Stigma of Addiction Summit
Lessons Learned and Priorities for Action

BACKGROUND INFORMATION

The National Academy of Medicine, Dell Medical School at The University of Texas at Austin, and Shatterproof co-hosted the Stigma of Addiction Summit (Summit) on June 10, 2021, to discuss the negative impact of stigma on people with substance use disorders (SUDs) and elevate action-oriented strategies to address and eliminate the harms caused by stigma. The event was organized by an interprofessional and interdisciplinary planning committee of individuals in recovery, clinicians, health profession educators, addiction medicine professionals, government stakeholders, and health system representatives. The members of the planning committee were Victoria Bosman, Cheyenne Johnson, John Kelly, Elena Mendez-Escobar, Joy Rucker, Margot Savoy, and Eri Solomon (https://nam.edu/event/stigma-of-addiction-summit/).

The Summit occurred at a critical point in the U.S. opioid epidemic and SUD crisis. In 2020, there were over 93,000 drug overdose deaths in the U.S., and most of those deaths involved opioids (Devitt, 2021). Additionally, the COVID-19 pandemic has exacerbated the overdose crisis, as many individuals with SUDs have been separated from their clinicians, support groups, and loved ones due to physical distancing protocols. Physical distancing has also made accessing medications for opioid use disorder (MOUD) challenging, further putting those experiencing addiction at risk. In fact, in the 12-month period ending in April 2021, the overdose death number increased to more than 100,000 (National Center for Health Statistics [NCHS], 2021).

There is an important distinction between people who carry a medical diagnosis of SUD or addiction and those who use drugs without meeting the criteria for SUD included in the Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition. For the purposes of the Summit and this discussion proceedings, the term SUD will be used to describe all of these groups, though we recognize that stigma is experienced differently by these categories of individuals. People with SUDs experience stigma in many different settings, including across the spectrum of health care delivery, and experiencing stigma can lead to feelings of shame, limit access to care, and contribute to the cycles of addiction (Atkins et al., 2020). The damaging impacts of stigma demonstrate the need for a coordinated national effort to reduce and ultimately eliminate stigma. The Stigma of Addiction Summit provided a forum for individuals from a variety of backgrounds to discuss stigma within the health care ecosystem and develop solutions to address it.

Expert speakers and panelists shared their lived experience and presented on current efforts to reduce stigma, discussed strengths and gaps in the evidence base, and identified areas for future stigma research and funding. Due to the deep connection between systemic racism and stigma around substance use, the Summit considered the impact of systemic racism on stigmatizing language and behaviors and sought to identify specific actions to combat racial disparities in access to treatment for SUDs. The content of the Summit was intended to encompass the stigma associated with all substances. However, current regulatory authorities and funding focus on opioids, resulting in a higher concentration on interventions for OUD. The view of the planning committee is that stigma reduction efforts, principles, and best practices are universal to people using any substances. Therefore, the planning committee emphasized engaging a diverse group of attendees and panelists who represent all facets and demographics of the communities impacted by SUD stigma.
The Summit discussions are particularly applicable to stakeholders from across the U.S. health ecosystem, those in clinical service delivery, health system stakeholders, universities and people in academia, public health organizations, professional member organizations, and any individual or group working to improve the system by which people with SUDs or who use drugs are cared for.

The objective of the Summit was to create a springboard for further collaboration, partnerships, and action between the planning committee, speakers, and attendees. Through a combination of individual presentations, breakout sessions, and panel presentations, the Summit served as a platform for elevating aspects of what could become a coordinated national research agenda to reduce and ultimately eliminate stigmatizing behaviors and attitudes toward individuals with SUDs.

