#### Addressing the Stigma of Psychiatric Disorders

Mental health and substance use disorders are the leading cause of disability worldwide, and the stigma and shame associated with mental health permeate all levels of society. The stigma around mental health and substance use disorders has had profound effects including preventing people from seeking treatment for these disorders, instilling shame among those who are affected and their family members and increasing the risk of suicide. Stigma has also contributed to an underfunded mental health system and inadequate services for persons with mental health and substance use disorders.

A study group was held at the ACNP Annual Meeting in December 2022 entitled, "Eliminating Mental Health and Substance Use Stigma: The Time is Now." Chaired by Dr. Mark Rapaport of the Huntsman Mental Health Institute in Salt Lake City, the session included presentations by persons who are addressing mental health stigma through their work. Dr. Rapaport described the Grand Challenge initiated by the Huntsman Institute to eliminate mental health and substance use disorders' stigma on a national scale by creating a network of 140 organizations. The network will unite brands, media companies, and non-profits to encourage people to take steps to improve their mental health and to share their stories. Seth Kahan, an executive strategy consultant on change and innovation initiatives, engaged the audience in an exercise in which persons shared their own experiences of stigma in small groups, underscoring the ubiquity and emotional power of stigma. Brandon Staglin from One Mind talked about his lived experience with mental illness and how self-stigma is a primary target for the campaign. Dr. Arthur Evans of the American Psychological Association (APA) talked about the efforts of the APA to address trauma and to engage men of color who, as a group, underutilize mental health care. Dr. Christine Moutier of the American Foundation for Suicide Prevention (AFSP) described the nationwide network of AFSP chapters which provide support to those affected by suicide and enable people to tell their stores. Stephenie Larsen presented about the Encircle program which she founded, and which provides a safe space for LGBTQ youth in Utah. Dr. William Smith of the Huntsman Institute made remarks about structural racism and the impact on black men. Dr. Gahan Pandina from the pharma company, Janssen, talked about their employee resource group for persons with neurodiversity including autism and mental illness. Dr. Rapaport emphasized that their goal is to have partnerships with thousands of groups and institutions interested in eliminating mental health and SUD stigma.

The ACNP Public Information Committee is also addressing stigma. The committee interviewed selected ACNP members about their perspective on the stigma associated with several mental health conditions and issues, the progress that has been made in reducing stigma, and future actions which are needed. The content of those interviews appears below.

Interview with Dr. Nora Volkow, Director of the National Institute on Drug Abuse (NIDA), on the stigma of substance use disorders



## 1. Please tell us how you became aware of problems related to the stigma of substance use disorders.

When I was around five years old, I recall my mother's devastation after learning that her father, who was expected to join her family in Mexico after they were separated by the Spanish Civil War, had died. My mother only mentioned to us that he had died of a heart attack. Decades later, when my mother herself was dying from ovarian cancer, she revealed the truth – my grandfather had been, as was then described as, "an alcoholic." In his last relapse and filled with shame and self-anger in his inability to stop drinking, he had taken his own life.

When I learned his story, I had completed my medical degree and residency in psychiatry and had been an addiction researcher for many years. Throughout my education and subsequent practice as a physician, I was appalled at how doctors were treating individuals suffering from an addiction. People were blamed for their substance use, which was mostly ignored or in many instances seen as a reason to withhold treatment.

These judgmental and moralistic approaches were counterfactual to what we were learning of how the brain works. The dissonance fueled my interest to better understand the association between the neurobiological effects of chronic drug use with the loss of control and compulsive drug taking in addiction and strengthened my resolve to help change the perception of addiction from a "character defect" to a chronic, treatable condition from which people can recover.

Even though I had dedicated my life to using scientific evidence to fight the misconceptions around addiction, I realized that this had been insufficient to overcome the feelings of shame and stigma within my own family. When I asked my mother why she had not told me the truth about my grandfather's death until decades later, she said that she did not want me to lose respect for him or love him less. She knew I was working to bring a scientific understanding of addiction into the medical field, but the stigma of addiction and suicide was so strong that it kept her silent.

#### 2. How would you characterize the stigma associated with substance use disorders?

Stigma, or negative attitudes toward people based on distinguishing characteristics, is associated with many mental health conditions and is a well-recognized issue. It is especially sinister in relation to addiction, as it can produce numerous negative outcomes including lack of empathy and rejection by others, as well as isolation, shame, depression, and suicide by the afflicted person. Stigma can also lead to a vicious cycle among people with substance use disorders, as it can contribute to further drug-taking as a way to alleviate the suffering from the experience of discrimination.

