



A Movement to End Addiction Stigma

Addressing opioid use disorder stigma:
The missing element of our nation's
strategy to confront the opioid epidemic



A Letter from Our Founder

The addiction crisis is pervasive and will almost certainly be intensified due to COVID-19. Family gatherings have been postponed and casual outings with friends canceled. Not only has access to treatment and recovery supports become more difficult to access, but physical distancing is also intensifying the existing isolation those addicted already feel, due to the stigma unjustly associated with this illness. And, COVID-related unemployment is anticipated to lead to millions more people becoming uninsured, which will make it more difficult for people with SUDs to access treatment. Rates of substance use disorders remain extremely high despite recent large-scale interventions across our country. With an opioid-related death occurring every 11 minutes, the opioid epidemic is devastating.

For many, this crisis is something that happens to other people. For me, it is personal. My son Brian's struggle with addiction began in high school. Over eight years, Brian battled his disease courageously, attending eight different treatment programs. On October 20, 2011, I was awakened in the middle of the night and told my son had just died. Perhaps more tragic, it was not addiction that took my son's life. On his last day alive, Brian researched suicide notes, wrote one of his own, lit a candle, and took his life. Alone.

When you lose a child, you spend countless hours revisiting what you could have done differently – the moments that may have made the difference. Shatterproof, like so many other philanthropic organizations, was born from profound loss and pain. For me, dedicating the remainder of my life to helping others avoid the tragedy my family had suffered started as a tribute to my son's life and has now grown to be a tribute to millions of Americans. Over the past seven years, I've had the opportunity to meet so many wonderful people, and together we have done so much to help so many. However, as effective as our accomplishments have been, all along, we've known that the true key to our mission, the ultimate change that must occur, lies in changing the way that people think about this disease. It lies in addressing and eliminating the stigma that causes so much shame, loneliness, and ultimately, so much tragedy.

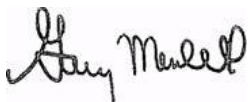
To this end, Shatterproof has exhaustively researched case studies and data from effective social-change movements, including those related to HIV/AIDS, marriage equality, and mental health, to create a comprehensive plan to engage people and institutions across our country in transforming how our society views the disease of addiction. Our research suggests that the stigma unjustly associated with this disease can be significantly reduced. And we built a plan to do so.

I often think about my son's last visit home, four months before he died. His last night at our house, we were sitting on the back porch talking, and the conversation turned to his addiction and stigma. Brian looked at me and said, "Dad, I wish that someday... someday people would understand that I'm not a bad person. I am a good person with a bad disease. And Dad, I am trying my hardest to be a good son." It's too late to bring my son back. But it's certainly not too late to save the next son, daughter, brother, or sister who suffers from addiction and has so much love to bring to their family.

This document has been built for those who are looking to learn how to best affect change to confront the pervasive stigma in this crisis. It includes a conceptual framework for combatting addiction stigma – and numerous, practical suggestions on how to impart that change. We focus specifically on the impact of stigma as it exacerbates the opioid epidemic, one of the most important components of the addiction crisis. Future publications will describe how Shatterproof's framework for combatting addiction stigma can be applied to other substances.

Maybe you're someone who's coping with addiction, or maybe you have a family member who is. Maybe you're a provider looking to improve the care you deliver, or maybe you're the CEO of a large company. Maybe you're someone who simply wants to help save lives. No matter who you are, this movement is built for you.

More information on how you and the organizations you represent can participate can be found at shatterproof.org/endstigma. Please read on, and please join us on the mission of our lives.



Gary Mendell
Founder and Chairman, Shatterproof

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Executive Summary

The Opioid Epidemic and Its Devastating Consequences: For 20.3 million adults living in America with a substance use disorder (SUD), the devastation caused by the disease can be crushing.¹ In 2018, more than 175,000 deaths in the U.S. were related to alcohol and other drugs – the third largest cause of death in the nation. Many of those deaths were from an opioid overdose. Fatal opioid overdoses in the U.S. were roughly 47,000 in 2018.² Recent estimates show as many as four million people in the U.S. living with opioid use disorder (OUD).³ And forty-six percent of Americans say the opioid crisis is impacting people like them.⁴ Not only does the crisis affect countless lives, but it also has a massive economic toll on society: estimates for the total cost to society due to the epidemic ranged from \$179 billion to \$696 billion in 2018 alone.^{5,6} These impacts are felt across a broad swath of society from health care to employers to the government.