MEETING SUMMARY

The Personal Impact of Stigma

The Summit began with a panel on the personal impact of stigma, moderated by First Lady of North Dakota, Kathryn Burgum. The panelists noted that stigma is the most pervasive barrier to overcoming the overdose epidemic and that sharing personal stories is a particularly effective way to reduce stigma. “Living proof is a stigma buster,” said panelist Laurie Johnson-Wade. Panelists focused on the power of peers in the recovery process and the therapeutic effects of their presence and stories. They emphasized the important role that people with lived experience can play, whether as a peer recovery coach, as a physician, or in helping to craft policy. However, it was noted that SUDs and stigma impact people differently, and diverse representation among peers and leadership within the recovery community is essential, as individuals of color with SUDs often experience greater stigma than their White peers, partly due to the disproportionate criminalization of addiction in communities of color. Johnson-Wade stressed the importance of having diverse individuals, including individuals of color, members of the LGBTQ community, and individuals using MOUD in leadership positions within the recovery community. Melissa Anderson stated that there are many different pathways to recovery, recovery may look different for every person, and individuals with SUDs need to be empowered to make the best decisions for themselves. This panel, and others throughout the day, highlighted the fact that there are evidence-based methods to treat SUD, namely MOUD, which are FDA approved. However, there are significant barriers to using these methods, such as access, challenges in maintaining continuous treatment, and additional obstacles not experienced by other FDA-approved medications, absent stigma. Panelists agreed that stigma exists within the recovery community and the public, and anti-stigma work should engage both groups.

Session 1.1 - Stigma of Drug Use, Treatment, and Harm Reduction

During this session, panelists stated that stigma and misunderstandings about SUDs make accessing addiction treatment and harm reduction services difficult. Panelists drew on their personal experiences with addiction and working with individuals with SUDs and noted the need for accessible treatment, trauma-informed care, and people-first approaches. Jon Giftos defined people-first approaches as those involving “programs that are for and by the people that are served” and using participant feedback to create warm, welcoming, and safe spaces. The panelists agreed that stigma is especially prevalent around the use of MOUD, and this stigma can create unnecessary barriers to accessing evidence-based treatment. Additionally, the increased stigmatization of addiction compared to other chronic diseases makes it difficult for individuals with SUDs to receive proper care, evidence-based treatment, and harm reduction services. Panelists advocated for the integration of SUD treatment and harm reduction into the broader health care system to assist in reducing stigma and increasing quality of care. Monique Tula stated that harm reduction measures are people-first approaches because they “put the power of choice in the hands of people who use drugs.” Other panelists emphasized that harm reduction measures can give people who use drugs greater autonomy and personal responsibility. Yngvild Olsen stated that minimizing harm and promoting health are key tenets of all other areas of medicine but are often excluded from addiction medicine due to stigma. Other panelists echoed this sentiment and encouraged people to view addiction and recovery as a spectrum on which each individual charts their own path to improving their health and wellness.

Session 1.2 - Stigma in the Health Care Setting

Session 1.2 focused on how stigma within the health care system makes it difficult to access care for SUDs, with a compounding impact on specific populations. Pooja Lagisetty noted that stigma is so pervasive in
the health care setting that 41 percent of primary care clinics reported being unwilling to schedule appointments for people who might need opioid therapy for pain (Lagisetty et al., 2019). However, this stigma is not distributed equally, and panelists stated that youth (in particular, adolescents and young adults), communities of color, and health care professionals with SUDs are more likely to experience stigma in health care settings than their peers. Panelists noted that stigma in the health care setting does not exist in a silo, and patients with chronic pain also experience stigma. Patients with chronic pain may not be believed when discussing their pain, and they may have difficulty accessing opioids for pain management. Panelists stated that efforts to address stigma in the health care setting should address stigma around opioids, regardless of how they are used, as stigma around opioids contributes to stigma for both individuals with SUDs and individuals with chronic pain. Panelists also stated that the separation of the SUD treatment system from other health care treatment settings perpetuates the cycle of stigma and makes care more difficult to access.

Panelists suggested strategies to improve care and reduce stigma, such as broadening education on SUDs for health professionals to better connect the history of drug use epidemiology, health and regulatory policies, pain management, and their ultimate influence on stigma; creating a more welcoming environment for health care professionals with a history of SUD; and integrating care for SUD into the primary care setting. As Lagisetty stated, “It is not our job as health care providers to deem someone worthy of treatment or not. We are all worthy of treatment.”

