arts from Wesleyan University in Middletown, Connecticut.









This program was developed with the support of Otsuka Pharmaceutical Development & Commercialization, Inc. and Lundbeck, LLC. The speakers are compensated contractors of Otsuka Pharmaceutical Development & Commercialization, Inc.

PsychU Virtual Forum Rules of Engagement:

Otsuka Pharmaceutical Development and Commercialization, Inc. (OPDC) and Lundbeck, LLC. have entered into collaboration with Open Minds, LLC. to explore new ways of bringing/increasing awareness around serious mental illness.

OPDC/Lundbeck's interaction with Open Minds is through PsychU, an online, non-branded portal dedicated to providing information and resources on important disease state and care delivery topics related to mental illness. One of the methods employed for the sharing of information will be the hosting of virtual fora. Virtual fora conducted by OPDC/Lundbeck are based on the following parameters:

When conducting medical dialogue, whether by presentation or debate, OPDC/Lundbeck and/or its paid consultants aim to provide the viewer with information that is accurate, not misleading, scientifically rigorous, and does not promote OPDC/Lundbeck products.

OPDC/Lundbeck and/or their paid consultants do not expect to be able to answer every question or comment during a PsychU Virtual Forum; however, they will do their best to address important topics and themes that arise.

OPDC/Lundbeck and/or their paid consultants are not able to provide clinical advice or answer questions relating to specific patient's condition.

Otsuka and Lundbeck employees and contractors should not participate in this program (e.g., submit questions or comments) unless they have received express approval to do so from Otsuka Legal Affairs.

OPDC and Lundbeck operate in a highly regulated and scrutinized industry. Therefore, we may not be able to discuss every issue or topic that you are interested in, but we will do our best to communicate openly and directly. The lack of response to certain questions or comments should not be taken as an agreement with the view posed or an admission of any kind.





- Discuss the current state of stigma within mental healthcare and the appropriate terminology for addressing the topic
- Consider how to target stigma to reduce barriers to care for individuals with mental health conditions
- Review some available resources and tools that may aid in breaking down stigma in clinical practice





STIGMA WITHIN MENTAL HEALTH: WHERE ARE WE NOW?



The Evolution of Stigma

- Definitions of stigma overlap with the concepts of social exclusion and discrimination¹
- Contemporary conceptualizations require 3 components¹:
 - 1. A mainstream negative stereotype¹
 - For example, people who have mental health conditions are weak, irrational, manipulative, dangerous
 - 2. Evidence/signs that a person has a mental health condition¹
 - For example, diagnosis, uncommon behavior, or a suspicion
 - 3. Avoidance, mistreatment, or discrimination against the person^{1,2}
 - Can be intentional behaviors like friendliness, or subconscious nonverbal behavior such as eye contact
- Stigma is a dynamic social/interactional process^{1,2}
 - The stigmatized person is labeled as different, linked to negative stereotypes, the stigmatizer exhibits behaviors that forge a separation, and the recipient responds accordingly
- 1. Horsfall J, et al. Issues Ment Health Nurs. 2010;31(7):450–45.
- 2. Dabby L, et al. Can J Psychiatry. 2015;60(10):451–459.





DISCUSSION



Stigma: Effects and Perpetuations

- For individuals living with mental health conditions, stigmatization forms a barrier to recovery and social integration^{1,2}
 - A major reason identified by consumers of mental healthcare for not seeking or continuing with treatment is the stigma that they encounter³
 - The stigma, myths, and misconceptions surrounding mental illness contribute to the discrimination and human rights violations experienced by people living with mental health conditions⁴
- In addition to individuals living with mental health conditions, their families and mental health professionals can also be the targets of stigmatization⁵
- There is increasing recognition that clinicians play an important role in perpetuating or mitigating stigma in the health care setting²
 - This is important, as evidence suggests that patients living with mental health conditions receive fewer physical and laboratory examinations, are provided with less preventative healthcare, and receive fewer therapeutic interventions²

• Psychiatry itself is an important target of anti-stigma initiatives⁵

- 1. Mårtensson G, et al. J Psychiatr Ment Health Nurs. 2014;21(9):782–78.
- 2. Dabby L, et al. Can J Psychiatry. 2015;60(10):451–459.
- 3. Ross CA, Goldner EM. J Psychiatr Ment Health Nurs. 2009;16(6):558–567.
- 4. Ngui EM, et al. Int Rev Psychiatry. 2010; 22(3): 235–244.
- 5. Schulze B. Int Rev Psychiatry. 2007;19(2):137-55.