#### 3. What problems do you see stigma related to substance use disorders as causing?

The stigma surrounding substance use disorders pervades every aspect of our society – across policy, medicine, communities, and individuals – and it is profoundly damaging. Much of this stigma stems from the incorrect belief that addiction is the fault of the person who uses drugs, without any consideration of the unique challenges and lack of opportunities that people are exposed in their lives, or the genetic vulnerabilities that make some individuals more prone to drug use and addiction.

For decades, drug use has been addressed as a crime rather than as a matter of public health, despite the fact that we know punishment does not ameliorate substance use disorders, and in fact, can exacerbate negative outcomes. Punishing drug use and marking people who use drugs as "criminals" has further heightened the stigma around addiction, disproportionately harming Black people and other communities of color. The negative impact of criminalization of people who use drugs transcends across generations, as children who live in a family with one parent who is incarcerated are at greater risk of drug use themselves.

The stigma associated with addiction is also entrenched within the health care system. Stigma contributes to clinicians being under-trained in addiction medicine, under-screening for substance use disorders, and under-prescribing lifesaving medications. Stigma also influences insurance not wanting to reimburse for care and treatment related to addiction, and reimbursement caps being set at lower levels for addiction than for other medical conditions.

As one example, we have three effective medications to treat opioid use disorder — methadone, buprenorphine, and naltrexone. Yet only half of addiction treatment facilities offer any FDA-approved medications, only a tiny fraction offer all three, and only 11% of people with opioid use disorder received them in 2020. Also, the inadequate level of reimbursement explains why some buprenorphine waivered physicians do not treat patients.

In addition, we know that people experiencing addiction often encounter stigma in healthcare settings, which impedes access to care and negatively impacts the quality of care that people receive. Internalized stigma from those negative experiences can lead

people with substance use disorders to avoid seeking treatment, out of fear that they will be criminalized or mistreated.

### 4. What do you say to people who have stigmatized attitudes towards persons with substance use disorders?

Substance use disorders are chronic, treatable conditions from which people can recover. But stigma can make individuals with substance use disorders less likely to seek treatment, and less likely to receive the compassionate, quality care that they deserve. Using person-first language that is scientifically accurate and free of negative bias is one easy action that everyone can take to reduce stigma around substance use and addiction. The National Institute on Drug Abuse provides a language guide for health professionals and the public to help destigmatize addiction: Words Matter - Terms to Use and Avoid When Talking About Addiction.

# 5. What progress has been made with the stigma related to substance use disorders, and what future steps are needed?

Our understanding of substance use disorders as chronic, treatable conditions that are strongly influenced by social determinants of health has come a long way over the past few decades. This is a huge advancement from where we are even a few years ago. However, we have a long way to go in our efforts to reduce the stigma that continues to be associated with the substance use and addiction.

It is crucial to take a public health approach to substance use and addiction, rather than punishing or criminalizing people who use drugs. It is also crucial to strengthen addiction training among all sectors of medical education and the health care field, so providers are confident and compassionate in providing quality, sustainable, and continued care to people with substance use disorders and those in recovery. We also need to invest in and support evidence-based harm reduction practices, such as naloxone distribution and syringe services programs, which can be lifesaving. Finally, we have to confront the lack of support for an infrastructure to provide prevention interventions that strengthen wellbeing and resilience and decrease the risks for substance use disorders, which have devastating personal and economic consequences to individuals and communities.

In 2020, more than 40 million people in the United States had at least one substance use disorder, and in 2021, more than 107,000 people died of an overdose. To prevent this staggering negative impact, a first crucial step is to combat the stigma that exists among healthcare providers, policy makers and our culture towards people suffering from substance use disorders. This will lead to better preparedness and resource allocation to prevent and treat substance use disorders and to accelerate recovery.

## Interview with Dr. Stephen Marder, Professor of Psychiatry and Biobehavioral Sciences at UCLA, about the stigma associated with schizophrenia



# 1. Please tell us how you became aware of problems related to the stigma of schizophrenia.

I became aware of my own biased beliefs early in my career as a psychiatrist. Working on inpatient wards we tend to see people at their most ill. When I later engaged with people I saw in the hospital while they were in their communities, I appreciated that I had failed to understand their potential for recovery. I later did a study of highly successful people with schizophrenia, and I learned that they had recovered from very severe illnesses.