Stigma Defined: There are four types of stigma Shatterproof has identified as priorities: public, structural, self, and the stigma against medications for opioid use disorder.

- **Public stigma** is society's negative attitudes towards a group of people, creating an environment where those addicted are discredited, feared, and isolated. These attitudes are informed by prejudices, discrimination, and stereotypes, which contribute to public stigma overall. In a recent survey, fewer than 20% of Americans said they were willing to associate closely with someone who is addicted to prescription opioids as a friend, colleague, or neighbor.⁷
- **Structural stigma** refers to systems-level discrimination, such as cultural norms, institutional practices as well as health care policies that constrain resources, opportunities, and wellbeing.⁸ It generates structures that explicitly or implicitly exclude a stigmatized population from participating in society.
- **Self-stigma** occurs when individuals internalize and accept negative stereotypes. It turns a "whole" person into someone who feels "broken" with little or no self-esteem.⁹
- **Stigma against medications for opioid use disorder:** despite their proven effectiveness, FDA-approved medications are thought by many to be "trading one addiction for another."¹⁰ As a result, these medications are under-prescribed, underutilized, overly restricted, often not covered by insurance, and even actively discouraged in some treatment or recovery settings.

Stigma's Impact on the Opioid Epidemic: Shatterproof identified nine commonly cited drivers of the epidemic: overprescribing, increased access to heroin and fentanyl, insufficient treatment capacity, gaps in evidence-based treatments, criminalization of SUD, insurance coverage disparities, social isolation, lack of help-seeking, and societal barriers to recovery. **Seven of the nine drivers of the opioid epidemic are either partially or entirely driven by stigma.**

Stigma related to addiction often overlaps and intensifies with other forms of stigma, discrimination, and bias, such as those related to race, class, gender, sexual orientation, occupation, and others. Most notably, the racialized policies of the War on Drugs led to sharp increases in mass incarceration that disproportionately affect Black and Latinx communities to this day. In addition, even though OUD rates are similar between Black people and white people, 35 white patients received a buprenorphine prescription for every one person of another race or ethnicity.

The Tragic Gap in Our Nation's Response: In response to the opioid epidemic, health care professionals, policy experts, advocates, and others in public health have generated solutions. Shatterproof has identified several of the largest responses to the epidemic, including improved prescribing practices, distribution of overdose-reversing drugs, expansion of medications for opioid use disorder, enhanced health care coverage, improved diversion for those leaving the criminal justice system, and others. **Significantly reducing all types of stigma is vital, yet no coordinated, national effort is directed at reducing stigma, leaving a tragic and enormous gap in our nation's response.**

Research and Findings: Recognizing this gap, Shatterproof launched a process with McKinsey and Company and The Public Good Projects to study 11 analogous social change movements, along with initiatives taken to reduce the stigma associated with substance use disorders and mental illness, to determine whether stigma could be reduced and if so, the most effective ways to do so.

Our research suggests that stigma can be reduced. We identified six factors from previous movements that we believe will be the most impactful in reducing addiction stigma.