What percentage of mental healthcare providers think that their patients feel shame about a mental health condition that they are living with?

- A. 0% to 20%
- B. 20% to 40%
- C. 40% to 60%
- D. > 60%



Attitudes Among Mental Healthcare Professionals

- Pessimistic views held by mental healthcare providers may be based on clinical experience with patients in the most distressed phase of mental illness and those who are challenging to treat^{1–3}
 - Stereotypical views in this population may invoke feelings of uselessness, helplessness, or hopelessness, which may impact both professional and patient¹
- Without effective diagnosis and treatment options, mental disorders are seen as untreatable, resulting in patients being undervalued and perceived as not able to contribute to society⁴
- Studies have reported a greater degree of stigma towards enduring mental illness versus short-lived psychotic episodes⁵
 - Greater negative attitudes from staff working in inpatient services versus those in outpatient services has also been reported⁶
- 1. Horsfall J, et al. Issues Ment Health Nurs. 2010;31(7):450–455.
- 2. Schulze B. Int Rev Psychiatry. 2007;19(2):137–155.
- 3. Dabby L, et al. Can J Psychiatry. 2015;60(10):451–459.
- 4. Ngui EM, et al. Int Rev Psychiatry. 2010; 22(3): 235–244.
- 5. Rao H, et al. J Psychiatr Ment Health Nurs. 2009;16(3):279–284.
- 6. Mårtensson G, et al. J Psychiatr Ment Health Nurs. 2014;21(9):782–788.





TARGETING STIGMA TO REDUCE BARRIERS TO ACCESSING CARE



Which form of stigma do you feel most commonly affects the individuals living with mental health conditions that you have worked with?

- A. The use of negative phrases historically associated with mental health or language that "distances"
- B. Defining the individual based on their illness
- C. Others having lowered expectations of the individual's capabilities
- D. Having diagnosis presented with expectations of poor outcomes



Mental Health Patient Perspectives on Stigma¹

- Attitudes/routine practices may be experienced as stigmatizing
 - Specifically, mental healthcare consumers have reported feeling stigmatized by:

A lack of in them and mental h histo	d their nealth			p	eld to a sychiatric nent		a way th an expe	agnosed in at conveys ectation of prognosis
	Not being sufficiently informed about and/or included in treatment decisions				Receiving poor quality mental health services			

Image based on: Schulze; 20071



1. Schulze B. Int Rev Psychiatry. 2007;19(2):137–155.

The Patient Perspective: What Mental Illness Feels Like¹



Images © Copyright Mental Health America¹. Downloaded September 2016.

1. Mental Health America. #mentalillnessfeelslike: Don't keep mental illness to yourself. There's power in sharing. Quotes available at: http://www.mentalhealthamerica.net/feelslike. Accessed September 2016.



Treatment Goals: What Patients Want

- To get this elephant off my chest
- To stop chasing a "normal" life
- To stop being told to try harder
- To stop feeling that I have to do everything, and that everything I do is crap
- To stop feeling that everyone has it together except me



The Importance of Dignity and Rights in Mental Healthcare¹

"Dignity and rights for people affected by mental health conditions are the counterpoint to a legacy of stigma, shame and discrimination that has caused social isolation, chronic underfunding of services, unnecessary levels of disability, and unacceptable levels of premature death. Public awareness must be led by people who have experienced these impacts personally, along with their supporters, allies and related professionals."

- Destination Dignity Coalition



Image from: Destination Dignity; 20161

1. Destination Dignity Coalition. March for Dignity and Change in Mental Health. Destination Dignity Website. 2016. Available at: http://www.destinationdignity.org/. Accessed September 2016.



10 Ways to Combat Discrimination With Compassionate Language¹

10 Ways to Combat Discrimination with Compassionate Language

A picture may be worth a thousand words, but words also paint vivid pictures—pictures that can evoke truth, strength, and empathy or, alternatively, fear, anger, and judgment. Many individuals feel that language is not of much consequence, that concern about it is overblown by the overly sensitive or a product of zealous political correctness. However, language is a powerful tool that shapes perceptions. These perceptions inspire actions, and actions, in turn, can lead to fundamental changes in our world—changes that, we hope, are for the better.