**Session 1.3 – Structural Stigma and How Systems Discriminate and Intersect**

Panelists in this session urged attendees to think about stigma not as an abstract concept but as an embedded feature of the medical and criminal legal systems. Much of the conversation in this session centered on the interconnectedness of stigma, policies, and the criminal legal system. Sheila Vakharia began the panel by asserting, “as long as addiction is actually the only so-called disease that's also a crime, I don't think we can persuasively and truly reduce stigma.” Panelists stated that substance use is often viewed through a lens of criminalization, and this perception has led to many of the harmful policies around substance use. These policies and systems simultaneously perpetuate stigma and the social factors contributing to SUDs, including trauma, isolation, and a lack of social and economic mobility. For example, the criminal legal system is often used to address SUDs, yet carceral settings rarely provide evidence-based treatments for SUDs like MOUD and peer support. The panelists emphasized the need to dismantle the policies that allow stigma to exist and grow while also recognizing that destigmatization does not benefit all groups and individuals equally. The panelists advocated for the involvement and compensation of people with lived experience, including those who are actively using drugs, throughout the policy reform process. They suggested a variety of ways to include people with lived experience, such as hiring them to serve on advisory boards, integrating them into research teams to assist in the development of research agendas, and assisting in the collection and analysis of data. Panelists agreed that some of the most impactful steps that can be taken to address structural stigma include translating research into actionable policy and identifying implementable, specific, and concrete changes.

**Session 2.1 – The Role of Advocates and Families**

Panelists with lived and familial experience discussed the role of advocates and families and relayed personal stories to demonstrate the impact of stigma on individuals with SUDs and their families. The impact of addiction and substance use disorder on the families and loved ones of those experiencing addiction was not discussed during this panel, and this session was informed by the individual experiences of the panelists. They described how families of those with an SUD may feel embarrassed or find the subject difficult to discuss but emphasized the importance of remaining supportive and open to discussion. Panelists urged family and friends of people with SUDs to support their loved ones on every step of their journey, noting that people with SUDs often do not receive the support they need from the legal and medical systems. To combat stigma, panelists suggested that health care professionals should reduce their use of stigmatizing language; families should provide compassion and empathy to individuals with SUDs while continuing to treat them with respect; and everyone should recognize that patients want to recover from SUDs while also understanding that addiction is a chronic, relapsing, and challenging disease. Panelists also urged family and friends to meet people at whatever stage of the recovery journey they are at while continuing to love them. Dinah Ortiz emphasized the importance of family and friends for people who use drugs: “If you lose all of your support, you lose all of your hope. If you are left to hit rock bottom, you lose all of your hope. All that is waiting for you is death.”
**Session 2.2 – How to Intervene or Change Behavior in Real-Time**

“The stigma that exists in our society is just as deadly as the drugs themselves,” noted Guy Felicella during Session 2.2. Panelists stated that society fails to address the trauma that can lead some people to use drugs, and the medical system heightens this trauma by further stigmatizing individuals who seek treatment for SUDs. Many individuals who seek care for drug use face stigma within the medical system, so panelists suggested establishing reporting options that allow students and medical residents to provide honest feedback to their supervisors when they observe harmful behavior without fear of retaliation. Panelists also stated that community-led programs are essential in harm reduction efforts because these programs are often better at engaging individuals and supporting people who use drugs than institutionalized programs. In addition to broader community efforts to reduce stigma, the discussion included advice for health care professionals to follow in order to reduce stigma. “Start with yourself,” emphasized Laura Guzman. Panelists urged attendees to challenge themselves and the systems around them by examining internal biases. Additionally, panelists discussed that involvement of people who use drugs should expand beyond the frontline level and further use and integrate their knowledge and feedback in the development and evaluation of SUD resources. The panelists advocated for including people who use drugs in policy development, program development, and implementation of services and calling out stigmatizing language and behavior when they occur in health care settings.

