

# THE IMPACT OF STIGMA ON PEOPLE WITH OPIOID USE DISORDER

## INCLUDING DISCUSSION OF STIGMA TOWARD YOUTH ENGAGING IN SUBSTANCE USE

*FINDINGS FROM KEY INFORMANT INTERVIEWS IN MAINE*



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## Summary of Findings from Interviews to Understand the Impact of Stigma on Adults with Opioid Use Disorder and Youth Engaging in Substance Use

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**Background:** CCSME hired Hart Consulting to conduct in-depth interviews with Maine-based experts on the impacts of stigma on people with opioid use disorder (OUD), including people with lived experience. MCD Global Health hired the same team to conduct similar interviews with people who work with youth in substance use treatment and prevention interventions.

“Stigma is a dynamic multidimensional, multilevel phenomenon that occurs at three levels of society—structural (laws, regulations, policies), public (attitudes, beliefs, and behaviors of individuals and groups), and self-stigma (internalized negative stereotypes). A hallmark of stigma, like stereotyping, is that it overgeneralizes. People who have mental or substance use disorders do not form a discrete, static, or homogeneous group.” (*National Academies of Sciences, Engineering, and Medicine, 2016*)

### Stigma Affects Every Aspect of Life

- Participants told interviewers that stigma **negatively impacts access to treatment and services** among people with OUD.
- While several participants said stigma has lessened over the years, they still see it **impacting many policies, places, people, and practices**.
- Participants noted that **not everyone recognizes OUD as a disease**.
- People with OUD or who are in recovery often **internalize stigma**, thinking that they themselves are weak. They may be ashamed and withdraw from the community support. Sometimes they anticipate stigmatized reactions from providers and community members.

*“I think people come in carrying a lot of shame. We talk about this in our training... they have internalized that stigma that they get from society as a whole that tells them that what they're doing is morally wrong. Then they get stigma from us in the healthcare settings because we treat them differently.”*

### Specific Settings Where Stigma Impacts People

- **Family/Community** – many people think OUD is a choice and therefore a moral failing.
- **Healthcare** – primary care, hospitals, ERs, surgical teams treat people with OUD differently
- **First Responders** – police, EMTs, ambulance may not want to provide referrals, Narcan, etc.
- **Housing** – applications ask for criminal history, difficult to find safe and secure housing
- **Commercial Pharmacies** – look down on people picking up certain medications like Narcan
- **Medication for OUD** – judgements about “swapping one drug for another,” specific opinions about means of recovery, communities don’t want clinics in their towns.
- **Employers** – some employers are averse to hiring people with past drug use history
- **Legal** – criminal to use illegal drugs, court system favors release/resolution over treatment

*“We stigmatize people .... when people decide to go on medication for opioid use disorder, society stigmatizes them for being on those medications. We tell them that they're not really sober...And so what that ends up doing is it makes people ambivalent about treatment.”*

### Affected Others are Stigmatized for Family Members' Substance Use

- Students may be ***treated differently in school if their caregivers use substances.***
- Students who ***use substances with their families are considered harder to treat.***
- Caregivers of youth and adults with SUD are stigmatized and are blamed for moral failure in raising troubled children.
- Parents ***do not understand the physical harm to youth in using cannabis.***

### Impact of Stigma on Youth Engaging in Substance Use

- According to participants, ***vaping and cannabis*** are the substances most used by youth, followed by alcohol. They get the substances from family and friends.
- Participants shared that youth who use substances are ***punished for their behavior rather than being referred to treatment.***
- Youth internalize negative labels. In small towns, this can mean that they don't get hired for a job or people are quick to call police if they are hanging out in public.
- ***Addressing the underlying social needs*** such as safe housing, food security, and positive environment is effective in helping youth change their habits.

### Access to Treatment for Youth is Lacking in Maine

- Youth who seek addiction specialists are usually there by ***court order or forced by their parents and so may not be cooperative.***
- Accessing services is particularly hard for youth who may ***forget about appointments, not have transportation, or show up late.*** This does not work with the "fee-for-service/time is money" healthcare system policies.
- Primary care ***providers may not be trained in youth addiction*** and oftentimes do not feel confident in treating youth with substance use.
- ***Beds for in-patient care for youth are scarce in Maine.***

### Resources Helping to Address Stigma for Adults and Youth

*Highlights from almost 70 specific programs/activities/resources listed by respondents.*

<b>Language</b>	Person First Language Resources
<b>Addiction Treatment</b>	Healthcare Providers, Medications for opioid use disorder (MOUD)
<b>Recovery Supports</b>	Recovery Centers, Peer Supports, Groups
<b>Prevention</b>	Maine Prevention Network partners, SAMHSA, CDC
<b>Recovery Friendly Employers</b>	Maine Department of Labor, Southern Maine Community College
<b>Housing First Resources</b>	Unhoused Outreach
<b>Harm Reduction</b>	Syringe Service Program, Narcan
<b>Education/Events</b>	Public, Families, Healthcare Providers, First Responders, Dental Professionals

## Contents

Background .....	1
Brief Review of the Literature/Web Scan .....	4
Opioid Use Disorder: The Current Situation in Maine .....	4
Defining Stigma .....	6
Research on SUD Stigma Reduction Interventions .....	9
Words Matter .....	10
Studies of Best Practices .....	10
Promising Practices.....	13
Interventions for Youth .....	15
Lessons in Maine .....	17
Resources for Reducing Stigma.....	19
National Resources for Reducing Stigma.....	19
Maine Resources for Addressing Stigma .....	20
Findings from Key Informant Interviews .....	23
Background.....	23
Detailed Findings.....	24
Stigma's Impact on People with Opioid Use Disorder in Maine .....	24
Internalized or Self-stigma .....	26
Social Stigma.....	27
Some Groups Face Added Layers of Stigma .....	28
Stigma has Lessened Somewhat in Maine.....	29
Stigma in Healthcare Settings .....	30
Commercial Pharmacies .....	33
Stigma Against Medications for Opioid Use Disorder .....	34
Law Enforcement .....	36
Emergency Medical Services (EMS) .....	36
Housing.....	37
Employment .....	38

Thoughts on Best Ways to Reduce Stigma Towards People with OUD .....	39
How to Reduce Stigma in Maine .....	39
Findings on Youth Affected by Substance Use and Ways to Reduce Associated Stigma ....	42
Youth Engaging in Substance Use .....	42
Youth Experience Stigma in Many Ways .....	43
Children of People with SUD are Stigmatized.....	44
Peer-to-Peer Stigma and Other Impacts on Social Life .....	45
Stigma Can Push Youth to Use Substances .....	46
Punitive Responses to Substance Use from School Systems, Criminal Justice System, and Within Families.....	47
Prevention of Stigma for Youth.....	48
Lack of Resources for Young People Using Substances .....	49
Healthcare Providers Lack Training in Youth SUD .....	50
Best Ways to Reduce Stigma for Youth Engaged in Substance Use .....	51
Conclusions/Recommendations .....	53
Appendix A.     Moderator Guide .....	56

## Background

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**This Study.** This study explores the impact of stigma on adults with opioid use disorder (OUD) as well as youth engaged in substance use. In the fall of 2024, Maine Health Access Foundation (MeHAF) enlisted the Co-Occurring Collaborative Serving Maine (CCSME) to complete an assessment of practices to reduce stigma related to substance use and co-occurring disorders to identify areas of success and opportunities for growth in Maine. As this was a broad scope, MeHAF agreed to narrow the scope to opioid use disorder (OUD) among adults. CCSME hired the team at Hart Consulting, Inc. to carry out part of the project under the guidance of an oversight committee of subject matter experts. Hart Consulting, Inc., a woman owned business based in Gardiner, Maine, has decades of experience conducting these types of studies on public health, behavioral health, and public opinion topics. Midway through the project period, MCD Global Health expanded the focus of the work by adding resources to allow the team to include how stigma impacts youth engaged in substance use.

**Guided by an Oversight Committee.** The work was informed and guided by an oversight committee that included representatives from CCSME, MCD Global Health, and Maine Center for Disease Control and Prevention (Maine CDC). The team worked closely with the Hart Consulting, Inc. team to provide their deep knowledge and expertise on the topics. They also helped identify and recruit interview participants.

**Study Focus.** At the start of this study, the oversight committee worked with the study sponsors to focus the work by defining stigma and narrowing the lines of inquiry to a specific substance and group of people. Initially, the group agreed to focus on adults with opioid use disorder (OUD) and later widened it to include youth impacted by substance use (either theirs or a family member's). The study was partitioned into two parts: Part 1) a brief review of the literature and web scan of best practices for addressing stigma related to substance use disorder; and Part 2) key informant interviews with experts, including people with lived experience with OUD or working with youth on substance use issues.

**Literature Review/Web scan.** The team at Hart Consulting, Inc. began the work by reviewing the literature and conducting a brief web scan of research that explored the impacts of stigma and identified the best or promising practices to reduce its impact. The study was iterative in that they reviewed the definitions and best practices for reducing stigma with adults with OUD and then circled back to cover the same topics for youth engaged in substance use. The findings are provided herein.

**Key Informant Interviews.** The second part of the study entailed interviews with subject matter experts, including people with lived experience. The goal was to speak with 14 people working with adults with OUD and 8 adults working with youth. The interviewers used a moderator guide to lead the discussions. Eight of the adult-focused interviews used only the adult questions; five of the adult interviews asked about adults and youth. Six of the youth-focused interviews used youth-only questions. More details on the approach appear in the findings section of this report.

**Focus Groups.** In addition to the one-on-one interviews, the Hart Consulting team conducted two focus groups via Zoom that engaged 24 people. The groups focused on discussing stigma's impact on adults with OUD, with a couple of mentions of youth and substance use. The moderator used the same interview guide and asked participants to share responses to three questions in Mentimeter online survey software.

**Definition of Stigma.** Throughout the project, the study team encountered widely varying understandings of the definition of stigma. Some participants see stigma as any action or condition that works against or appears to work against someone with OUD or youth engaged in substance use. Others had a narrower view that stigma is found explicitly in language, policies, and practices, but not all barriers are necessarily stigma or stigmatizing. This study includes experts' definitions in the literature review section and weaves in the participants' thoughts in the interview findings section.

**Use of Language.** Communication is at the heart of community building and connection. Using affirming and supportive language is a key strategy to reduce stigma and support recovery from substance use. The most effective ways to reduce stigma start with positive, person-centered language. This study preserves the word choices used by researchers in the citations and in quotes by interview participants to honor the variability that exists in language use related to substance use, prevention, and treatment.

**Limitations.** As with any qualitative study, this one has some important limitations. Firstly, the literature review is a cursory review of literature found in the public domain and is neither comprehensive nor all-inclusive of the body of work on the topics. Moreover, most of the literature is not specific to Maine and so will need interpretation and further reflection on local application. Secondly, the key informant interviews are limited in number and represent the views of each respondent. While we have coded responses for themes and highlighted unique ideas, collective thoughts cannot be generalized to the public. The findings do provide a valuable window into how individuals experience stigma related to substance use and can inform the work in Maine.

**How to Read this Report.** This report has two parts – the summary of the web scan/literature review of publications sharing effective stigma reduction strategies and the findings from the key informant interviews. Each part has an overall section of findings that includes findings for adults and those specific to youth.

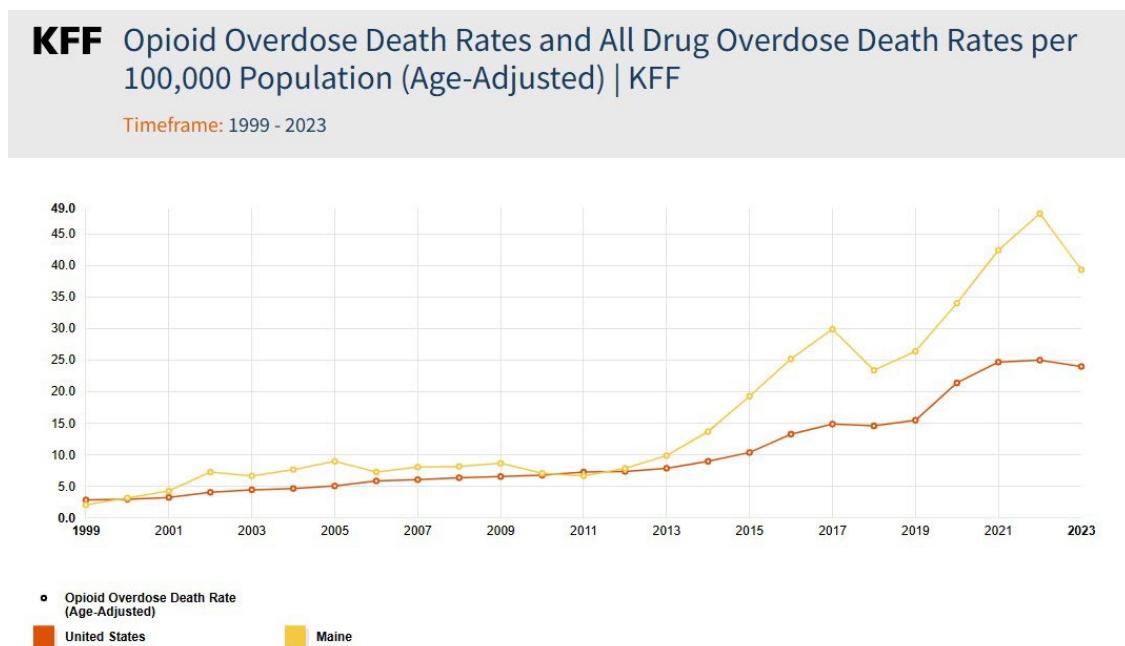
## Brief Review of the Literature/Web Scan

### Opioid Use Disorder: The Current Situation in Maine

#### Adults

According to the 2022 and 2023 National Surveys on Drug Use and Health, an estimated 21.32% of Mainers 18 and older had a substance use disorder in the prior year, 2.06% had opioid use disorder in the past year, and 2.88% misused opioids in the prior year (this number does not include use of illegally made fentanyl). For the same years, 77.07% of Maine adults who needed substance use treatment in the past year did not receive it.<sup>1</sup> Sadly, Maine's overdose rates have exceeded the U.S. rates since 1999, with deaths increasing rapidly from 2011 to 2022. Recently, while still far higher than the national average, Maine's rates have dropped. See Figure 1.<sup>2</sup>

**Figure 1.**



<sup>1</sup> SAMHSA, Center for Behavioral Health Statistics and Quality, National Surveys on Drug Use and Health, 2022 and 2023. Maine 2022-2023 NSDUH: State-Specific Table. Accessed July 8, 2025 at <https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health/state-releases>.