The language we use to talk about mental health is especially important. It can have powerful consequences. While some may intentionally use unkind labels to describe individuals with mental health conditions, most people are just unaware that their language choices are harmful.

To promote better understanding of appropriate language for mental health and to combat discrimination against individuals living with these challenges, the Depression and Bipolar Support Alliance (DBSA) has created ten principles of compassionate language. Whether you are a peer, family member, co-worker, clinician, or member of the media, we encourage you to adopt them. By doing so, you help work against the stigma that so often surrounds mental health.

The choice of what picture you will paint with words is yours-we ask only that you consider altering your color palette



Depression and Bipolar Support Alliance

Image from: DBSA Website¹

Depression and Bipolar Support Alliance (DBSA). 10 Ways to Combat Discrimination with Compassionate Language. DBSA Website. Available at: http://www.dbsalliance.org/site/PageServer?pagename=dbsa_language. Accessed September 2016.



"The choice of what picture

you will paint with words is

yours—we ask only that

you consider altering your

color palette."

The information provided by PsychU is intended for your educational benefit only. It is not intended as, nor is it a substitute for medical care or advice or professional diagnosis. Users seeking medical advice should consult with their physician or other healthcare professional.

1.

10 Ways to Combat Discrimination With Compassionate Language (continued)¹

Defy Definitions

Use of "mental illness" imply a perpetual state of abnormality whereas mental health conditions often present episodic challenges

Choose Thoughtfully

Many negative phrases historically associated with mental health have become part of the common vernacular but can be harmful

Avoid Distancing

Use language that references people or individuals, instead of "them", "those", or "the mentally ill"

Don't Make Assumptions

Refer to individuals as people living with (or experiencing) mental health challenges

Separate the Person From the Condition

Avoid reducing an individual to their condition (for example, "he is bipolar")

1. Depression and Bipolar Support Alliance (DBSA). 10 Ways to Combat Discrimination with Compassionate Language. DBSA Website. Available at: http://www.dbsalliance.org/site/PageServer?pagename=dbsa_language. Accessed September 2016.

Image based on: DBSA Website¹



10 Ways to Combat Discrimination With Compassionate Language (continued)¹

Allow for Personal Choice

DBSA acknowledges the individual right to terminology of choice, but encourages more wellness-focused language

Accept Responsibility

Choose language that is accurate, respectful, and caring

Portray People Realistically

Avoid showing a person only in an acute episode or in shock-value behavior. Represent the broad experience of people living with mental health conditions

Avoid Sensationalizing

Avoid emphasizing the most shocking and tragic aspects of a situation. Don't use headlines designed to shock and evoke fear

Don't Assume Mental Health Is a Factor in Violent Crime

For mass shootings, avoid insinuating/stating that a shooter has a mental health condition when there is no or questionable substantiation

Depression and Bipolar Support Alliance (DBSA). 10 Ways to Combat Discrimination with Compassionate Language. DBSA Website. Available at: http://www.dbsalliance.org/site/PageServer?pagename=dbsa_language. Accessed September 2016. Image based on: DBSA Website¹

© PsychU. All rights reserved.

The information provided by PsychU is intended for your educational benefit only. It is not intended as, nor is it a substitute for medical care or advice or professional diagnosis. Users seeking medical advice should consult with their physician or other healthcare professional.

1.



CLINICAL RESOURCES FOR TARGETING STIGMA



Which of the following do you think is the most important tool to use in initiatives to reduce stigma?

- A. Rating scales (paper or electronic; for example, the Opening Minds Scale for Health Care Providers [OMS-HC])
- B. Social media awareness campaigns
- C. Education tools
- D. Awareness "paraphernalia" (for example, flyers, billboards)