**Session 2.3 – Research, Evidence, and Mechanisms for Action**

Throughout Session 2.3, panelists stated that stigmatizing attitudes are pervasive and persistent among the public and in professional settings, and a key driver of stigma is the belief that SUDs are a personal choice and a moral failing. To combat these false narratives, panelists suggested that communication strategies such as using people-first language, presenting solution-oriented messages, sharing personal stories, and emphasizing the societal factors that contribute to drug use can all reduce stigma. Other suggested strategies included integrating stigma-reduction work into evidence-based practices and fostering opportunities for positive social contact with people who use drugs. While panelists noted it would be difficult, they advocated for changes that could shift the culture around treatment of drug use. They recommended increasing the involvement of people with lived experience at all stages of the research process and improving SUD treatment by ensuring those involved in treatment have compassion for their patients. Tom Hill underscored the importance of respect in SUD treatment: “if you treat people right, you treat people well, they'll feel comfortable and they'll come back, if they feel respected and honored.” Panelists urged individuals to view stigma through an intersectional lens because of the deep connections between race, identity, stigma, and society’s view of people who use drugs. Finally, panelists highlighted areas for future research including rigorous evaluation of stigma-reduction strategies, a greater focus on the causes of SUDs and the role that trauma plays in substance use, and ways to build SUD treatment systems that are engaging over the long term for people who use drugs.

**Innovation Session Video Presentation**

To promote connections between attendees and to lift up innovative strategies to combat stigma, the Summit conducted a broad call for approaches to reduce stigma across the health care ecosystem. The Summit received 99 submissions, six of which were featured during a live video presentation at the Summit. All submissions that met the inclusion criteria were included in a compendium with full abstracts and contact information for each stigma initiative (https://nam.edu/wp-content/uploads/2021/06/Innovation-Abstract-Packet_final.pdf). The six featured videos highlighted a wide range of strategies, including using the Project ECHO model to reduce stigma around MOUD; measuring Arab American public stigma toward substance use; destigmatizing substance use, pain, and addiction in the media; developing a toolkit to educate on treatment options, legal rights, and resources for people with OUD; reducing self-stigma in justice-involved populations using MOUD; and developing a harm reduction and stigma curriculum for providers distributing naloxone and safer consumption supplies.

**Closing Keynote**

The closing keynote presentations featured Regina LaBelle, Acting Director (AD) of the Office of National Drug Control Policy (ONDCP), and Keith Wailoo, Henry Putnam University Professor of History and Public Affairs at Princeton University. AD LaBelle provided an overview of the steps ONDCP is taking to address overdoses and reform addiction treatment. For the first time in its history, ONDCP has explicitly included harm reduction and advancing racial equity in its drug policy priorities. AD LaBelle provided an overview of the
Biden administration’s drug policy priority areas, including expanding access to evidence-based treatment and recovery support services, confronting racial equity issues related to drug policy, enhancing harm-reduction efforts, supporting evidence-based prevention efforts related to youth substance use, reducing the supply of illicit substances, expanding the addiction workforce, and expanding access to recovery support services. Wailoo spoke about drug use and stigma through a historical lens, highlighting trends in drug use and stigmatization over time. He described how “the tools of destigmatization [often] become stigmatized,” and noted how this has occurred recently with MOUD and syringe exchange services. Wailoo argued that many conventional norms will be challenged in order to reduce stigma, including those that paint different pictures of public and private substance use. He also noted that past examples of anti-stigma work related to disability, sexuality, and racial identity can inform anti-stigma efforts around drug use. At the conclusion of the panel, AD LaBelle emphasized the importance of being patient, working together, and engaging in collaboration that can lead to change. Together, Wailoo and AD LaBelle encouraged attendees to reflect on their own views about drug use and engage in difficult conversations to continue reducing stigma.

AREAS OF FUTURE FOCUS AND PRIORITIES FOR ACTION

Richard Bottner, DHA, PA-C, Dell Medical School, The University of Texas at Austin; Alanna Boulton, MSHA, PMP, Dell Medical School, The University of Texas at Austin; Rachael Cooper, MFS, Shatterproof; and Matthew Stefanko, Shatterproof

The Summit highlighted several key themes and priorities for action to combat the stigmatization of people who use drugs. It is indisputable that stigma surrounding drug use and treatment of SUD hinders access to high-quality and evidence-based care and results in preventable loss of life for patients (NCHS, 2021). This stigma extends beyond the individual and interpersonal levels and exists throughout societal systems, including the health care system. It is demonstrated by the apparent reluctance or inability to establish policies that would improve the addiction prevention, treatment, and recovery system. For example, despite the strong evidence base, MOUD is not uniformly used across treatment settings, and patients who take these medications often experience high levels of stigma. Two specific examples discussed include patients of color, who face greater barriers to care than their White counterparts do because of the interconnected nature of stigma, substance use, and racism; and clinicians with SUD, who face unique barriers to care due to the misconception that clinicians are “too smart” or “too moral” to develop an SUD. In addition, they may fear losing their license to practice because of their addiction. Stigma has led to, and perpetuated, these inequities in care.