<sup>2</sup> KFF analysis of Centers for Disease Control and Prevention (CDC), National Center for Health Statistics. Multiple Cause of Death 1999-2023 on CDC WONDER Online Database. Data are from the Multiple Cause of Death Files, 1999-2023, as compiled from data provided through the Vital Statistics Cooperative Program. Accessed 1/31/25 at <https://wonder.cdc.gov/mcd-icd10-expanded.html>. KFF analysis accessed 8/8/25 at <https://www.kff.org/mental-health/state-indicator/opioid-overdose-death-rates/>.

Substance use has profound impacts on individuals and the economy. An article on drug-related morbidity and mortality in Maine published in the *Maine Policy Review* found that in 2019, more than \$271 million was lost in annual productivity due to drug-related morbidity.<sup>3</sup>

Research has shown that treatment can be effective in reducing or stopping use in many cases. Unfortunately, people may be dissuaded from seeking treatment due to the shame and barriers placed before them as people as they seek treatment, and as they recover. The stigma comes from all around – internalized stigma like personal shame, societal stigma, and structural stigma that create barriers for people struggling to access services and affect the quality of the services that they receive. Reducing stigma on all levels to remove obstacles to high-quality care is an important way to help people with substance use disorder recover.

### *Youth*

Substance use is a health risk and a challenge for youth and young adults. Alcohol, tobacco, and cannabis are all legal substances for adults/anyone over the age of 21 in Maine and are easy to obtain from friends and family. With this exposure and easy access, youth and young adults may be more likely to experiment with substances.

Findings from the 2023 Maine Integrated Youth Health Survey show the percentage of high school students who used these substances at least once “in the past 30 days”: 15.6% had vaped in the past 30 days, 20.5% had used alcohol, and 18.7% had used cannabis. This means that close to one in five students had used vapes (tobacco, cannabis or other substance), alcohol, or cannabis in the last 30 days. When asked, “How much do you think people risk harming themselves through regular use of alcohol?”, 35.1% of students answered, “no risk” or “slight risk.” More than one-third of students, 34.9%, reported that they lived with someone who had a problem with drugs or alcohol.<sup>4</sup>

While diagnoses of SUD are rare for young people, these data show that at least one out of every five youth in Maine are exposed to and experimenting with substances. Starting to

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<sup>3</sup> Daley, Angela, Prianka M. Sarker, Liam Sigaud, Marcella H. Sorg, and Jamie A. Wren. (2022.) Drug-Related Morbidity and Mortality in Maine: Lost Productivity from 2015 to 2020. *Maine Policy Review* 31.1, 8 -18. <https://digitalcommons.library.umaine.edu/mpr/vol31/iss1/1>.

<sup>4</sup> Maine Department of Health and Human Services and Maine Department of Education. (2023). 2023 Maine Integrated Youth Health Survey Maine High School Report. Accessed July 4, 2025, at [https://www.maine.gov/miyhs/sites/default/files/2023\\_Reports/Detailed\\_Reports/HS/MIYHS2023\\_Detailed\\_Reports\\_HS\\_State/Maine%20High%20School%20Detailed%20Tables.pdf](https://www.maine.gov/miyhs/sites/default/files/2023_Reports/Detailed_Reports/HS/MIYHS2023_Detailed_Reports_HS_State/Maine%20High%20School%20Detailed%20Tables.pdf)

use substances at an early age increases their risks of unhealthy brain development and for developing substance use disorders later in life. Living with people who use substances can be traumatizing, increasing the risk for poor health and lower resilience. It is important to address youth's understanding of the impact of substances on their health and offer access to supportive services should they need them. Like adults, youth feel the impacts of stigma – they may internalize negative labels or keep secrets to avoid feelings of public shame. Youth are often punished for experimenting with or using substances rather than receiving restorative support and treatment. Youth who live with adults who use substances may also feel stigma by association.

## Defining Stigma

Stigma is a pernicious aspect of human communication and behavior that negatively impacts people who are seen as different. As humans, we have implicit biases based on our personal experiences, education, socio-economic status, and sources of information that may lead to assumptions about groups of people who may be different than us. Stigma or stigmatizing actions often stem from misinformation and lack of awareness. Words, actions, thoughts, policies, and practices can lead to people feeling stigmatized for who they are (gender, race, ethnicity, age, sexual orientation) or for their health conditions. In general, some groups that may feel stigmatized as a result of false generalizations about medical conditions include people who are overweight, people with disabilities, people with mental health disorders, and people with substance use disorders. While many know what it feels like to be stigmatized, to be “othered” and judged, a solid definition of stigma that includes its wide reach is elusive. Several groups have provided important definitions of stigma and stigmatizing actions towards people with substance use disorder (SUD).

- “Stigma is a dynamic multidimensional, multilevel phenomenon that occurs at three levels of society—structural (laws, regulations, policies), public (attitudes, beliefs, and behaviors of individuals and groups), and self-stigma (internalized negative stereotypes). A hallmark of stigma, like stereotyping, is that it overgeneralizes. People who have mental or substance use disorders do not form a discrete, static, or homogeneous group.” (National Academies of Sciences, Engineering, and Medicine, 2016)<sup>5</sup>
- “Stigma refers to a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid and discriminate against people with mental illnesses.

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<sup>5</sup> "Summary." National Academies of Sciences, Engineering, and Medicine. 2016. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press. doi: 10.17226/23442.

Stigma is not just a matter of using the wrong word or action. Stigma is about disrespect. It is the use of negative labels to identify a person living with mental illness. Stigma is a barrier. Fear of stigma and the resulting discrimination discourages individuals and their families from getting the help they need.” (SAMHSA, 2004)<sup>6</sup>

Stigma emanates from different sources and appears in many ways. Prejudice and bias fueling stigma can be found within an individual, a policy, societal views, language, and professional culture. The National Alliance of Mental Illness (NAMI) identifies seven types of stigma in a figure that is cited by Substance Abuse and Mental Health Services Administration (SAMHSA). See Figure 2.<sup>7</sup>

## Figure 2. Seven Types of Stigma

1. **Public stigma** – when the public endorses negative stereotypes and prejudices, resulting in discrimination
2. **Self-stigma** – when a person with SUD internalizes public stigma
3. **Perceived stigma** – the belief that others have negative beliefs about people with SUD
4. **Label Avoidance** – a person chooses not to seek treatment to avoid the stigmatizing label
5. **Associative Stigma** – when stigma is extended to a family member or friend
6. **Structural Stigma** – policies that decrease opportunities for people (treatment, jobs, housing, etc.)
7. **Health Practitioner stigma** – when stereotypes and prejudices about SUD influence patient care.

**Stigma’s Influences.** Stigma’s influence and impact is found in multiple layers – individual, family, institutional, community, and policy. The socio-ecological model, first developed in the 1970s and refined by the public health community over the years, shows how individuals are impacted by the multiple spheres of influence, with the individual at the

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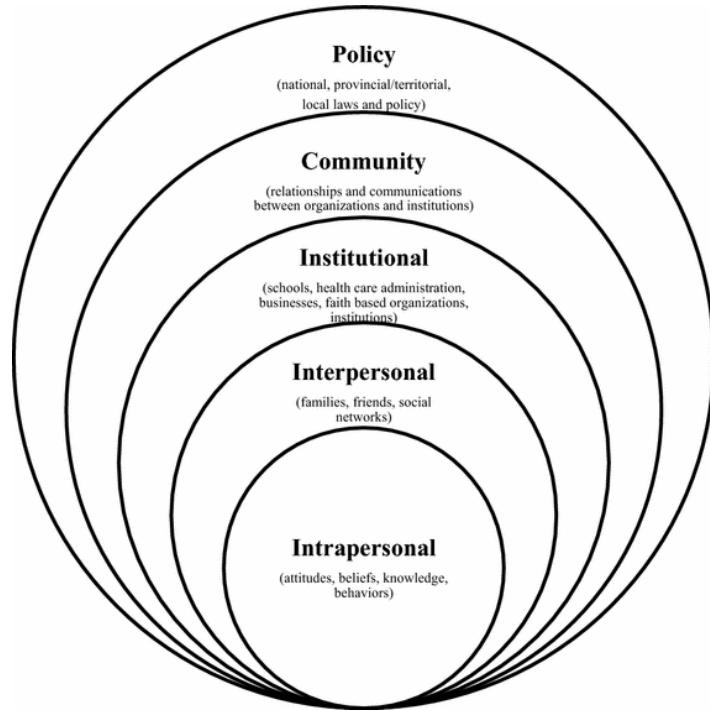
<sup>6</sup> Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2004). *Eliminating Barriers for Learning; Social and Emotional Factors that Enhance Secondary Education*. Accessed July 7, 2025, at

[https://www.academia.edu/9740691/Eliminating\\_Barriers\\_for\\_Learning\\_Social\\_and\\_Emotiona...\\_Enhance\\_Secondary\\_Education](https://www.academia.edu/9740691/Eliminating_Barriers_for_Learning_Social_and_Emotiona..._Enhance_Secondary_Education)

<sup>7</sup> Grappone, G. (October 2018). *Overcoming Stigma*. National Alliance on Mental Illness. <https://www.nami.org/depression-disorders/overcoming-stigma/>

center surrounded by influences of family, community, organizations, and society (policies and laws). Each layer reinforces messages through language, actions, environment, policies, and practices. This model has been used to describe influences on people struggling with mental health, substance use, eating habits, obesity, tobacco use, and other health concerns. See Figure 3.

**Figure 3. Spheres of Influence on Individuals: The Socio-Ecological Model<sup>8</sup>**



**Mental Illness is More Accepted than Substance Use.** The literature shares that progress has been made in the U.S. on reducing stigma towards people with mental illness after decades, if not centuries, of effort. Improvements in understanding and awareness have helped to change public messaging. In recent years, it has become more common for people to share their personal experiences with mental illness, specifically anxiety and depression. Now, rather than being “othered,” people working to stay healthy are embraced and applauded for their efforts. This is not so true for people with substance use disorder. In fact, in many ways society pushes laws and rules to punish people who possess, use, or are addicted to substances, making acceptance harder to normalize. More research needs to be done to understand the stigmatizing messages in policies, culture, and behaviors toward people with substance use.

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<sup>8</sup> Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

- “Significantly more is known about the stigma of mental illness and related processes than about the stigma associated with substance use, abuse, and addiction. Surveys of public attitudes about multiple stigmatizing labels indicate that drug and alcohol misuse are viewed significantly more negatively than depression or schizophrenia (Schomerus et al., 2011). More research is needed on the nature, extent, and dynamics of stigma toward people with substance use disorders and the associated social- and psychological-related processes to better inform intervention and behavior change-related research.”<sup>9</sup>
- “Although advocates and providers identify stigma as a major factor in confounding the recovery of people with SUDs, research on addiction stigma is lacking, especially when compared to the substantive literature examining the stigma of mental illness”<sup>10</sup>

## Research on SUD Stigma Reduction Interventions

Over the years, there have been many studies on mental health, addiction process, and effective treatments, but research on how to reduce stigma on people with SUD is limited (Krendl & Perry, 2023).<sup>11</sup> Researchers further note that “the dearth of data on what works to reduce stigma is particularly acute as it relates to substance use disorders, and it is not always clear that findings related to mental illness can be generalized to substance use disorders.”<sup>12</sup>

The literature includes several important meta-analyses of stigma-related studies (2012 Livingston et al. and 2021 Bielenberg, et al.). In general, the studies show that using approaches that humanize people with SUD, incorporate trusted narrators, and tailor the contact to the audience (health care professionals, first responders, policy makers, etc.) have positive short-term impacts. The studies highlight the benefits of training in

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<sup>9</sup> “Part 5 – Research Strategies.” National Academies of Sciences, Engineering, and Medicine. 2016. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/23442>.

<sup>10</sup> Corrigan, P. W., Schomerus, G., Shuman, V., Kraus, D., Perlick, D., Harnish, A., Kulesza, M., Kane-Willis, K., Qin, S., & Smelson, D. (2017). Developing a research agenda for reducing the stigma of addictions, part II: Lessons from the mental health stigma literature. *The American journal on addictions*, 26(1), 67–74. <https://doi.org/10.1111/ajad.12436>

<sup>11</sup> Krendl, A. C., & Perry, B. L. (2023). Stigma Toward Substance Dependence: Causes, Consequences, and Potential Interventions. *Psychological Science in the Public Interest*, 24(2), 90-126. <https://doi.org/10.1177/15291006231198193> (Original work published 2023)

<sup>12</sup> National Academies of Sciences, Engineering, and Medicine. 2016. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/23442>.

motivational interviewing and using Screening, Brief Intervention and Referral to Treatment (SBIRT) to give providers a framework for positive interactions. The following discussion shares summaries of findings from selected studies.

## Words Matter

Language is powerful. Words reinforce our beliefs and establish connections and create disconnections. Negative language used to describe people with SUD and their behaviors reinforces biases and creates stigma. Studies have shown that using positive, respectful language to describe addiction or people with SUD can go a long way toward reducing stigma and increasing access to effective treatment. The research points out that when labels are removed and person-first words are used, people feel less shame and stigma. The use of supportive language sets an important tone in families, communities, organizations, and settings such as healthcare. In general, individuals and organizations can work to lessen stigma by:<sup>13</sup>

- Using person-first language reinforces that people are not their behaviors
- Using medical terminology to describe treatment, which reinforces that addiction is a disease like other chronic diseases
- Promoting recovery language that can be affirming
- Avoiding slang and idioms

Throughout the literature discussing stigma and SUD, the recommended interventions use person-first, person-centered language.