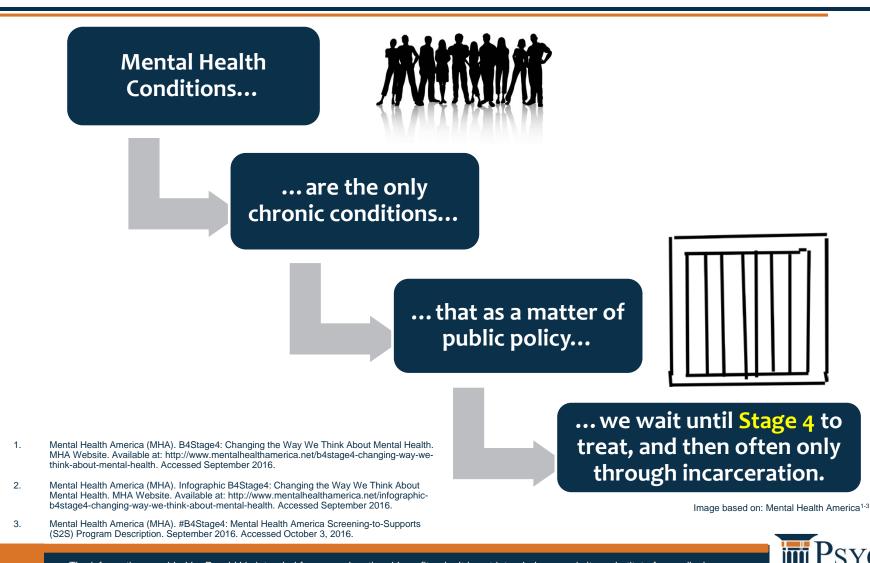
Stigma-reduction Strategies¹

Stigma-reduction Strategies						
Level	Strategies					
Impersonal level	 Treatment Counselling Cognitive behavioral therapy Empowerment Group Counselling Self-help, advocacy and support groups 					
Interpersonal level	Care and supportHome care teamsCommunity-based rehabilitation					
Organization / institutional level	 Training programs New policies (for example, patient-centered and integrated approaches) 					
Community level	 Education Contact Advocacy Protest 					
Governmental / structural level	Legal and policy interventionsRights-based approaches					

1. Heijinders, et al. Psychology, Health & Medicine. 2006.



We Are Trapped in Stage 4 Thinking^{1–3}

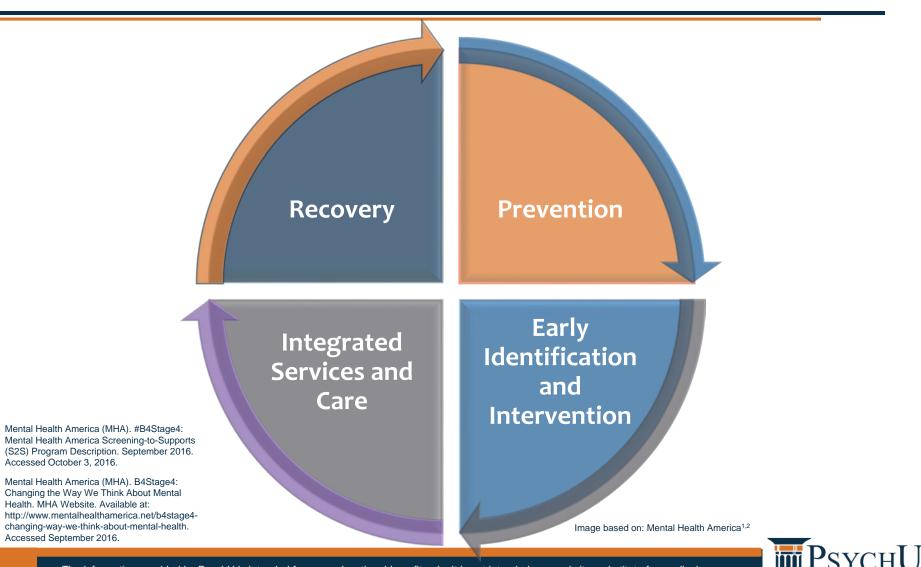


The information provided by PsychU is intended for your educational benefit only. It is not intended as, nor is it a substitute for medical care or advice or professional diagnosis. Users seeking medical advice should consult with their physician or other healthcare professional.

Improving mental health care ... together

© PsychU. All rights reserved.

Promoting Wellness and Recovery: #B4Stage4^{1,2}



The information provided by PsychU is intended for your educational benefit only. It is not intended as, nor is it a substitute for medical care or advice or professional diagnosis. Users seeking medical advice should consult with their physician or other healthcare professional.

Improving mental health care ... together

© PsychU. All rights reserved.

1.

2.

Early Intervention: Mental Health America Screening-to-Supports (S2S)¹



Image based on: Mental Health America; 2016¹

DIY, do it yourself.

1. Mental Health America. #B4Stage4: Mental Health America (MHA): #B4Stage4: Screening-to-Supports (S2S) Program Description. September 2016.



Depression and Bipolar Support Alliance (DBSA): Target Zero to Thrive Campaign¹



Image from: DBSA; 2014¹

If a person doesn't achieve zero symptoms, they haven't failed, but if they are never given the opportunity to achieve that goal, the system has failed them.