- A well-funded, central actor or set of coordinated actors mobilized rapid change
- Key actions taken in three categories: educating, altering language, and changing policies.
- Educational initiatives implemented contact-based strategies (messaging between those with a stigmatized condition and those without it) to humanize the disease and emphasize treatment is effective
- Movements sequenced to first activate influential institutions and ultimately achieve mass adoption by the public
- Positive and negative incentives employed to change relevant stakeholder behavior
- Actions mobilized at both the "grassroots" and "grasstops"

Our Evidence-Informed Initiative: Shatterproof will be launching in the coming months a national movement to **End Addiction Stigma** to catalyze the change needed to reduce the stigma shattering so many families. As the central coordinating body, Shatterproof will deliver the following:

- A stakeholder map within each of the six systems we believe will have the largest impact: employers, health care, government, criminal justice, media and entertainment, and local communities. Those with lived experience and in recovery will be a crucial audience and partner across each of these systems and the stigma initiative as a whole. The maps will depict tiers of institutions based on estimated impact and influence to reducing the stigmas described above.
- Evidence-informed, implementable Action Plans tailored to each stakeholder in the six targeted systems. Action Plans will include two components: 1) Action Items which are specific activities focused on educating with contact-based strategies, adjusting language, and eliminating harmful policies; and 2) Implementation tools with "off-the-shelf" content to enable each Ally organization that implements stigma-reducing Action Plans to easily incorporate Action Items into their organization. These tools will include online education, language materials, and prototypes for policy change.

- Continual engagement of a core group of Partners and Coalition Members (roles defined on page 30 of the Appendix) who can generate an outsized impact upon the launch of the movement and help sustain momentum over an extended period by building a national coalition of organizations implementing its evidence-informed Action Plans and reaching a “tipping point” of Action Plan adoption, where tens of thousands of institutions are implementing evidence-informed Action Plans.
- Baseline results and recurring publication of an **Addiction Stigma Index**, a first-of-its-kind, comprehensive measurement system to address knowledge, attitudes, and behaviors related to stigma. The Index will measure the levels of public stigma, policy attitudes, and beliefs about addiction as a disease from the general public. It will also capture specific measures of self-stigma.
- A stakeholder certification process to publicly recognize institutions for implementing Action Items and leading innovation around additional actions.
- A well-orchestrated media plan, executed on national and local levels that promotes the launch of the movement, its progress and impact, and ways for individuals and institutions to get involved.

Although Shatterproof will help coordinate, it is essential to emphasize that the movement will be driven by hundreds and, eventually, hundreds of thousands of people and organizations. This is not about a few doing a lot, rather, many making small changes. And although anti-stigma efforts have not been coordinated nationally, many organizations have been working to reduce stigma related to addiction in their communities for decades. Shatterproof will look to bring together its resources with other organizations’ expertise to create meaningful and impactful partnerships.

A National Call to Action: This movement aims to significantly reduce the four types of stigma associated with SUD, with an immediate emphasis on OUD given its widespread impact. We invite you to join us to help launch and implement a national movement to **End Addiction Stigma** and significantly reduce the devastation of the addiction crisis in our country.



The Opioid Epidemic and Its Devastating Consequences

Impact of the opioid epidemic

In 2018, fatal opioid overdoses in the U.S. killed nearly 47,000 people¹¹ as the epidemic continues to take a massive toll. Although the human and economic costs of the epidemic should spur an overwhelming reaction, the current response to it in the United States has left many without evidence-based treatment and care.

While alcohol, tobacco, and other illicit drugs like cocaine or methamphetamine are widespread problems requiring their own responses from this movement, the opioid crisis has been uniquely impactful since the turn of the millennium. Compounding upon multiple decades of heroin epidemics from the mid-20th century, today's opioid epidemic has steadily intensified since 1999; since then, approximately 400,000 lives have been lost.¹² Annual opioid overdose deaths now exceed annual car crash deaths as the leading cause of accidental injury.^{13,14} And the epidemic is a primary contributor to the third straight year of declining U.S. life expectancy from 2014 to 2017 – the most prolonged period of decline in the U.S. in over a century.¹⁵

For the millions of Americans who have opioid use disorder,¹⁶ the impact can be overwhelming:

- Individuals with OUD are at greater risk of physical co-morbidities, and 64% of adults with OUD have a co-occurring mental illness¹⁷
- OUD is correlated with increased rates of infectious disease,¹⁸ homelessness,¹⁹ low educational attainment,²⁰ and unemployment²¹
- And tragically, many will die of an overdose or suicide²²