## Studies of Best Practices

In 2014, SAMHSA commissioned the National Academy of Science (NAS) to summarize the state of the research literature on the topic of stigma related to behavioral health. The 2016 report, “Ending Discrimination Against People with Mental and Substance Use Disorders,” presents a series of conclusions and recommendations for addressing stigma; recommendations include designing, implementing, and evaluating an evidence-based national strategy to reduce stigma. The report highlights the list of effective strategies found in Figure 4.

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<sup>13</sup> Broyles, L. M., Binswanger, I. A., Jenkins, J. A., Finnell, D. S., Faseru, B., Cavaiola, A., Pugatch, M., & Gordan, A. J. (2014). Confronting Inadvertent Stigma and Pejorative Language in Addiction Scholarship: A Recognition and Response. *Substance Abuse*, 35(3), 217-221. doi:[10.1080/08897077.2014.930372](https://doi.org/10.1080/08897077.2014.930372)

**Figure 4. Best Practices for Reducing Stigma<sup>14</sup>**

Intervention	Description
Education	Develop mental health literacy campaigns
Advocacy	Letter writing and Twitter campaigns, etc.
Contact-based programs	Facilitate social contact between people with and without behavioral disorders
Contact-based education programs	Combine contact with education designed to raise public awareness of selected issues or increase public knowledge about mental and substance use disorders
Media campaigns	Use a range of platforms, including traditional and newer social media
Peer programs	Peers offer their experience and expertise to individuals and families, programs that range from informal peer-led programs to peer specialized services in health services systems.

### Positive Narrative and Contact Based Strategies

In 2008, Luty et al. found that a positive narrative associated with SUD decreases stigmatized attitudes. They provided people with either a “short, ‘upbeat’ leaflet with a description of a patient in remission and a photograph of a man in a business suit; or a simple description of a fictional patient” (not in remission). The study found that “a large and statistically significant difference in stigmatized attitudes was observed when hypothetical patients were presented positively compared with baseline descriptions of patients with active symptoms. This was observed with hypothetical patients with schizophrenia. The effect was significantly larger with substance misuse disorders.”<sup>15</sup>

### Focused, Local, Credible Contact

In 2011, Corrigan et al. published a list of best practices for “strategic stigma change,” arguing that “targeted, local, credible” contact between people in recovery and targeted members of the public is “fundamental to public stigma change.” Strategic stigma change principles were developed by investigators at the National Consortium on Stigma and Empowerment, and while they are tailored to address stigma related to mental illness, they may also apply to stigma related to SUD. Contact, investigators argue, should be targeted (both message and audience should be specific—for example, landlords or health care

<sup>14</sup> National Academies of Sciences, Engineering, and Medicine. 2016. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/23442>.

<sup>15</sup> Luty, J., Rao, H., Arokiaswamy, S. M. R., Easow, J., & Sarkhel, A. (2008). The repentant sinner: Methods to reduce stigmatized attitudes towards mental illness. *Psychiatric Bulletin*, 32, 327-332. 10.1192/pb.bp.107.018457.

providers), local (geopolitically or socio-politically), and credible (relatable to the audience and in recovery). Finally, multiple contacts over time are more effective than a one-time contact.<sup>16</sup>

### **Tailored Interventions**

In 2012, Livingston et al. conducted a systematic review of 13 interventions for stigma reduction and the effectiveness of these interventions. Of the 13 interventions, three were focused on people with SUDs (targeting self-stigma), two were focused on the general public (targeting social or public stigma), and seven were focused on medical students and other professional groups (targeting structural stigma). The review found that “The limited evidence indicates that self-stigma can be reduced through therapeutic interventions such as group-based acceptance and commitment therapy. Effective strategies for addressing social stigma include motivational interviewing and communicating positive stories of people with substance use disorders. For changing stigma at a structural level, contact-based training and education programs targeting medical students and professionals (e.g. police, counsellors) are effective.”<sup>17</sup>

### **Personal Narratives and Highlighting Structural Barriers**

In 2015, the Johns Hopkins Center for Mental Health and Addiction Policy Research convened a policy forum on how communication strategies influence public support for mental illness and SUD policies. Reporting on the forum’s findings, the leaders of the forum (McGinty et al.) highlight key strategies’ impacts on stigma and policy support.<sup>18</sup> Strategies found to have a positive impact or no negative impact on public stigma include:

- “Strategies that use personal narratives to engage audiences and highlight structural barriers to treatment are particularly promising; the current research suggests that such strategies can increase the public’s support for policies benefiting people with mental illness or substance use disorders without increasing stigma.” The authors note that for the purposes of policy support, it is important to address structural barriers as part of the storytelling.

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<sup>16</sup> Corrigan, P. W. (2011). Best practices: Strategic stigma change (SSC): Five principles for social marketing campaigns to reduce stigma. *Psychiatric Services*, 62(8), 824-826.

[https://psychiatryonline.org/doi/10.1176/ps.62.8.pss6208\\_0824](https://psychiatryonline.org/doi/10.1176/ps.62.8.pss6208_0824)

<sup>17</sup> Livingston, J.D., Milne, T., Fang, M.L., and Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: A systematic review. *Addiction*, 107(1), 39-50.

<https://doi.org/10.1111/j.1360-0443.2011.03601.x>

<sup>18</sup> McGinty, E., Pescosolido, B., Kennedy-Hendricks, A., & Barry, C. L. (2018). Communication Strategies to Counter Stigma and Improve Mental Illness and Substance Use Disorder Policy. *Psychiatric services (Washington, D.C.)*, 69(2), 136-146. <https://doi.org/10.1176/appi.ps.201700076>

- Messages highlighting structural barriers to mental illness and SUD treatment do not elevate stigma and “can increase the public’s willingness to allocate additional resources to mental illness and substance use disorder treatment.”
- Messages focused on treatment effectiveness may decrease stigma when compared with narratives portraying individuals with untreated SUD, which increase stigma.

## Promising Practices

There are several anti-stigma promising practices that can be effective, at least in the short term. They include education-based programs, community conversations, and structured contact sessions with trusted speakers. These interventions have been evaluated for short-term impact and outcomes, but authors of those studies recommend more robust and in-depth study of the facilitators and barriers.

### Education-Based Interventions and Campaigns

In the “Rural Community Action Guide: Building Stronger Healthy, Drug-Free Rural Communities”, Addiction Policy Forum recommends that rural leaders “use statistics and the latest science to teach the community about addiction and work with stakeholders in the community to disseminate knowledge and resources like overdose reversal kits, the brain science of addiction, and other educational materials.” They further suggest that facts about SUDs be used in locally tailored anti-stigma marketing plans to counter inaccurate stereotypes or myths and contradict negative attitudes and beliefs.<sup>19</sup>

The “Promising Practices” supplement to the Action Guide shares<sup>20</sup> promising examples of anti-stigma campaigns and educational initiatives across the country, including:

- Maryland’s “Distorted Perceptions” public education campaign to challenge misconceptions and assumptions associated with mental illness and addiction through dialogue about the real and damaging impact of stigma. This campaign is now titled “Refocus: Look Again.” <https://refocuslookagain.org/>
- The “State Without StigMA” campaign awareness campaign in Massachusetts. <https://www.mass.gov/state-without-stigma>

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<sup>19</sup> U.S. Office of National Drug Control Policy. (2020). Rural Community Action Guide: Building Stronger Healthy, Drug-Free Rural Communities. <https://www.usda.gov/sites/default/files/documents/rural-community-action-guide.pdf>

<sup>20</sup> U.S. Office of National Drug Control Policy. (2020). Rural Community Action Guide: Building Stronger Healthy, Drug-Free Rural Communities – Promising Practices Supplement.

<https://www.usda.gov/sites/default/files/documents/rural-community-action-guide-promising-practices.pdf>

## Community Conversations

Research and program evaluation studies have shown that interventions such as community conversations hold real promise for reducing stigma. The interventions include actions to convene community members, provide education on SUD and the impacts of stigma on people's ability to seek treatment, and work as a group to identify and enact solutions. A January 2025 article on combatting stigma published by SAMHSA concurs that "community engagement initiatives also play a vital role in reducing stigma. When local organizations, religious institutions, and community leaders come together to support recovery efforts, the partnership creates a network of understanding and support. Implementing educational programs that teach providers about SUD as a brain disease can help reduce stigma.<sup>21</sup>

The Addiction Policy Forum's *enCompass* is a training program that seeks to reduce stigma at the individual and family level. The 8-hour multi-disciplinary training is designed for families helping loved ones with SUD. The intervention "includes information on SUD, treatment options, communication strategies and self-care tips. It also aims to provide practical content to help individuals understand prevention, early intervention, and treatment of substance use disorders, as well as how to engage someone struggling with addiction and develop an action plan." The findings from an outcome evaluation of the *enCompass* training showed that it improves knowledge and understanding among participants and reduces negative perceptions of people with SUD.<sup>22</sup>

A second training developed by Addiction Policy Forum, Responding to Addiction, is a 3-hour training program that increases participants' knowledge about addiction and helps them develop skills and strategies to respond to addiction in their communities.

The University of Rochester Rural Center of Excellence on SUD Prevention's Community Conversations on Opioid Use Disorder workshops seek "to shed light on substance use disorder (SUD)-related stigma as a barrier to recovery and to collaborate with rural communities to develop local solutions that reduce it. These are not academic workshops.

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<sup>21</sup> Peacock, M.B., & Baillieu, R. (January 14, 2025). *Combatting Stigma with Knowledge*. SAMHSA Blog. <https://www.samhsa.gov/blog/combatting-stigma-knowledge>

<sup>22</sup> Earnshaw, V. A., Sawyer-Morris, G., Kelly, B., Collier, Z. K., Qiu, X., Shadwick, A., & Hulsey, J. (2024). *enCompass: evaluation of a community-based substance use disorder stigma intervention*. *Journal of Addictive Diseases*, 1–5. <https://doi.org/10.1080/10550887.2024.2431374> or <https://www.tandfonline.com/doi/full/10.1080/10550887.2024.2431374>

They are conversations where participants explore stigma, how we support people with SUD and their families, and how we work together in our communities to reduce stigma.”<sup>23</sup>

The program, along with the university’s Indigenous Community Conversations, creates safe spaces where people can share stories, obtain information, and work to find a common solution. These programs have reached close to 2,000 people in 29 states, held 164 workshops, and trained 706 facilitators from November 2021 through May 2025.<sup>24</sup>

### Digital Campaigns

[Life Unites Us](#) is a digital campaign that shares personal stories of people living with addiction in Pennsylvania.<sup>25</sup> A partnership between the Pennsylvania Department of Drug and Alcohol Programs; the Douglas W. Pollock Center for Addiction Outreach and Research at Penn State Harrisburg; and Shatterproof and The Public Good Projects, the campaign leverages personal stories from people with SUDs, families, healthcare providers, community organizations to shed light on addiction as a disease to reduce stigma. A formal evaluation of this digital campaign and approach showed positive outcomes in increasing understanding and reducing OUD-related stigma within the first six months.<sup>26</sup> Another online source of resources is Faces & Voices of Recovery, which provides support for advocacy, accreditation, trainings, and a recovery data platform.

### Interventions for Youth

Many believe that the primary intervention for youth engaging in substance use is prevention. While prevention is important, more must be done to provide services to youth who actively use substances and to encourage youth to engage in these services. Like adults, youth are likely to be impacted by stigma personally, among peers, friends, and family, and in society. There have been very few studies that describe the impact of stigma on youth or the effectiveness of efforts to counter this stigma. According to a 2023 study, “alcohol and other drug (AOD) use disorders are stigmatized conditions, but little is known about youth’s experience of this stigma, which may threaten their developing social identity and recovery process.”<sup>27</sup>

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<sup>23</sup> University of Rochester Rural Center of Excellence on SUD Prevention. (June 2025). *Developing a Rural Community Approach to Overcoming Stigma*. <https://recoverycenterofexcellence.org/learn/developing-rural-community-approach-overcoming-stigma>

<sup>24</sup> University of Rochester Rural Center of Excellence on SUD Prevention.

<sup>25</sup> Life Unites Us. *About Us*. (n.d.). <https://lifeunitesus.com/about>

<sup>26</sup> Bonnevie, E., Kaynak, Ö., Whipple, C. R., Kensinger, W. S., Stefanko, M., McKeon, C., Mendell, G., & Smyser, J. (2022). Life unites us: A novel approach to addressing opioid use disorder stigma. *Health Education Journal*, 81(3), 312-324. <https://doi.org/10.1177/00178969221077409> (Original work published 2022)

<sup>27</sup> Blyth, S. H., Cowie, K., Jurinsky, J., & Hennessy, E. A. (2023). A qualitative examination of social identity and stigma among adolescents recovering from alcohol or drug use. *Addictive Behaviors Reports*, 18. <https://doi.org/10.1016/j.abrep.2023.100505>.