#### 2. What problems do you see stigma related to schizophrenia as causing?

Among clinicians, it leads to a lack of appreciation of an individual's ability to recover and an underuse of psychosocial and rehabilitation interventions. In patients, it leads to an inability to understand that they can thrive even in the presence of active symptoms. It also leads to a reluctance to accept a diagnosis of schizophrenia and its treatment. Finally, patients may see a bleak future and lower their personal goals.

## 3. What do you say to people who have stigmatized attitudes towards persons with schizophrenia?

Support groups for patients and families often include the parents of patients who are doing poorly. This can be discouraging. I will recommend books or other materials that demonstrate people who are able to live full and productive lives with schizophrenia.

# 4. What progress has been made with the stigma related to schizophrenia and what future steps are needed?

I would advocate for renaming the disorder since the stigma associated with being diagnosed with schizophrenia is hard to overcome. We also need to change the face of the illness so when people think of schizophrenia, they associate it with people who living well with the illness.

Interview with Dr. William Carlezon, Professor of Psychiatry at Harvard Medical School, about how the language we use may contribute to the stigma of mental health and substance use disorders



### 1. Please tell us how you became aware of problems related to the stigma that still surrounds mental health.

In my case, I work at a psychiatric hospital (McLean Hospital) that has been at the forefront of efforts to reduce stigma. It is something that our community thinks about deeply. With respect to efforts at ACNP, I can share an anecdote that occurred during my term as Principal Editor of our journal, Neuropsychopharmacology (NPP). One morning our team noticed discussion on social media about a recently published NPP paper that included the term "addict". This prompted us to become more proactively engaged in understanding the impact of the use of stigmatizing language and devising steps that would help NPP (and by extension, ACNP) provide guidance for its official activities. The NPP team reached out to the Directors of NIDA, NIMH, and NIAAA—all of whom are ACNP members—to ask for their insights. By the end of a day that started with a flurry of social media activity about a word in an NPP paper, we had commissioned an article on person-centered language by the world's leading experts. As of today, "Choosing appropriate language to reduce the stigma around mental illness and substance use disorders" by Drs. Nora Volkow, Joshua Gordon, & George Koob has been accessed more than 24,000 times, suggesting a broad and sustained impact in our community and beyond. This paper has served as a roadmap for discussions on guidelines at NPP and ACNP. It can be freely viewed and shared with this link: https://rdcu.be/cZvEX

## 2. What problems do you see the use of inappropriate language related to mental health as causing?

There is considerable evidence that stigma can lead to demonstrable changes in care that correlate with poorer outcomes; this is beautifully articulated in the person-centered language article described above. Personally, I've become more sensitive to how we are all surrounded by stigmatizing language every day, in virtually all aspects of our lives. Having noticed it, it is impossible to un-notice it. We seem to be at a time in our culture where the use of slang terms pertaining to mental health conditions, including substance

use disorders (SUDs), is so common and routine that we barely recognize it. Casual use of terms including "insane" and "crazy"—paradoxically, often to portray something as being really good—can normalize them, distract from their true meaning, and perpetuate their use. I believe that our community should be more attuned than most, since many of us have dedicated our lives to bringing comfort to people affected by mental health conditions. Even small improvements in mindfulness about the way we use language can be part of a much larger process.

### 3. What do you say to people who have stigmatized attitudes towards persons with psychiatric disorders?

I remind them that we are talking about people. Considering the prevalence of mental health conditions, most of us have a family member, friend, or colleague who is suffering on a daily basis. We should be conceptualizing these conditions like any other medical condition, and treating people affected by them as we would treat a loved one: with understanding, compassion, and empathy. Dignity is a critical element of recovery.

## 4. What progress has been made with the stigma related to mental health and what future steps are needed?

ACNP is an organization with a world-renowned reputation for excellence and leadership. I think a lot of progress has been made by starting these discussions and taking concrete steps. With respect to future steps, those of us who are current or prospective ACNP members should be at the forefront of setting the standards of how we talk about mental health conditions, whether when at our home institutions, traveling for events such as our annual conference, or in the public sphere (e.g., at grocery stores, restaurants, our children's schools, and beyond). The words we use in our papers and presentations, as well as in our casual conversations, can set a powerful example for the ways in which our communities think about and discuss these conditions and people affected by them. ACNP has commissioned a workgroup to make recommendations on the use of language for its publications (including its journal and websites) and annual conferences. Part of the plan is to generate materials that can provide a roadmap that can be used in our work-related activities and beyond. Change takes time, but the first steps are mindfulness, and the ACNP membership can feel proud about our organization's commitment to being a force for positive change.