Although recognizing the detrimental impacts of stigma on access to high-quality addiction care and implementing anti-stigma campaigns are important first steps, much more work needs to be done to eliminate stigma toward people who use drugs and experience addiction. The authors of this section recognize that the issues raised during the Summit are inherently nuanced and complex and that not all the necessary intricacies could be addressed during the event itself, necessitating ongoing and dedicated discourse. Nonetheless, the authors of this section, drawing on conversations at the Stigma of Addiction Summit, suggest several priorities for action:

1. **Strategy:** At the state and federal levels, prioritize stigma reduction centrally to ensure a widespread, coordinated response.
2. **Policy:** Focus efforts on the development of anti-discriminatory policies designed to reduce stigma, improve access to SUD treatment and mental health care, and advance racial and health equity in the substance use field, as well as adjacent spaces.
3. **Research:** Establish an agreed-upon framework and methodology for researching stigma of SUD, its broad impact, and an approach to evaluating interventions for reducing stigma, especially within the health care delivery system.
4. **Representation:** Integrate people with lived experience, including those in recovery, in treatment, and those who are actively using drugs, into all conversations, programs, policy- and decision-making processes, and initiatives designed to increase access to SUD resources. This includes treatment and harm reduction, as well as non-SUD-specific programs in adjacent spaces, such as those addressing mental health, employment, and housing.
5. **Equity:** Ensure all communities are well represented when developing and delivering interventions for
those with SUD, including but not limited to individuals of color, members of the LGBTQ community, and those with disabilities. These communities are differently impacted by SUD-focused policies and programs and have differing access to treatment, recovery, and other support systems.

6. **Funding:** Ensure funding for anti-stigma efforts are executed as public health interventions with appropriate evaluation and oversight. Direct increased resources to mitigate and eliminate the stigma of addiction within health care settings from all levels of local, state, and federal government.

7. **Education:** Develop evidence-based, in-depth educational initiatives and campaigns targeted at health care professionals. These initiatives should be designed to normalize SUD as a chronic medical condition and improve treatment quality for those with SUD. Actively disseminate patient-centered person-first language around SUD.

8. **Inclusivity:** Study and implement interventions targeted at reducing discrimination and the increased stigma of addiction around specific populations, which include but are not limited to pregnant people, adolescents, people with chronic pain, and those currently or recently incarcerated.

References


DISCLAIMER: This Discussion Proceedings was prepared by Aisha Salman, Emma Freiling, Richard Bottner, Alanna Boulton, Rachael Cooper, and Matthew Stefanko as a factual summary of what occurred at the meeting and areas of future focus and priorities for action. The statements made are those of the rapporteurs or individual meeting participants and do not necessarily represent the views of all meeting participants; the planning committee; members of the associated program; the National Academy of Medicine; or the National Academies of Sciences, Engineering, and Medicine.

REVIEWERS: To ensure that it meets institutional standards for quality and objectivity, this Discussion Proceedings was reviewed by John F. Kelly, PhD, MGH Recovery Research Institute; Margot Savoy, MD, MPH, FAAFP, FABC, CPE, CMQ, FAAPL, Temple University and Temple University Health System; and Joshua Sharfstein, MD, Johns Hopkins Bloomberg School of Public Health.

SPONSORS: This workshop was held in collaboration with Dell Medical School at The University of Texas at Austin and Shatterproof. Any opinions, findings, or conclusions expressed in this publication do not necessarily reflect the views of any organization or agency that assisted in the development of this project.

For additional information, please visit https://nam.edu/event/stigma-of-addiction-summit/.