### **Stigmatizing Attitudes Among Youth**

One national study conducted in 2020 asserts that in the general population, younger adults showed stigma toward people with SUD, but they showed less stigma than older adults, who carried stronger negative opinions. The authors found that younger adults with more experience with someone with SUD were less likely to stigmatize the person or persons. They suggest that “late adolescence might be a particularly opportune time for interventions to reduce stigma and discrimination, while attitudes are both less stigmatizing and more malleable.”<sup>28</sup>

### **Recommendations to Reduce SUD-Related Stigma for Youth**

Findings from a 2023 qualitative pilot study of social identity and stigma among adolescents in recovery suggest that youth in recovery “benefit from having social supports who understand their experience and support their recovery efforts, such as those that are provided in recovery high schools, alternative peer groups, young people’s meetings, or recovery clubhouses. Importantly, these supports can mitigate isolation and stigma.” The authors recommend that “addiction providers” ask youth how they prefer to talk about their experiences of substance use disorders and be guided by their responses as they engage them in treatment as a way to combat stigma in clinical settings.<sup>29</sup>

According to the Jamie Daniels Foundation, a national nonprofit focused on providing education, resources, and support to youth with SUD, “schools and healthcare organizations can reduce stigma by implementing stigma-awareness training for staff and integrating addiction treatment into general health and counseling services. Treating childhood SUDs like other chronic conditions, such as asthma or diabetes, helps eliminate judgment and barriers to care.” Further recommendations include encouraging evidence-based interventions instead of punitive responses in schools and juvenile justice systems, promoting integration of SUD treatment into primary care services, and expanding access to effective school-based prevention programs.<sup>30</sup>

In 2022, Starlings Community, a Canadian nonprofit organization focused on young people with lived and living experience of a parent’s substance use, published research on how

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<sup>28</sup> Adams, Z. W., Taylor, B. G., Flanagan, E., Kwon, E., Johnson-Kwochka, A. V., Elkington, K. S., Becan, J. E., & Aalsma, M. C. (2021). Opioid Use Disorder Stigma, Discrimination, and Policy Attitudes in a National Sample of U.S. Young Adults. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*, 69(2), 321–328. <https://doi.org/10.1016/j.jadohealth.2020.12.142>

<sup>29</sup> Blyth, S. H., Cowie, K., Jurinsky, J., & Hennessy, E. A. (2023). A qualitative examination of social identity and stigma among adolescents recovering from alcohol or drug use. *Addictive Behaviors Reports*, 18. <https://doi.org/10.1016/j.abrep.2023.100505>.

<sup>30</sup> Jamie Daniels Foundation. Understanding and addressing stigma around substance use disorders in children. Accessed July 10, 2025. <https://jamiedanielsfoundation.org/understanding-and-addressing-stigma-around-substance-use-disorders-in-children/>

stigma harms children who are exposed to a parent's substance use disorder. The report identifies several key gaps in support and services available to parents with SUD and their children and makes recommendations to increase support and reduce the stigma associated with these supports. Authors emphasize the importance of proactively offering support to children and their families to reduce associated structural and internalized stigma.<sup>31</sup>

The strategies and activities that may reduce stigma among youth and young people with SUD are primarily adult interactions with youth in treatment or recovery. At the same time, the evidence-based practices for prevention promote strength-based approaches for youth to build resilience skills. Research shows that the programs that provide specific information on drugs or show consequences of using substances can have a negative impact on youth rather than a preventive impact.<sup>32</sup> The outdated strategy of bringing speakers into school assemblies to share stories of harm or recovery has not shown a positive prevention impact on youth.

## Lessons in Maine

In 2013, **Maine Health Access Foundation (MeHAF)** began a multi-year grantmaking project to support community-based solutions for local health issues. Using a participatory approach, the grantees identified root causes of and barriers to their communities' health issues. A 2019 report completed for MeHAF, "[Community-Driven Strategies to Address Stigma and Build Healthier Communities in Maine](#)," tells the story of three Maine communities that dedicated grant resources to stigma reduction as part of their MeHAF-funded Healthy Community program work. Grantees in Cumberland and Knox Counties spent time sharing stories and data and having community conversations about SUD stigma reduction.<sup>33</sup> The report shares the successes that grew from these efforts. Some key lessons learned working with communities included:

- “Engage community members early in the process to learn about root causes of complex health issues;
- Seek to understand the experiences and feelings of someone who enters a system;

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<sup>31</sup> Starlings Community. (2022). A new path forward: a report on the harm stigma imposes on children exposed to parental substance use disorder and recommendations for a new path forward.

[https://www.starlings.ca/\\_files/ugd/990b28\\_72b55fe6369c4f01955bf3b0c49932f1.pdf](https://www.starlings.ca/_files/ugd/990b28_72b55fe6369c4f01955bf3b0c49932f1.pdf)

<sup>32</sup> Jewell, J., Hupp, S.D.A. Examining the Effects of Fatal Vision Goggles on Changing Attitudes and Behaviors Related to Drinking and Driving. *J Primary Prevent* **26**, 553–565 (2005). <https://doi.org/10.1007/s10935-005-0013-9>

<sup>33</sup> Foster, S. & Doksum, T, (2019). *Community-Driven Strategies to Address Stigma and Build Healthier Communities in Maine*. Maine Health Access Foundation. <https://mehaf.org/wp-content/uploads/Community-Driven-Strategies-to-Address-Stigma-and-Build-Healthier-Communities-in-Maine.pdf>

- Identify system inequities. Community member involvement is critical to understanding how stigma feels, and which system functions and behaviors need to be changed in order for people to feel comfortable accessing services and supports;
- Explore and learn about provider attitudes, bias, and effect on people's experience of the system; and
- Cultivate a learning mindset in organizations and communities.”

Researchers from the **University of Southern Maine's Maine Rural Health Center** conduct studies to understand the impacts of stigma on people with substance use disorder in rural Maine. A recent study, “Experiences of stigma among individuals in recovery from opioid use disorder in a rural setting: A qualitative analysis,” showed that people with OUD are greatly impacted by stigma in their access to care in rural areas. The study’s focus group participants shared that they experience stigma in the emergency department, government, workplace, primary care, pharmacy, among other places. The stigmatizing language and behaviors led them to keep secrets, feel like failures, and experience resignation and fear.<sup>34</sup>

The study identified strategies to address stigma associated with OUD to be used with individuals, clinicians, organizations, and the public. These include:

- acceptance and commitment therapy and vocational training to improve self-stigma
- SUD-focused training in medical education
- crisis intervention training for police
- motivational interviewing
- adopting family-friendly policies in health care and social service organizations
- shared decision models in clinical settings
- anti-stigma training or partnering with existing anti-stigma programs

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<sup>34</sup> Burgess, A., Bauer, E., Gallagher, S., Karstens, B., Lavoie, L., Ahrens, K., & O'Connor, A. (2021). Experiences of stigma among individuals in recovery from opioid use disorder in a rural setting: A qualitative analysis. *Journal of substance abuse treatment*, 130, 108488. <https://doi.org/10.1016/j.jsat.2021.108488>

## Resources for Reducing Stigma

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### National Resources for Reducing Stigma

Several national organizations offer resources on OUD and stigma. They include universities, government agencies, non-profit organizations, philanthropic organizations, and healthcare organizations.

In the United States, three Rural Centers of Excellence on Substance Use Disorders are currently receiving funding from the federal Health Resources and Services Administration (HRSA) to build the evidence-base to reduce substance use disorder, including OUD, in rural communities. While each Center of Excellence has a different area of focus, all three have done work related to stigma reduction.

- The **University of Rochester's Recovery Center of Excellence** (based in Rochester, NY) focuses on enhancing integration of SUD/OUD into primary care practices and adapting evidence-based stigma reduction workshops at the individual, provider, and community levels.<sup>35</sup>
- The **University of Vermont's Center on Rural Addiction, or CORA** (based in Burlington, VT), is focused on developing provider training and enhancing access to SUD/OUD services, including medications for opioid use disorder (MOUD), as well as other co-occurring behavioral health disorders.
- The **Fletcher Group Rural Center of Excellence** (based in London, KY) focuses on expanding access to quality evidence-based recovery housing, recovery supporting services, and research activities. One of their recently published studies examined the effects of five different types of interventions on SUD stigma.

The **Substance Use Stigma Reduction Collaborative** at the Penn State Social Science Institute (based in University Park, PA) is a working group established by Penn State University's Consortium on Substance Use and Addiction consisting of academic scholars, professionals, and practitioners throughout Penn State University. The mission of the collaborative is to examine and understand stigma toward substance use to identify ways to reduce its impacts. Members of the Collaborative coordinate several outreach initiatives, including the Story Powered Initiative and the Life Unites Us Campaign, which is focused on reducing stigma surrounding OUD in Pennsylvania.

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<sup>35</sup> <https://www.amhc.org/news/conversations/>

The **Research Recovery Institute**, a nonprofit research institute of Massachusetts General Hospital, an affiliate of Harvard Medical School Teaching Hospital, is dedicated to the advancement of addiction treatment and recovery. As part of this work, they regularly share information on new addiction recovery science research and founded the *Addictionary*, which describes how certain words and terms may be stigmatizing.

**National Non-profits.** Several national nonprofit organizations are deeply invested in national advocacy and stigma reduction work. The following organizations have launched anti-stigma campaigns and projects:

- Shatterproof,
- Faces & Voices of Recovery,
- Addiction Policy Forum,
- Stop the Addiction Fatality Epidemic (SAFE) Project, and
- Wisconsin Initiative for Stigma Elimination (WISE)

Several national organizations and nonprofits that serve children and their families have developed resources to help combat stigma related to caregivers' substance use. Head Start, for example, has created materials focused how their staff and communities can help families impacted by substance use (including materials focused specifically on stigma).<sup>36</sup> Sesame Workshop offers videos, stories, and other resources to help children affected by parental addiction.<sup>37</sup> The National Association for Children of Addiction (NACoA) is focused on the needs of children, whose caregivers have SUDs; they offer a library of resources for children and families.

### Maine Resources for Addressing Stigma

There are several important resources available to address stigma against OUD in Maine. The Governor's Office has a specific initiative focused on opioids and the state's response. Philanthropic organizations have recognized the important role stigma plays in creating barriers to SUD prevention and treatment. State universities have well-established research units that have been exploring the impacts of stigma and making recommendations for action.

Responding to the state's opioid crisis is a priority initiative for the **Governor's Office of Policy Innovation and the Future** (GOPIF). Maine's 2023-2025 Opioid Response Strategic

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<sup>36</sup> <https://headstart.gov/mental-health/article/understanding-addiction-substance-use-stigma-what-you-can-do-help>

<sup>37</sup> <https://sesameworkshop.org/topics/parental-addiction/>

Action Plan asserts that “To be treated effectively, SUD must be addressed as a chronic medical condition. Accordingly, eliminating stigma and discrimination shall be an essential foundation underlying all other actions in this Strategic Action Plan.” The plan identifies “[investing] in local and statewide efforts to improve public understanding and reduce stigma and discrimination regarding substance use disorder and opioid use disorder” as a key strategy for building Maine’s opioid response infrastructure. It lists seven actions that Maine will take in order to invest in these local and statewide stigma reduction efforts. The plan also notes that GOPIF has already supported the development of short documentary films as vehicles for storytelling to reduce stigma and has sponsored or participated in community events to share the films and promote discussion.<sup>38</sup>

The **Maine Substance Use Disorders Learning Community**, which supports prescribing clinicians and their teams to provide more evidence-based treatment to individuals and their families affected by SUD and OUD, offers a curated list of resources related to stigma, noting that stigma “significantly hampers individuals’ ability to seek and receive help, perpetuating a cycle of shame and isolation.” The Maine Substance Use Disorders Learning Community is coordinated by the Co-Occurring Collaborative Serving Maine (CCSME) with support from the Catherine Cutler Institute e-learning team.<sup>39</sup>

The **Substance Use Research & Evaluation (SURE)** unit of the Catherine Cutler Institute at the University of Southern Maine aims to support the development of novel policies and treatment interventions designed to mitigate the negative public health, social and economic impacts of substance use on affected individuals, families, and communities. SURE’s research and evaluation of SUD-related projects in Maine and New England address stigma reduction as an important factor in SUD prevention and treatment work.

The **Maine Health Access Foundation (MeHAF)** is the state’s largest private nonprofit health care foundation dedicated to promoting access to quality health care and improving health. Projects funded by MeHAF have examined stigma’s impacts, and effective stigma reduction strategies, in Maine communities.

The **Maine Recovery Access Project (ME-RAP)** is a grassroots advocacy network of people in Maine working “to redefine and reimagine justice, access, connection, and recovery in our state laws, county policies, municipal ordinances, schools, workplaces, and in our

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<sup>38</sup> Maine Governor’s Office of Policy Innovation and the Future. (2023). *Maine Opioid Response 2023-2025 Strategic Action Plan*. [https://www.maine.gov/future/sites/maine.gov.future/files/inline-files/GOPIF\\_OpioidReport\\_2023.pdf](https://www.maine.gov/future/sites/maine.gov.future/files/inline-files/GOPIF_OpioidReport_2023.pdf)

<sup>39</sup> ME SUD Learning Community. (n.d.). *Stigma*. <https://mesudlearningcommunity.org/resources/stigma/>

daily lives.” ME-RAP’s policy platform prioritizes the voices of people with lived experience and advocates for the kinds of access, support, and connections that many of the people interviewed for this report mentioned as tools for reducing stigma. The organization also hosts meetings and community-building events to foster connection and healing.

**ME-RAP’s Youth Caucus** is led by young people in Kennebec, Penobscot, and Washington counties who are in recovery, practicing harm reduction in their own lives, or have been impacted by loved ones’ substance use. Caucus members organize projects in their communities, implement peer-led naloxone trainings, and build community.

In addition to a variety of peer support options available to adults in Maine, Community Care will offer a **Youth Peer Support Statewide Network** beginning in 2025. Maine residents between the ages of 14 and 26 can work with peer support professionals who have self-identified with the experience of mental health and/or substance use challenges and are specially trained in Peer Connect youth peer support. The **Penquis Substance Affected Youth (SAY) Program** uses trauma-informed practices to work with youth affected by other people’s substance use. The SAY Program offers Youth Activity Groups and individualized and group mentoring for youth age 10 – 18.<sup>40</sup>

People interviewed for this report pointed to a lack of resources for young people using substances or affected by loved ones’ substance use in Maine. As one key informant put it, “If we saw a number of young people affected by any other medical condition or impacted through the parents in that way, how would we be responding and why aren’t we responding in that way?”

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<sup>40</sup> <https://www.penquis.org/services/youth-services/>

## Findings from Key Informant Interviews

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### Background

To understand the impact of stigma on people with substance use disorder in Maine, the team at Hart Consulting, Inc. conducted 21 one-on-one interviews and two focus groups with experts in the fields of addiction treatment, recovery, and prevention, including people with lived experience. The purpose of the interviews was to learn more about how stigma appears in local communities, how it impacts people and interacts with healthcare access and quality, and to identify potential ways to mitigate it.