OUD is also costly to society. According to a recent study by the Society of Actuaries, the estimated cost of the opioid epidemic from 2015-2019 in the U.S. was \$819 billion, with the primary costs being seen in health care (\$270 billion), mortality (\$327 billion), and lost productivity (\$124 billion).²³ There is also widespread consensus that costs are rising. The same analysis suggests that if these trends continue for the next five years, it will cost society \$1 trillion over that period. Other estimates of the impact of the opioid epidemic are even higher. According to the Council of Economic Advisors (CEA), the estimated cost of the opioid epidemic was \$696 billion in 2018 alone or 3.4% of U.S. Gross Domestic Product.²⁴

Stigma Defined and Its Impact on the Opioid Epidemic

Defining stigma

Stigma is the “labeling, stereotyping, separation, status loss, and discrimination” of and against people with a particular social identity.²⁵ Academic research explains how stigma manifests in several forms:

- **Public stigma**, also known as social stigma, relates to society’s attitudes toward a group of people. Public stigma creates an environment in which individuals feel unwelcome, judged, blamed, feared, and rejected. It shapes how individuals see themselves in society and can perpetuate self-stigma. The public stigma around substance use is driven by stereotypes of those with OUD, such as their perceived dangerousness or “moral failing.”²⁶ The stigmas of moral failing have reappeared during this epidemic, suggesting addiction is a result of an individual’s irresponsibility. Higher levels of public stigma toward people with OUD are associated with greater support for punitive policies and lower support for public-health-oriented ones.^{27,28} Public stigma can even become codified in policy, exacerbating and creating structural stigma.²⁹ Finally, public stigma has a role in generating self-stigma as well as anticipated stigma driving those with the stigmatized condition to “expect others will devalue them based on their chronic illness,” amplifying the impact of public stigma, creating a perception that people will experience stigma in the future – even if that stigma were not to occur.³⁰
- **Structural stigma** occurs at the systems level through policies and practices. It generates structures, either explicitly or implicitly, which exclude a stigmatized population from being able to participate in society. This reduces capacity in our treatment system: a study conducted in Massachusetts found 24% of emergency, family, and internal medicine providers believe their practice would attract undesirable patients if they treated OUD.³¹ For those in the criminal justice system, less than 1% of prisons offer a key medication to treat OUD (Vivitrol),³² despite one study finding formerly incarcerated individuals being 40 times more likely to die of an opioid overdose in the first two weeks after being released compared to someone in the general population.³³ Other examples of structural stigma in health care include separating methadone clinics from the rest of health care providers, requiring additional waivers to prescribe MOUD, and inadequate insurance coverage.
- **Self-stigma** – which is also referred to as “internalized stigma” – refers to the process by which “stigmatized individuals accept societal stereotypes and consequently experience reduced self-esteem and self-efficacy.”³⁴ Those addicted often believe stereotypes others have for them (e.g., I am lazy, and this is my fault), causing them to lose self-respect and the ability to create change for themselves. Self-stigma – which can also manifest from anticipated stigma developed from those who have experienced public stigma – can discourage people from seeking treatment: among people who know they need substance use treatment but do not receive it, 15% cite not wanting their neighbors or community to have a negative opinion of them as a reason to not seek treatment, and 1 of 6 cite that it may have a negative effect on their job.³⁵ It can also exacerbate the social isolation generated by public stigma.

- The opioid crisis uniquely faces **stigma against medications for opioid use disorder (“MOUD”)**, an evidence-based treatment, across the three types of stigma described above; public, structural, and self-stigma. One common misconception about MOUD is that it involves “trading one addiction for another.” For example, many participants in a Pew Charitable Trust focus group saw patients in MOUD programs as “still ‘addicted’ or ‘not clean.’”³⁶ This misconception often exists in peer support groups, where medication stigma can hinder recovery.³⁷ Another study found local news coverage in states with high opioid overdose rates highlighted more negative than positive consequences of MOUD, and fewer than 40 percent of news stories about the medications mentioned they were underused.³⁸ Although the stigma against MOUD is not traditionally categorized as a fourth type of stigma in the academic literature (typically being described as a part of the other three stigmas), our research identified it as such a significant barrier that we believe identifying it separately is needed to allow the movement to track and prioritize this stigma to the same degree it addresses the others.