Allen Doederlein, DBSA President

1. Depression and Bipolar Support Alliance (DBSA). Target Zero to Thrive This April: DBSA Targets Raising Expectations for Mental Health Treatment. DBSA Website. 2014. Available at: http://www.dbsalliance.org/site/PageServer?pagename=target_zero_home. Accessed September 2016.



Depression and Bipolar Support Alliance (DBSA): Target Zero to Thrive Campaign (continued)

The cost of settling for reduced symptoms is simply too great because when symptoms persist, individuals who have mental health conditions are¹:

- At significantly greater risk of relapse^{1,2}
- More likely to experience significant functional impairment, making the day-to-day demands of job and family challenging, and too often, debilitating^{1,3}



- More likely to have life-threatening co-occurring conditions, such as heart disease, hypertension, and diabetes—a huge factor in why individuals with mental health conditions die up to 25 years younger than those without mental health conditions^{1,4,5}
- At a higher risk to die by suicide^{1,5}
- 1. Depression and Bipolar Support Alliance (DBSA). Target Zero to Thrive This April: DBSA Targets Raising Expectations for Mental Health Treatment. DBSA Website. 2014. Available at: http://www.dbsalliance.org/site/PageServer?pagename=target_zero_home. Accessed September 2016.

 World Health Organization (WHO). Information sheet: Premature death among people with severe mental disorders. WHO Website. http://www.who.int/mental_health/world-mental-health-day/2014/en/. Accessed October 2016.



^{2.} Judd LL, et al. Am J Psychiatry. 2000;157(9):1501-4.

^{3.} Simon GE, et al. J Clin Psychiatry. 2007;68(8):1237-45.

^{4.} Kilbourne AM, et al. *Bipolar Disord*. 2004;6(5):368-73.

Depression and Bipolar Support Alliance (DBSA): Better Is Not Well Initiative

- Treatments may work well, moderately well, or not at all, depending on the person and situation^{1,2}
 - Need to strive for treatment that has a goal of wellness or complete remission rather than modest/step-wise improvement or symptom reduction
 - Function/ability to live life is also important (eg, work, have relationships, etc.)
- Many patients do not seek treatment until their condition is severe
 - Leads to treatment focusing on stabilization and not fine-tuning thereafter
- Mental illness is often not only a condition of the brain, but also affects the body^{3–5}
 - Whole health/Integrative health needs to be a focus
- Culture of research: Many who are participating in research are acutely ill
 - Research on this population does not allow for investigation into questions of how we go from moderately functional to fully functional
- 1. Depression and Bipolar Support Alliance (DBSA). Better is Not Well [video]. 2014. Available at: http://www.dbsalliance.org/site/PageServer?pagename=education_events_binw. Accessed September 2016.
- 2. Culpepper L, et al. Am J Med. 2015;128(9 Suppl):S1-S15.
- 3. De Hert M, et al. *Eur Psychiatry*. 2009;24(6):412-24.
- 4. Korff MV, et al. British Journal of Psychiatry. 1996;168(30):101-8.
- 5. Power AK. Psychiatr Serv. 2009;60(5):580-4.





DISCUSSION

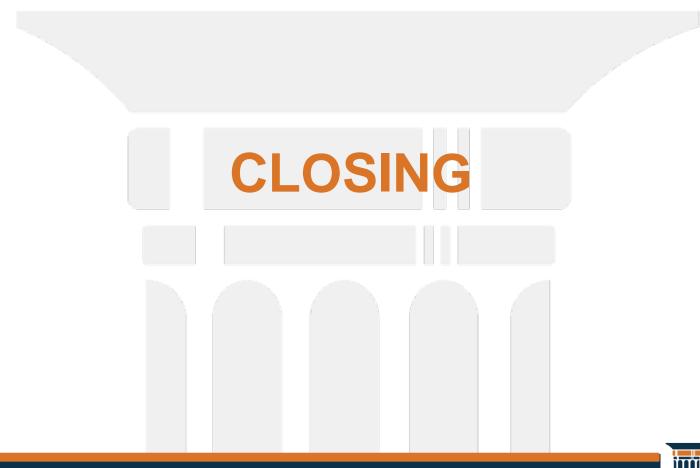




QUESTIONS







PSYCHU

Improving mental health care ... together

© PsychU. All rights reserved.