### *Participants*

The study team worked with an oversight group to identify participants for the one-on-one interviews. The initial goal was to speak with 14 adults working with adults on opioid use concerns; this was expanded to add eight interviews with people focused on youth. In the end, six of the 14 adult-focused participants also shared their thoughts on youth and SUD. The list of proposed participants included people from a variety of backgrounds, professions, lived experience, genders, ages, and parts of the state. See Figure 5 for the disposition of the participants by role. In addition to the interviews, 24 people participated in one of two online focus groups.

**Figure 5. Professional Role of Interview Participants**

Role	Number
Physicians, Addiction Specialists	3
Law Enforcement	1
School Staff (Social Worker, Nurse, Peer)	2
Corrections-Connected	1
Advocates (Peers)	3
Public Health	5
Public Policy	2
Researcher	1
Community Health Worker	1
Community Youth Support	2

### *Methods*

The study team worked with the oversight committee to develop a structured set of interview questions to guide the discussion. The questions were pared down for three sub-groups: adult-only questions, adult and youth questions, and youth-only questions. The

discussion averaged about 45 minutes for interviewees who spoke to only adult or youth questions and closer to one hour for interviewees who responded to both adult and youth questions. The study team assured respondents that responses would not be attributed to any individual.

With permission from the participants, the interviews were recorded and transcribed with Rev.com AI-powered software. The study team coded the transcripts using an inductive approach for themes and then grouped similar responses to understand the strength of shared ideas. The coding was conducted by one person who revisited the transcript to adjust assignments after the initial pass through the data. The themes and key outliers are discussed in this report.

#### *Views of Stigma Vary*

The interview participants' discussions revealed varying ideas and definitions of stigma. Some people saw stigma as a multi-level, multi-sector construct that permeates all parts of society, while others limited it to the use of sharp and accusatory language. The findings shared herein reflect the range of the participant ideas and have not been changed to meet the social science definition of stigma found in the literature.

#### *Language*

As much as the definitions of stigma varied across interviewees, so did their choice of words in their responses. Some used person-centered, supportive language, while others used what might be considered stigmatizing language. The quotes shared in this report preserve the respondents' word choices, grammar, and pauses. People are complex and so is their use of language.

## **Detailed Findings**

### **Stigma's Impact on People with Opioid Use Disorder in Maine**

To open the discussion, the moderator asked participants to share where they observed and sometimes experienced stigma about opioid use disorder (OUD) in Maine. They were quick to share many settings, deep feelings, and harsh experiences. They said they see it in families, community, healthcare, pharmacies, first responders, housing, employment, legal settings, and internalized within people. Participants described stigma related to medications for opioid use disorder (MOUD) and harm reduction strategies, even though individuals' engagement with these resources reflects efforts to seek help. One respondent pondered the difficulty of defining stigma as it is a topic of growing interest and can be

applied broadly. Figure 6 illustrates where the focus group participants indicated that they observed stigma toward adults with OUD.

**Figure 6. Places where focus group participants see stigma toward people with OUD.**



#### *Settings with Stigma*

- “I think there's just a societal moral judgment around drug use and that that's manifested itself in terms of our drug laws, but also in how we make care hard for people to access.”
- “I mean [stigma] is in our bodies, it's everywhere. It goes everywhere. It's very portable, it's really travel-sized and you can just take it everywhere you go. It shows up everywhere.”
- “It's very strong in the medical field, which is so counterproductive, and it's obviously there in the housing, it's there in law enforcement. It's real strong in job applications. I think it affects every aspect of life.”
- “And we have put a lot of barriers in place for people who want to get treatment, but we also stigmatize people who are not interested in treatment, people who just don't want to die from their drug use.”
- “It bothers me a lot that, as I say, the bottom line on that is that there's stigma associated with the illness and there's stigma now associated with the medication.”

### *Definition of Stigma*

- “I wish stigma was a more tangible, graspable topic. It's hard, because it's not well defined what it is, and it might mean different things to different people, and it's a buzzword of the year, so to speak. It's been used more with depression than with substances. And at least our college population buys into the concept that depression is suicidal stuff, that we need to remove stigma behind it and accept mental health across the board. But I'm not sure that's transferred over to substances the same way.”

### **Internalized or Self-stigma**

During the discussions, most of the respondents shared thoughts and experiences with self-stigma for themselves, their peers, or the people they see in their jobs. Internalized stigma has two sources – it comes from 1) messages and behaviors from others or the community, and 2) internalized stigma from the anticipation of stigma from others as well as holding negative thoughts about oneself. Self- stigma internalizes shame and guilt and can lead to a sense of hopelessness that keeps people from seeking help. Participants shared that people with OUD carry a lot of anxiety about how others will react based on their past experiences, particularly with their families and in healthcare settings, including emergency departments.

- “I think people come in with carrying a lot of shame. We talk about this in our training... they have internalized that stigma that they get from society as a whole that tells them that what they're doing is morally wrong. Then they get stigma from us in the healthcare settings because we treat them differently.”
- “I mean, they get in that dark place where they don't see a way out. And when there's so much stigma out there already, it's hard for them to dig themselves out. So I think what's important for them is to have those people in their lives that do care and want to help, even if they aren't ready for it yet, at some point they may be...”
- “[Internalized stigma] creates a barrier for seeking help. So when you think about people who are in recovery and say that you're in recovery for a year, but then there's the stigma of this return to use, and so you keep the use that you're now experiencing [a secret]. There's so much shame and stigma behind saying that 'Yes, I've returned to use and now I need services.'”
- “I think it's based on a guilt and shame based on an individual's own idea of the pain that they've caused, the pain that they have with themselves, they'll never get better, this is who I am. It's weird because even in the recovery community, we provide a lot of mixed messaging in different places depending on where you go.”

### *Anticipatory Stigma*

- “I see less stigma from the community and employers than I do self-talk that says, ‘Oh, these people are not going to be good with my substance use history or recent or even distant substance use history.’ But in most situations now I find that to not be true.”

### **Social Stigma**

Social stigma stems from negative beliefs about people with OUD. Respondents shared that while progress has been made in recent years, many people still harbor harsh judgement for people struggling with OUD. Many people do not understand that the disorder is a chronic disease like heart disease, cancer, or diabetes. They believe that using substances is a choice and those who do use substances are morally wrong. Participants shared that there is a widespread belief that people who use opioids can and should simply stop using opioids.

Respondents also described a lack of empathy and understanding for people with OUD. This closed mindset, which can come from family, friends, loved ones, is hurtful to people with OUD and can stymie or derail their path to recovery. Families, too, can feel the sting of stigma as they search for solutions and supports for their loved ones.

### *Lack of Understanding of OUD as a Disease*

- “There's so little understanding or empathy or sympathy or even willingness to understand that this disease is...you just can't stop. I hear statements like, ‘Well, this person has children and they abandoned their children. And even with all of these opportunities that were put in their lives,’ and yeah, it's a disease, it doesn't make any sense. And it's just so hard for people to grasp that this is a disease. Even to the point where some people just don't even like to hear that it's a disease. It's like, ‘No, this is some sort of moral failing,’ which... we've had these discussions for many, many, many years about that kind of stigma.”
- “Family does have a lot to do with it. Of course, there's a lot of bridges that get burned with families because we're the ones that are subject to the lies and even the theft... But once again, it comes back to if the families understand why this is the behavior or, ‘This isn't the person,’ I used to say when I [presented], I would say ‘Substance use disorder steals the soul.’”
- “Most people who have used that I've talked to have been treated poorly in some way because of it by their family, by community members.”

- “If they have treatment, again, it's the other people in folks' lives, so it's their family members, maybe friends that may not really understand especially treatment.”

#### *Flawed Assumptions that People with OUD Should Not be Helped*

- “I think the general overview that people have of anyone who might even be perceived as using drugs not to be worthwhile or worth helping. So do not even get them to the emergency room, don't even get them to housing... in general, just the starting point is that they're not even worth anything.”

#### *Social Stigma Stymies Recovery and Harm Reduction*

- Stigma impacts the feasibility of some steps that could be taken to help people with OUD, like creating overdose prevention centers.
  - “The average person, I don't know how we're ever going to get a safe use site in the state of Maine. And the only reason why I say that is if you are a politician in any town, most towns in the state of Maine, and pushing for a safe use site, I don't know if you can get elected. Maybe in Portland, maybe certain parts of the state that are more liberal, but most of the parts of the state that I'm hanging out in, oh my gosh, don't even bring it up.”

#### *Families Feel the Sting of Stigma*

- “For a middle class family, they're ashamed. They're embarrassed. They're frustrated. They don't know what to do. They're not likely to go down to one of our syringe exchanges and get free Naloxone<sup>41</sup>. So for them, that's the group that they don't mind going in and paying \$44 for a double kit of Narcan plus their insurance covers it.”

#### **Some Groups Face Added Layers of Stigma**

Some groups face deep criticisms and stigma about OUD. Mothers and pregnant people are treated especially harshly. This can be particularly hard for mothers who want the best for their children and unborn babies. The maternal health system has limited experience and understanding to help this population. On top of this, resources for people in recovery may not be designed for parents; as one example, there is a lack of recovery housing where mothers can live with their children. Justice-involved people with OUD are another group that is “othered” and treated badly in the community. Opportunities and resources (including housing, employment, and sometimes child custody) are limited for this group.

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<sup>41</sup> In Maine the overdose reversing medicine Naloxone – trade name Narcan – is widely distributed and, by law, should be available in every pharmacy.

Unhoused people with OUD are sometimes refused service, whether that be in a store, by delivery people, or by transportation services.

#### *Mothers with OUD are Treated Harshly*

- “We still see a lack of understanding for women that are in particular, that are pregnant and have substance use disorder. It can oftentimes, whether we're talking about in the criminal legal system and in some medical settings, be reverted to a moral failing, you're pregnant, you shouldn't.”
- “There's work about addressing stigma in the setting of pregnant moms with substance use through the [Maine] MOM program. But as far as that type of stigma, I don't know that we're doing a great job.”

#### *Unhoused People with OUD are Often Mistreated and Refused Service*

- “..people are just yelling at them. Stuff that goes about stigma, get a job or yelling the J word for slurs at people.”
- “So pizza delivery people... and .. taxis, if they know it's at a trap house or next to a trap house or a place that's a bad area, they won't go there.”

#### *Justice Involved People Have Fewer Options*

- “At a community level, there's a significant intersection that I see and in my work, and it's hard to sometimes tease out, but is the intertwined stigma around justice involvement and substance use disorder.”
- “I had a gentleman who was trying to get heating assistance ..we took him to the town hall where he lives and they basically didn't tell us the truth about the funding because they know this guy and he has a bad reputation. So the stigma of him in his past having been in prison and all the time, all the things he did prior, he's not that person now and they just weren't willing to give him a second chance.”

#### **Stigma has Lessened Somewhat in Maine**

Respondents who have been active in the fields of addiction, recovery, and prevention noted that while stigma is an on-going problem, it has diminished over the years. They believe this is due to more and more people knowing someone firsthand who has been affected by the opioid crisis, as well as general education on the disease model.

- “[Stigma] is not as prevalent as it used to be because more and more people have family members or people they know or coworkers or whatever. They may not

completely understand it, but they've come to a better understanding. And maybe there's been this kind of slight shift toward some level of understanding."

- "Unfortunately as more people are touched by deaths and overdoses, that to me has been kind of the single most catalyzing factor, mobilizing factor because it touches everyone. And I mean people of all sorts of income and race and age and political affiliation and gender. Everyone's experienced a loss related to drug use..."
- "I also think it's getting better and that there's been almost an entire cultural change regarding how people look at addiction. And there's a lot of reasons for that, but it's still there. There still needs to be work done on it."
- "But I'll also say, being in this work and starting in it through my own experience, [I'm] seeing significant advancements and broader understanding and acceptance, I think particularly as so many people are touched by it in their own personal lives."
- "I really do want to also hold up how much work has been done, how we've seen significant advancements, and I like to take that pause to look back to really just highlight that work and recognize and acknowledge that there will always be work to do."

### **Stigma in Healthcare Settings**

Stigma in the healthcare sector was a common topic of discussion, mentioned by both providers and people who have lived experience. They described structural stigma which exists on many levels – at the organizational level and the practice level, within emergency departments, and from individual providers. The healthcare sector oftentimes does not easily accommodate a population that faces many social challenges such as lack of transportation and/or job flexibility to get to appointments. Missed or cancelled appointments are lost productivity for medical personnel who are measured by how many billable dollars they bring in. The fee-for-service healthcare system prizes time and money over outcomes. This inflexible system is not always able to provide services to people with OUD during the window of time when they are ready for help.

Efforts underway in Maine provide training and education to healthcare professionals. The Thousand Lives Campaign, led by the Maine Medical Association and endorsed by the Maine Hospital Association focuses on addressing stigma toward people with OUD in healthcare and educating providers on treating people with medications for addiction.

### ***Systemic Stigma in Healthcare Systems***

- "I'll say some youth and the families they come from are often troubled. So if you miss two or three appointments, you're kicked out of practice. If you're late by more than 10 minutes to an appointment, people won't see you. I mean, part of me gets

that, but part of me is like, 'Well, just tell your patients you're going to run behind or tell them they're going to be seen, but they're going to be seen when you can work them in,...That's a great opportunity to start something. And people sometimes have no idea what it took to get through that door. Don't kick 'em out. So the system doesn't help."

- "I see it in particular in healthcare that people who use substances are blamed for having this chronic condition. If they have a substance use disorder, we blame them the way we don't blame people who have asthma and diabetes for their health decisions that they make, that there's something wrong with them and that if they just were stronger or wanted it more that they would be able to stop using."
- "When it comes to actually getting addiction treatment, if they've had bad experiences with prior providers, they delay that care. They feel like people aren't going to really believe them or listen to them. And so that affects their engagement in treatment."
- "[The Thousand Lives Campaign] is an attempt by healthcare to basically address ... stigma in its own ranks and to step it up and treat people particularly with medication and fill some of those gaps."

#### *People Treated Differently in the Hospital*

Participants shared how people with OUD are treated differently from others when they seek care. These stigmatizing experiences may affect the quality of the care that they receive and discourage them from accessing needed services. People with OUD are searched and talked down to in hospitals. Many providers do not know how to factor the present or past substance use in with the treatment plan – sometimes altering it needlessly, other times disregarding interactions. People with OUD may be successful in accessing care, but they may not receive quality care. When their health issues are not resolved, they are less likely to return for care in the future.

- People we spoke to shared examples of how stigma impacts patients' experiences:
  - Providers may be hesitant to prescribe needed medications
  - Providers may direct individuals toward OUD/SUD treatment, sometimes without asking if someone is still using substances
  - There can also be ignorance of interactions (example: suboxone interferes with anesthesia)
- "When [people with SUD] come into the hospital for something, their belongings get screened, they get treated differently when they come into the hospital, they are told that they have to sign behavioral contracts, that if they use drugs on the

premises, they can be asked to leave. There's just a lot of structural stuff that happens that stigmatizes people."

- "Doctors see substance use on charts and change their treatment approach/behavior."

### *Stigma in Emergency Departments*

Several of the interviewees recounted stories of bad experiences with bias and stigma in the emergency departments. Patients with SUD or OUD can be treated with disdain and/or made to wait longer than others to be seen. People going to the emergency department for an overdose are not always referred to services for follow-up. They are stabilized and then discharged, with nowhere to go for help in recovery. If someone with OUD goes to the emergency room for a health condition that presents with a lot of pain, sometimes they are not given any pain relievers because the providers think the patient is seeking drugs. With many negative experiences, people with OUD/SUD may delay seeking help, and when they do finally ask for help, they may be scolded about waiting too long.

### *Emergency Department Visits are Stigmatizing*

- "It's been quite shameful when individuals arrive at the emergency department and are told, well, we will see you after we see people who are actually ill. It's been shameful how people with active addiction who need help have been treated."
- "This is anecdotal, but what I'm hearing from community members that may be transported to the hospital after experiencing an opioid overdose is that they're not given a referral. They're given very little information and they walk out the door. They feel like as though they're not treated kindly."
- "I've done these hour, hour and a half drives to get people into treatment, sat there with people, and then they're turned away and they don't get the treatment that they need. And this whole kind of thing of, it's opiates, you're not going to die..."

### *Pain Not Managed Properly*

- "The way [people with OUD] feel like they're treated is that people think that they're drug seeking, that they want to get opioids. And so concerns are not addressed in the same way that if they didn't have that on their problem list or if it wasn't apparent to the provider, that they would get treated differently, they feel like their pain gets undertreated and it probably does."
- "Their tolerance is really high and you have to give them a lot of opioids if they have a painful condition. And so we undertreat their pain, which makes them look like they're drug seeking when they just want relief of their problem. And so they delay care. They try to take care of stuff on their own for as long as they can until they

absolutely have to. And then when they show up, they get the, 'I can't believe you let it go like this.'"

#### *Education and Training is Hard in Busy Emergency Departments*

- "It can be harder to engage ED staff and physicians in conversations..."
- "Because our hospitals are kind of our front line and the contact point, it would be nice to have a whole lot more compassion in those spaces. But that's not what I'm seeing. And I thought we would've changed by now."

#### *Provider Stigma*

Interviewees described the interpersonal stigmatization that occurs with providers and others working in the healthcare setting. Not all providers are trained on SUD/OUD and some do not feel comfortable treating individuals with these disorders. Some providers do not want to take on patients with OUD because they assume they are riskier to treat, more time intensive, and non-adherent to treatment. Some providers do not want to learn how to prescribe MOUD so they can avoid working with the population.

#### *Provider Lack of Training*

- "Most primary care physicians don't have any idea of what really, it blows my mind how little they know about substance use disorder, especially opioid use disorder."

#### *Some Healthcare Providers Don't Want to Take on Patients with SUD*

- "Within the provider world, there's people who maybe don't want--we're actually seeing improvement there--People who don't want to take on patients who have OUD, be their prescriber for the medication, they think they're harder patients, they're usually not. They're usually pretty rewarding patients from a lot of people we've heard [from] who have worked with the population for a long time."
- "I have heard physicians say things like, 'I don't want to take the training so I can prescribe because that population is trouble, too complicated. I just don't have the bandwidth to accept patients who are going to be that time intensive.'"
- "I work with a lot of individuals that work in private practices, whether it's substance use disorder or not, and they're really stuck in their ways of not trying to change their language and sticking with the old model in that sense."

#### **Commercial Pharmacies**

Commercial pharmacies sell both over-the-counter and prescription medications. In Maine, the public can legally purchase naloxone without a prescription in a retail

pharmacy. Interviewees shared that despite the laws, pharmacies do not always carry naloxone, nor do they make it easy to access if they do have it on-site. People purchasing harm reduction supplies such as naloxone, syringes, or prescription medication for substance use have been treated poorly and have sometimes been shamed as they make their purchases. Interactions with pharmacies have been stigmatizing, which keeps patients from asking questions about their prescriptions and may lead to stopping the MOUD treatments. One respondent pointed out that there is an opportunity to work with pharmacies to understand the stigma and perhaps work through it.

#### *Naloxone is not Always Available in Pharmacies*

- Retailers and pharmacists may be hesitant to keep naloxone stocked in pharmacies
- “Naloxone is now available over the counter, but you can’t find it OTC in many commercial Maine pharmacies.”
- “Theft of naloxone can be a real problem.”

#### *Interactions in Pharmacies can be Negative*

- “People definitely say that they've been told they're not allowed to buy needles at the pharmacy or not allowed to buy Narcan or feel like they're put on the back burner for prescriptions and feel like they get a lot of attitudes from pharmacy staff when they're picking up their MOUD.”
- “We hear a lot of the stigma at the pharmacy for people with opioid use disorder because they get their Suboxone there and they get their medication there. That helps them stay in treatment and in recovery.”

#### *Opportunity for Improvement*

- “We would love to talk to more pharmacists about this without being accusatory about what's going on. ‘What do you see when people come in?...What are you seeing as why are these people challenging or why do you think they feel like there might be stigma in the pharmacy?’ We have not ever really been able to talk to them. They're busy and they're just not the type of provider that's in an office that can sit and have a Zoom with us. So that is a gap.”

#### **Stigma Against Medications for Opioid Use Disorder**

MOUD is an effective treatment to help people with OUD. In recent years, more providers have become familiar with several treatment options. More people with OUD are accessing this treatment, but more people would benefit from this modality. However, respondents share that people look upon the MOUD with skepticism and judgement believing that if a

person is still on medication, they're not in recovery. They also share that some family members, friends, and others think that people with OUD should be totally abstinent from medications because they think substance use is a choice.

- “The bottom line...is that there's stigma associated with the illness and there's stigma now associated with the medication.”
- “And then we still hear from people whose families don't think that they should be on MOUD because they say things like, ‘It's trading one drug for another,’ or ‘Why can't you just stop on your own?’ They don't really understand the science and the physiology behind addiction.”
- “There's also this idea that if you're doing a certain one and not a certain other one, then it's not the same. Methadone clinics, I mean, a lot of stigma is the methadone clinics have lines outside...”
- “There's a 12 step group that calls [medications for opioid use disorder] ‘DRT,’ which is ‘drug replacement therapy.’ You can't get much worse than that. In fact, their literature actually calls it that...”
- “[Some jail staff], I think the best way to put it, are not that well educated or that easily convinced that this is really treatment. And the funny thing is that's the same attitude of the people who are incarcerated...there's a good number of folks that are incarcerated that think that these folks over here that are getting treatment for substance use disorder, that especially opioid use disorder, they, they're just going to another drug and ‘Why are we doing this?’ and this kind of abstinence-based mentality.”

#### *Stigmatization can Lead to Early Cessation of MOUD*

- “We stigmatize people when they seek care by, in particular, when people decide to go on medication for opioid use disorder, society stigmatizes them for being on those medications. We tell them that they're not really sober...And so what that ends up doing is it makes people ambivalent about treatment. They can see their lives getting better, but yet the message they get is that it's not okay that they're on this and they really should come off of it. And then what happens is they come off of it too soon and they have returns to use and they overdose or they get hepatitis C again or bad outcomes. And we tolerate that because we don't value their lives the same as we value lives of people who don't use drugs.”
- “So the truth is not everybody on MAT takes [it] correctly. Individuals that do MAT correctly, you probably wouldn't even know they were on MAT.”

## Law Enforcement

Law enforcement has been at the forefront of the opioid crisis since the beginning. Respondents described how police are often the first to arrive in an overdose emergency. By law, they are required to carry and be trained to administer naloxone.<sup>42</sup> Respondents said that law enforcement officials, like many in the community, may hold varying opinions about substance use. Some officers see it as a crime, while others understand it is a chronic disease. They see firsthand the needs of people with OUD and must balance those needs with the legal implications that can be intertwined with substance use. One respondent described that some people may not appreciate the complex role of law enforcement when it comes to illicit drugs, OUD, and overdose. In addition, some respondents shared that some law enforcement misunderstand opioids and fentanyl; for example, some think they themselves will overdose if they touch someone who is overdosing.

- “I’m not saying all law enforcement have this attitude, but yeah, we did see a number of them. They see it as a, it’s a crime, it’s a choice. They’re bad people. It’s a moral issue, and let them die. And that’s really a shame.”
- “When a person overdoses, the first people that arrive are the police. So sometimes they’re kind of at odds with the advocates because the advocates tend to see things sometimes too black and white, that now if it’s associated with law enforcement and the police and sheriffs, that’s bad. Everything else is good. It’s way more complicated than that.”
- “....in Maine, it was really law enforcement that started putting people into treatment, that Project Hope in Scarborough and Chief Moulton...it was law enforcement in Maine that stepped up a lot quicker and with a lot more enthusiasm than healthcare did in recognizing that, no, we can’t arrest ourselves out of this problem. These people need treatment. They don’t need to be incarcerated.”

## Emergency Medical Services (EMS)

Like law enforcement, EMS and firefighters are among the first people on the scene of overdoses. Since 2021, the Maine EMS licensing board and state statutes have required EMS providers to be trained to administer Narcan and provide naloxone kits in the event of an overdose.<sup>43</sup> Because they have witnessed the increase in substance use and overdoses, they have been active in seeking solutions. Like law enforcement, first responders may have personal biases that stem from burnout or compassion fatigue, such as responding to

<sup>42</sup> Sec. 2. 22 MRSA §2353, sub-§3-A

<sup>43</sup> <https://legislature.maine.gov/statutes/32/title32sec85.html>

difficult calls, lack of staffing, responding to multiple overdoses, or inadequate training. When people with OUD are treated poorly by first responders, they are less likely to call again for help when they need it in the future.

#### *Frontline Work in Combating OUD*

- "...in consortiums around the state, like the ones I mentioned to you, first responders are at the table and they're really responsible and responsive and understand, trying to learn and understand and be helpful. And for the most part they are."
- "We're seeing first responders that are sometimes working on limited budgets and limited staffing that are really passionate about this work and are working to implement new strategies, legislation that has come down around, whether it's leave behind Narcan, and of course the efforts around even buprenorphine"
- "Yeah, there's been a huge change there. I think that [first responders] actually get more training than hospitals do. I think that they actually respond better than they ever have. And I think if they have the right resources, they use 'em more."

#### *Burnout from the OUD Epidemic and Lack of Resources*

- "I want to learn how to help our volunteers that may be new to this, that haven't been exposed to these sort of events. Just recognizing that responding to these sort of events are very traumatic. And so I hold that too, the work that our responders are doing to keep our community safe, but the resources and supports that they have, particularly at our volunteer levels, like our volunteer firefighters, emergency services that might be responding to some of these events, the resources for them."
- "[Some first responders] feel like they're helping the same people over and over again, and the helping doesn't help. And so they believe these types of strategies won't get us where we want to go. So I think it's just like, that's a lost cause and that just plays out in their willingness to take part in activities like Narcan distribution and things that can be helpful because I think they're just burnt out."
- "So I think the problem with first responders is when [a person with OUD] calls or they have an issue or they try to utilize the service, if [they] don't get it the first time, [the person with OUD] is not calling back again. It's that first impression piece with first responders..."

## Housing

Stable housing is critical for anyone to live a secure and successful life. In recent years, the housing shortage in Maine has made it difficult for many people to find a place to live.

However, people with OUD face additional obstacles in finding available, affordable housing. Typical rental applications ask about criminal history and require references from prior landlords. If someone with OUD has a criminal history for drug possession or they had a bad interaction with a landlord over substance use, these circumstances could keep them from renting an apartment. Respondents shared that communities may push back when a recovery residence opens in a neighborhood. Neighbors have unfounded fears about increases in crime and substance use. Housing is one of life's basic needs, and without it, recovery and stability become that much harder.

#### *Substance Use and Criminal Histories can be Barriers to Housing*

- “[When landlords] do background checks, if they have substance use, if they have brushes with the law on their background checks and they are refused housing. And it's a snowball. I mean, even if you have the money for housing, you get rejected.”
- “Maybe not stigma-related, but women struggle to find sober housing where they can also have their kids...”

#### *Neighborhood Pushback Against Recovery Residences*

- “The housing, that's more where we hear the stigma is about the towns. People who don't want a recovery house or don't want a group home or whatever in their towns. And honestly, I think it's because people aren't even getting to the landlord stage.”

## **Employment**

Social stigma carries over to many aspects of day-to-day life. Respondents discussed how stigma against OUD can impact employers' hiring decisions. Job applications include questions about criminal history and may ask about substance use, despite this practice being illegal in Maine. Some jobs may require urine drug screening prior to hiring. These requirements can be exclusionary for people with OUD and people with OUD taking MOUD. Respondents described successful efforts underway in Maine to educate and support employers as they hire people in recovery and reduce stigma in the workplace environment.

- “It is often fear-based because it's been perpetuated by the stigma associated with what it means to be a person with substance use disorder or opioid use disorder or someone that's been justice involved or involved in the criminal legal system. And that's where a lot of my work currently sits...working with employers and educating employers to have a real depth of understanding of what substance use disorder is

and not be fearful of individuals that either disclose or of course, living in rural communities, sometimes it's not a personal disclosure.”

- “Really out of just necessity, employers have learned more and more and more, or attempted to learn more and more, about the challenges for folks both that are incarcerated and folks that suffer from substance use disorder, whether it's opioids or anything else, and have been willing to make accommodations...what these folks have learned through this kind of process is that if you find good employees and you invest in their level of trust, you come to understand that they do good work.”

## Thoughts on Best Ways to Reduce Stigma Towards People with OUD

### How to Reduce Stigma in Maine

At the end of each conversation, the interviewer asked the question, “If you had a magic wand, what would you do to reduce or end stigma towards people with OUD in Maine?”

Almost every person said the best thing to do was to increase kindness and empathy and to lessen fear and judgment. Respondents hoped people would take the time to learn more about the disease, meet people with OUD, and think about the challenges people face. Some respondents thought that policymakers should reach out to people in recovery and to people who use drugs to understand their needs. Likewise, they thought people with lived and living experience should have a seat at the decision-making table. Others thought that people in recovery could tell their stories and share their journeys through OUD. Some said that enlisting leaders to carry messages would slowly help people understand their own biases as well as the barriers and challenges faced by people with OUD. Harm reduction was mentioned by a few, specifically syringe service programs.

### *Empathy, Kindness, and Less Fear*

- “I would just love for everyone to be in relationship with each other, to have love and compassion for their neighbors and for their community members that walk different paths than them and [for] us not to live in fear..”
- “My magic wand would focus on ‘What can I do? What can we do as part of the care community?’, which is address the stigma within our own walls and places where people come to access care, be trauma informed, be nonjudgmental, be welcoming and loving.”
- “If we could just teach people to be more compassionate, it's not a moral failing. It is disease based. It's a health situation that people reach out to substances. I think we need something that educates everybody universally.”

- “When you recognize that people are people, and that could be your mother, father, sister, brother, son, daughter, whatever, it makes a lot of difference when you can't put that barrier in front of you.”

#### *Education and Connection with Policy Makers and Leaders*

- “Anyone who's making decisions, policies, processes, rules and regulations that impact someone who's using drugs, someone who wants to seek services to support their path and recovery..... should go spend some time with someone who's actually using drugs and who's in chaotic use. Go hang out, go to an encampment, have conversation, not just one conversation, but have continuous contact with people who are using drugs because it changes, their needs, their insights changes so often.”
- “The inclusion of lived voices authentically embedded in every single process at every level and even at the highest level. And when I say lived, that also means people who are in active use because they have their ear to what is happening most currently.”
- “And sometimes I feel like that is one of the biggest challenges [is] to be in shared uncomfortable shared space on hard topics. But what I've seen, you asked that question earlier, what has worked is when that has effectively been brought together, whether it's someone facilitating that relationship or that learning. And then we've seen leaders in those sectors, whether it's in the workforce sector or leaders that are saying, ‘This does work,’ or ‘This is what we've learned,’ or ‘This is how we've implemented this into our practice.’ And they have that credibility and then others in that sector saying, ‘Okay, we want to learn or grow in this area too.’ So I think that's something that we've just seen is how do we have, I say leaders, but an advocate from those sectors.”

#### *Share Stories of Lived Experience*

- “More people need to share their stories more and they need to have a platform and a megaphone or whatever to share the stories that they have...because people love success stories. They love to hear about people who are in long-term recovery and doing great. Then people who are struggling need to talk, too. But again, there's a stigma. You don't want to share that. But I think the more that people can share or the more that people who are researching the topic can share the information, I think it helps a lot with stigma. And that goes to the policymakers, to the people in town who don't want the recovery [housing].”

*Harm Reduction Strategies*

- “I think we need a comprehensive, effective strategy for syringe disposal because I think that's causing a lot of strife and contributing to stigma...and [we need] funding.”

## Findings on Youth Affected by Substance Use and Ways to Reduce Associated Stigma

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A portion of the study included interviews with people familiar with youth affected by substance use who are experiencing stigma. The study team asked 11 people questions about youth and stigma to understand how young people's experiences might echo or differ from adults' experiences. In this line of questioning, most people responded about youth in high school; however, some discussed college-aged young adults. For this component, respondents referred to substances as tobacco (vape), alcohol, and cannabis, as very few see opioid use among youth.

### Youth Engaging in Substance Use

Throughout the interviews, respondents talked about youth substance use experience. For the most part, adults know that some youth are experimenting with substances and some may be dependent on nicotine from vaping. They shared that youth did not understand the risks of harm, and while some parents might understand those harms better than their children do, many do not. Cannabis, vaping, and alcohol use have become normalized in Maine's communities and parents share mixed messages with their children about the potential harms. Respondents said they observed very little opioid use among youth. Youth that use illicit drugs were not likely to disclose for fear of having to quit or fear of getting in trouble with adults.

A few respondents described the need to address the underlying challenges faced by youth – poverty, violence, housing, food insecurity, mental health conditions – to effectively address the SUD. They explained that these drivers of health are oftentimes the drivers of SUD among young people.

### *Youth Do Not Always Understand the Harms of Using Substances*

- “Most teenagers do not see substances as a problem and they feel that, yeah, there's some risk, but it's such a small risk that it's not a realistic risk compared to everything else in life, and especially the low-lying marijuana type thing that they just don't see a problem at all.”
- “I'd say there's some level, for the low-lying use with marijuana that we're just seeing so much of nowadays, there's a cultural norm that's been accepted and that's frustrating from my end because from a medical standpoint, that's not substantiated as far as all the reasons they're using 'em for anxiety, sleep. And from

a medical standpoint, we have really good data from Denver saying it's detrimental for brain development..."

- "The schools seem to turn a blind eye to the drugs being used in their own bathrooms. That's why they thought it was so important to have Narcan allowed in their schools, because they know the problems there. But the administration is turning a blind eye to it."

#### *Youth Fear Punishment for Using Substances*

- "...as far as stigma, they definitely don't want to advertise their use when they are seeking care. And sometimes they will say, "Don't tell my parent, don't tell anybody else, I don't want my relatives to know."

#### *Focusing on Social Determinants of Health Helps Address Youth SUD*

- "...I could solely look at housing, food supply, mental health issues, and the substance issue will disappear if I do that. And so I don't necessarily need to focus directly on substance use. Yes, we do focus on that, sometimes that's the carrot that gets 'em in the door to talk about everything else, but the reality is I have to focus on social determinants of health and that's going to be much more effective at the end of the day with the younger people."
- "We need to get rid of the barriers of transportation, of parent barriers, of insurance barriers."

#### **Youth Experience Stigma in Many Ways**

Like adults, youth engaged in substance use experience stigma in a variety of settings. Respondents said that youth who engage in substance use are looked down upon and may be bullied in school by their peers. People do not realize that substance use occurs across all families and walks of life. Much of the stigma and bias comes from parents and adult community members. Adults' use of language on the topic can be biting and mean. Some of the respondents described deficiencies in schools. No matter what the source, stigmatization can push youth further into substance use as they internalize the negativity and loss of self-worth.

#### *Bullying and Harsh Language*

- "From what I've heard, they do get bullied at school. They're looked down upon by the other youth because the other youth are hearing it in their homes from their parents, that it's a moral failing" [referring to youth who use substances]

- Language used by adults to talk about SUD can make youth feel stigmatized: “We use words like ‘in your recovery,’ and a 14-year-old hears that and is stigmatized by that. They don't see themselves [as] in recovery.”
- “It is such a strange time for the stigma because you do, on the one hand, have a group of adults and people who are like, ‘You're bad for doing this.’ And then on the other hand, we have a lot of parents who are like, ‘I'll just kind of look the other way.’ I don't know really. It makes for a tricky time, I think.”

### *Stigma from Teachers, Administrators, Other Adults*

- “Sometimes I get very frustrated with the administrators. Even the ones who are well intentioned, they don't recognize their own biases towards these kids. ‘Well, that family, the best we can go forward is that they show up.’ And you can't tell me if you have that feeling that it's not impacting the kids.”
- “So some faculty, they treat 'em differently, but an almost coddling manner, in a sympathetic manner, in a sense, in a different stigma. And there's still a stigma. I would say it's just in a different light.”

### **Children of People with SUD are Stigmatized**

Children of people with SUD bear a great burden to keep family secrets. Respondents described how home life impacts how youth interact with people at school and the community. Youth may be afraid their parents will die of an overdose or may experience the chaos of a household in distress. Parents, too, experience stigma related to their children's use (whether those children are youth or adults). They are sometimes seen as bad parents for their children's situation, which is sometimes referred to as associated stigma. Youth and their families may also experience anticipatory stigma, fearing they will lose opportunities or be judged if people know about substance use in their family.

### *Youth with Parents/Caregivers with SUD Face Additional Challenges*

- “Children of people with OUD – feel a lot of fear that their parents could overdose at any time”
- “Youth who are with parents or caregivers who are experiencing bias based on stigma, that's one more thing for them to bear... having a parent who uses substances is actually a risk factor. So that's the antithesis of the tool in the toolbox. And so with those kids especially, you need to make sure that they have a lot of tools in their toolbox and you need to pay special attention to them and you need to make sure you're not singling them out or making them feel bad that their clothes reek of cigarette smoke.”

### *Students and Families Fear Being Judged*

- “Maybe they don't want to say that their families are struggling because they're afraid that that's going to be said about them, that they're not a good family, that their parents are this and they're that.”
- Fear that talking about parents' substance use will prevent them from having opportunities [paraphrased quote].
- “I think the kids become the secondary and tertiary victims of the stigma of substance use disorder. The family is not, if they're dealing with active misuse or even if they're in recovery, they know people look at 'em differently. So therefore, they want to keep the family secret. And kids are very inclined to perpetuate that. They learn... from subtle hints that 'We don't talk about this stuff.'”
- “When teachers and administrators are identifying the kids [to participate in our groups for affected others], we don't let them identify for us who the kids are, who are affected others, because we have found that they won't identify the straight A student. They won't identify the star athletes. The perception is that those kids can't possibly be affected.”

### **Peer-to-Peer Stigma and Other Impacts on Social Life**

Youth care deeply about what their peers think, and when substances are involved the stigma is difficult on these peer relationships – whether it be pressure to continue substance use or avoidance because of substance use. Respondents shared their observations of youth putting pressure on their peers to stop or continue using tobacco products. This can be particularly difficult in small towns and rural areas.

### *Peers Play a Big Role in Using or Not Using Substances*

- “Stigma is huge. I think it's probably one of the tougher things with the youth is [that] a big part of what they see as important is their peers. So if there's stigma involved around quitting vaping for example, it just makes it that much harder for them to make that initial step even. And I've seen it firsthand where some students will come to me and be like, 'I want to quit vaping.' Then another student will...say something negative towards them.”
- There's some peer-to-peer stigma, right? There's a whole group of kids that just looks down and they ostracize kids that use substances, and so they're not part of that club. There's adults that do that to kids too.”

### *Stigma Can Come from the Community*

- “If you're seen out late at night, if you're seen at certain places, certain people, when you get on the community, there's hotspots for who and where you're surrounding

yourself with, as we know...I think it looks different depending who you are and what exactly you're being seen around or who you're seen with. But I will say it can look like things like dirty looks to anything like not getting looked at for a job."

### Stigma Can Push Youth to Use Substances

Respondents shared the continuous feedback loop that youth hear about their substance use. Youth who are caught using substances are punished, labeled, and told they are not worthy. This reaction is stigmatizing and often leads to more substance use. The cycle erodes their self-esteem and makes it harder to build resilience and healthy coping skills. This type of stigma can come from the community, families, youth, and general public discourse.

- “A huge part of stigma for kids is you're not a good kid if you use substances. So there's very much that you're causing trouble. So you get punished for using, because right away you're disobeying an adult, you're disobeying rules. So there's this fear of getting in trouble, fear of punishment, and then because of that punishment, and sometimes you interact with the criminal justice system because in more severe cases, so then you're definitely labeled not a good kid or a troublemaker. And sometimes in the school system, and again, just in communities, those kids will get walled off and because that will just follow them and they are good kids, they just can sometimes make some unfortunate choices for themselves.”
- “I think generally students who are struggling with any kind of addiction, the stigma that's attached to them by adults or staff or teachers at the high school is that they're naughty, they're bad. It's kind of their fault, they're making the choice, they should make better choices, things like that....I think it just gives them more motivation to use substances, unfortunately...If people are telling you that you're bad or naughty or you're not, it's like they're receiving a message that they're not worthy, that they don't deserve to help or the time of adults around them. And I think it's a big loop because the kids that are most likely going to use substances are the ones that don't have the self-esteem that are sort of lacking something anyway. So when the stigma goes directly at them, it just feeds that and it's a continuing loop of the message that they're not worthy or they're not good.”

## Punitive Responses to Substance Use from School Systems, Criminal Justice System, and Within Families

Respondents described that youth may be punished for their substance use rather than given supports or treatment. They are told they are bad, they disobeyed, and so they will be held accountable. Youth who reveal substance use, either voluntarily or involuntarily, may lose privileges such as use of a car, playing on a team, etc. Respondents shared that not only is this approach ineffective, it also encourages youth to keep their use a secret and discourages them from seeking help. This occurs in schools, the criminal justice system, and within families. It even occurs in treatment, as youth may be ordered to go into treatment by the court or by their family. These punishments reinforce the myth that using substances is morally wrong.

### *Youth Fear Punishment if they Report their Substance Use or Family Substance Use*

- “Youth face any sort of judgment. If someone finds out that they're using, there's this judgment, right? Like, oh, it's their choice. Oh, they're bad, or they're this, or they're that. None of that is true, but that's what they hear. That's the message they get. So they're afraid of disclosing. Substance use disorder...sometimes we respond to it by, or it's responded to by punishment. You're never going to be able to punish use out of anyone. So kids, they're afraid of punishment.”
- “And there's a lot of reasons I think why kids don't feel like they want to report. They're afraid that their parents are going to get in trouble. They don't understand that substance use disorder is a disease. So there's that stigma out there that it's a choice and actually it is a disease.”
- “When kids are being disciplined for having to deal with whatever's going on at home and having to go to school late or whatever, not doing their homework or all of those things, I would say that that is because of stigma... all built within that system, structural system. And they're not being treated for their problems or issues.”

### *Youth Fear the Loss of Privileges if They Disclose Substance Use*

- “Stigma does prevent youth from getting help. They don't want to get in trouble. There's rules for kids that are using on athletic teams and clubs in schools and high schools that you won't be able to participate in the activities of the athletic team, when honestly that [participation] is protective from getting even into more trouble. So there is some sense of shame.”
- “And within families, kids will not disclose that they're in trouble until it's readily apparent or there's a crisis because either they're so afraid of being punished, losing privileges. Some kids are afraid of physically being harmed when they're disobedient

to parents' rules in some households with really very rigid parental styles. So there's a whole host of things that can affect that disclosure in children."

#### *Youth May Be in Treatment Involuntarily*

- "Where adults... recognize the problem and seek care, teenagers are usually forced into care because their parents or the system or the law or something like that. And so that's one thing to recognize with teens, young adults that differentiates them from adults."

#### **Prevention of Stigma for Youth**

Some respondents thought that prevention work at an early age helps to reduce stigma and that youth have an easier time talking about substance use than adults do. One person thought younger people held less stigma than older people because they were educated about it early on and understood the disease model. They said that young people have been exposed to more person-first language and may know people who have OUD or SUD.

#### *Prevention Messages Reduce Stigma with Youth*

- "I think with prevention and the conversations that are happening in the prevention spaces—when I think of prevention, I think of young people, and that's where stigma starts getting knocked down too. The more open we are about these subjects and talking about them, they're right in front of us."

#### *Youth Harbor Less Stigma than Older Adults*

- "I believe stigma is generational. I believe that if you talk to the youth, they have a complete different outlook on substance use disorder and opioid use disorder than you talk to the individuals that have been using fentanyl meth for 10 years, or the community that grew up at the beginning of the fentanyl or opioid use disorder crisis. I'm going to call it a crisis, right? And in the end, it has shifted. I think if you talk to anyone 21 years old, they have a much kinder outlook to an individual with substance use disorder, opioid use disorder compared to an individual that is a parent of someone with substance use disorder."
- "The thing about this generation, I think is they are, they're more aware of any generation before, honestly, I have not seen [stigma]. I have seen more of with this generation, them supporting each other."
- "I think one of the things that really changed was language. When the language started to change, then you really saw organizations trying to make an effort to try to change as well. So as we stop saying addict, as we stop saying substance abuse,

and the language started to change, I think the harm reduction model started to set in a little bit more. And that started to change all of the behavioral health organizations.”

### **Lack of Resources for Young People Using Substances**

Respondents described the lack of resources for youth across the state who may be engaged with substances. They said waitlists for clinical services are extremely long or services don't exist in parts of the state. School staff are left with the responsibility of working with students to manage their behaviors. A couple of respondents mentioned that the underlying social determinants of health and adverse childhood experiences (ACES) need to be addressed before anything else. If youth do not have food, shelter, and safety – any other intervention will not be effective.

### ***Schools are Unprepared and Overwhelmed***

- “One of the barriers that I see is our schools have a depth of understanding of how to respond to youth substance use. There's not always a clear plan.”

### ***Lack of Clinical Services for Youth***

- “If we saw a number of young people affected by any other medical condition or impacted through the parents in that way, how would we be responding and why aren't we responding in that way?”
- “I think this is a huge gap that we have in our community when we are talking about youth and their experience of substances and how stigma plays a play into that. I think it's a huge gap when you're talking about resources for them to help navigate that.”
- “We need IOP [intensive outpatient programs] programs, which we don't have. We need treatment facilities, which we don't have. And it all comes down to, I guess, funding.”

### ***Address the Social Determinants of Health – Food, Shelter, Safety***

- “And again, people just not being aware, as far as I'm concerned, if you treat the ACEs [adverse childhood experiences], if we treat the ACEs in education, everything else is going to get better because everything stems from the ACEs as far as I'm concerned. But no, there are not a lot of services at all out there for the kids. And there needs to be.”
- “One thing I keep preaching over and over is in the adult world, the substance use is the problem. Until you fix the substance use, you're still going to have problems with

housing, marriage, job, all these other social type things, social determinants of health. In teenagers it's the complete opposite. It's the environment that's the problem. And to me, the substance use is a symptom of the environment..”

## Healthcare Providers Lack Training in Youth SUD

Like services for adults, healthcare providers find that treating youth for substance use takes more time than they can give. Respondents shared that many young patients do not disclose, and providers may not ask about substance use. They explained that young people using substances may be complicated cases, so providers may not take them on. Primary care providers find that there are few resources for referral and limited specialized treatment available for youth and their families.

### *Treating Young People Takes Time*

- “One, providers don't get a lot of training, so they're often frustrated, so they don't know what to do with it. Two, often patients don't want to disclose it to healthcare providers, even though they know. I think at this point, healthcare providers know they should be looking for it in young people and trying to intervene to help do something. But that takes time. And so providers that have this expectation of meeting coding and billing requirements often, often feel pressure to take the amount of time. So sometimes it's sort of like don't ask, don't tell.”
- “So there's stigma around providers not wanting to have to manage some of these youth that can come in and some often are complicated. They may have very complex issues, and then finding appropriate interventions for them can take time. So it just is layers upon layers of how complex they can be when they interact with the healthcare system. So sometimes providers don't look, or some practices won't take certain issues, they just kick the can down the road.”

### *Providers Lack Awareness*

- “I don't even think it falls on their radar as providers that when they're seeing a kid who's sick with pneumonia or cough or bronchitis to even ask or think about if they're inhaling anything regularly, I just don't think they're as informed.”

### *Lack of Resources for Referral*

- “My impression is that there just aren't a lot of places or answers for primary care providers to give parents of youth who are using substances. And so I've actually had the experience of interacting with a lot of really concerned primary care

providers who do see youth in their practices and they don't know what to do with them. That story is more common than any other I've heard."

### **Best Ways to Reduce Stigma for Youth Engaged in Substance Use**

In closing, respondents shared their thoughts on the best ways to reduce stigma toward youth engaged in substance use. The responses varied but all were centered on education for providers, educators, community members on youth substance use as well as creating more options for youth for treatment. All respondents hoped for a kinder, more supportive response for youth in need of support.

#### *Community Education*

- “I would give everyone the education. I would find a way to give everyone the education about substance use disorder. That's what I would do.”
- “I would fund more programs like ours. ..We're a community partner... It takes somebody who's kind of outside but recognizes their role as a partner to advocate jointly for the kid and the school to make both parties successful. I really believe it takes somebody who is removed from being invested in the process to help both sides succeed.”

#### *Healthcare Provider Education and Clinic Improvements*

- “I'd probably make it part of mandatory education for providers and staff at offices. We have so many other things they mandate on us. I'd rather know about this than how to shoot a fire extinguisher.”
- “In a perfect world, I want to remove the stigma by having a texting system. Our whole system has blocked us from texting [for] medical legal reasons. And these are the kids that you'd have better access to by texting and they text when they have needs and text back when they're willing to listen...When they're calm, that's kind like teachable moment. You got to grab it right then and there. I think we miss those opportunities.”

#### *Provide Connection to Youth*

- “I think that if more people were to want to provide connection for the youth rather than activities, I think it would be beneficial to the youth. And the stigma involved around substance use. One of the simple Band-Aids I hear a lot is, ‘Let's give 'em activities. Let's give 'em sports. Let's give 'em basketball, let's give 'em this.’ Basketball ain't just enough sometimes, kids get high and play basketball. It is just

how it is. It's not a lack of activity, it's a lack of connection. They don't have the support and the positive [socialization] that they need."

- "More positive experiences for them and more showing of the community caring for them. There's a lot of pressure put on your normal sort of academic success. And it's not always the most important things for every kid to be academically successful."
- "I would really just wish for more understanding. ..if more people would just be a little more open-minded and treat people with kindness and love, I think that we would get a lot further in this world around the stigma especially. And if you don't know, don't know. It's okay to say you don't know. You don't have to have an opinion on everything."

#### *Magic Wand Wish for Community Support*

- "I think what I would like them to feel like when they finally recognized, wanted to get into treatment, that it would feel to them like...when somebody goes into the hospital, gets a diagnosis, the neighborhood knows, and they're making the meal plan chart, the hospital's welcoming you, somebody gives you the nice pink socks when you come in and they're like, 'Okay, these are the services we can offer you and we can get you in.' And everybody's nice and warm, and you feel like this rush of care from people instead of people kind of running away...I would sort of make people coming to your aid sort of like that communal, wraparound with all of those aspects of your life. 'We can get you medicine for that, but wait a minute, everything else in your life is important and it's fallen apart because of your substance use,' just like a cancer diagnosis can for somebody. I would make it happen the same way."

## Conclusions/Recommendations

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This report aims to shed light on promising practices for reducing stigma toward adults with OUD and youth affected by SUD. The literature identifies six strategies that have been shown to reduce stigma and increase awareness of the challenges faced by the people with SUD. In the interviews, respondents shared their observations of stigma and how they think it can be reduced. The following section lists strategies for reducing stigma and maps suggestions from respondents to these strategies, recommending ways that advocates and policy professionals can address stigma in Maine. Importantly, research reinforces the need for positive language across all strategies:

- Using person-first language reinforces that people are not their behaviors
- Using medical terminology to describe treatment reinforces that addiction is a disease like other chronic diseases
- Promoting recovery language can be affirming
- Avoiding slang and idioms avoids disrespect and further stigmatization

### **Education**

Implement OUD education and awareness messages to increase knowledge about and understanding of the condition and the negative impacts of stigma. Respondents suggested the following:

- Continue to educate health care professionals, law enforcement, first responders, pharmacy personnel, and school staff on OUD and youth affected by SUD, emphasizing that OUD/SUD is a disease and not a moral failing
- Emphasize the value of harm reduction in reducing and treating OUD
- Educate the public with messages that promote kindness and understanding
- Work with policy makers and leaders to educate them on the disease of OUD/SUD and how stigma impacts treatment and recovery

### **Advocacy**

Advocacy is important in reducing stigma. Advocating for policy and practice changes, as well as advocating for an individual, can both reinforce the need for stigma reduction and break through the barriers and challenges faced by many. Specially, respondents recommended:

- Connect with policy makers, introduce them to people with OUD and youth affected by SUD
- Advocate for more harm reduction options and educate policy makers and the public on the importance of distributing aids like Narcan, syringes, etc.

- Actively engage people with lived experience in advocacy efforts
- Work to change internal policies or practices in healthcare settings that impede treatment. This could mean implementing same day access to care for youth and using texting as a means of communication
- Revise school policies to be restorative rather than punitive for youth who might violate a rule

### **Contact-Based Programs**

One of the best ways to reach the public with education is to use a trusted messenger to make that important contact. That person can be from a particular profession (such as a police officer, mayor, educator, or coach) and/or be someone with lived experience; the messenger may differ for every audience. Effective messengers include community leaders, trusted individuals, and people with lived experience. The interviewees recommended the following:

- Support leaders, such as employers, in sharing positive stories. An employer might speak to other employers about their experiences hiring people with OUD who pursue treatment and go on to be loyal and productive workers
- Identify healthcare professionals to share their experiences with their colleagues on successfully treating people with OUD
- Engage school staff or community members to educate school staff on stigma and trauma response and how to work with trauma-affected youth
- Host community-wide events to share information and resources

### **Media Campaigns**

Media campaigns communicate ideas to a variety of audiences by using appropriate messages, messengers, and media channels. Typically, these efforts use a mix of broadcast, print, online, radio, presentations, and other media to reach the intended audience. Respondents recommended the following:

- Create and promote messages for TV
- Attend or table at sporting and community events
- Share social media messages on the disease of OUD/SUD, prevention, harm reduction
- Promote Narcan distribution and use
- Deploy door knocking campaigns to share information and Narcan
- Create SUD prevention campaigns, including messages highlighting the dangers of cannabis use by youth and young adults

## **Peer Programs**

Peers share their experiences and knowledge with people with OUD and their loved ones.

Peers engage with individuals to help them navigate health care, the justice system, and housing. They help people when they are struggling by providing encouragement, support, and problem-solving. The respondents recommended the following:

- Engage peers in treatment and recovery programs
- Enlist peer voices in advocacy
- Connect peers to families
- Use peers in community outreach and media messages

## **Youth-Specific Interventions**

There is little research on actions to reduce stigma for youth affected by SUD/OUD. Studies point to the importance of evidence-based prevention programming and using a strengths-based approach rather than a deficit-based approach. The interview participants recommended the following actions to reduce stigma for youth:

- Address the social determinants of health for youth – food, transportation, shelter, safety
- Educate school staff on trauma-informed approaches to discipline and classroom management
- Increase access to Narcan in schools and provide training on administering Narcan
- Replace punitive policies for substance use with restorative approaches
- Add addiction counselors to school staff rosters (find funding)
- Offer same-day addiction care appointments to youth
- Educate health care providers on youth SUD and how to talk to youth about substance use
- Advocate for more youth-focused services to treat SUD – in-patient treatment, counselors, and follow-up services

## Appendix A. Moderator Guide

1. How do you observe or experience stigma toward people (youth) with opioid use disorder in your work/interactions/life? How does stigma impact people with opioid use disorder? (Potential prompts if needed:
  - a. Ask about the three “levels” of stigma explicitly here (Societal, provider, self stigma)
2. What are you doing to address stigma reduction?
3. How do you think stigma could/should be addressed in Maine?
4. What resources are available to reduce the stigma associated with opioid use disorder? What resources are available for people with the disorder, their families, and friends?
5. What resources are available for medical and mental health providers, community officials, landlords, and others to increase their understanding of substance use disorder? What kinds of interventions have you heard about that are successful in reducing stigma?
6. What groups are working on this topic? In what settings?
7. Can you refer us to others who can provide another perspective?