Community stories

“The stigma that surrounds substance use disorder is shattering. We ‘addicts,’ as society calls us, carry enough guilt and shame for our use and the pain it has caused. We need our communities to come together, get educated, de-stigmatize, and become shatterproof.”

Anne Emerson

Understanding the dynamic nature of stigma

Stigma related to addiction often overlaps and intensifies with other forms of stigma, discrimination, and bias, such as those related to race, class, gender, sexual orientation, occupation, and others. “Intersectional stigma” is the coming together of multiple stigmatized identities within a person.³⁹

- **Race and ethnicity:** There are significant racial disparities in experiences of stigma and treatment access for substance use disorders.⁴⁰ In previous drug use crises in the U.S, stigma was closely tied to racism. This trend has continued. Most notably, the racialized policies of the War on Drugs led to sharp increases in mass incarceration that disproportionately affect Black and Latinx communities to this day.⁴¹ Content analysis of news media coverage finds racial and socioeconomic discrepancies in characterization of opioid misuse, with more coverage and sympathetic portrayals of white individuals versus criminalized language used in coverage of Black and Latinx individuals. Even though OUD rates are similar for these groups (3.5% for Black individuals, 4.7% for white individuals), 35 white patients received a buprenorphine prescription for every patient of another race or ethnicity who received one.⁴² Further, racial/ethnic minority individuals are more likely to experience negative criminal legal outcomes for drug-related offenses. For example, an analysis of drug offenses in Texas demonstrated higher likelihood of negative legal dispositions for Black and Latino men than other groups, and longer prison sentences for Black men than other groups.⁴³ Finally, the most dramatic manifestation of the lack of attention focused on Black communities and opioids is the rate of increase of Black drug overdose deaths between 2015-2016: 40 percent compared to the overall population increase at 21 percent.⁴⁴
- **Sexual orientation:** LGBTQ+ individuals are at higher risk for substance use disorders and seek SUD treatment at a higher rate than non-LGBTQ+ individuals.⁴⁵ However, a significant number of counselors in treatment programs endorse negative attitudes towards LGBTQ+ clients.⁴⁶ LGBTQ+ individuals with SUD are more likely than their non-LGBTQ+ counterparts to have other co-occurring psychiatric disorders and are at increased risk for HIV, both of which are stigmatized.⁴⁷

The above are just two examples where intersectional stigma related to substance use can contribute to worse outcomes for marginalized populations. It is critical to understand and address the co-existence of these issues. Shatterproof will look to partner with the many organizations addressing these intersections, recognizing that, as we address stigma, we must inevitably address the numerous ways stigma augments and exacerbates other issues of discrimination, racism, and bias.

Key drivers of the opioid overdose epidemic

Our research identified several well-documented drivers of the opioid crisis in the United States. Stigma partially or entirely contributes to seven of these nine drivers.

- 1. Marketing of prescription opioids as non-addictive and resulting overprescribing:** Pharmaceutical companies marketed prescription opioids through the 1990s and 2000s, targeting physicians who treat chronic pain patients without highlighting the risks of addiction.⁴⁸ In 1999, the number of opioids prescribed was 180 morphine milligram equivalents (MME) per capita, which increased by 334% to 782 MME in 2010. Although this amount eventually declined, it was still more than 3 times higher in 2015 than in 1999.⁴⁹ By 2002, overdose deaths from prescription opioids had surpassed those from heroin and cocaine.⁵⁰ Drug overdose is now a leading cause of injury-related death in the U.S., and most of those deaths involve a prescription or illicit opioid.⁵¹
- 2. Increasing access to heroin and fentanyl:** Over the past decade, lower street prices and higher availability have driven the increased use of heroin, especially by people who misuse prescription opioids.⁵² Nearly 80% of people who use heroin reported using prescription opioids first.⁵³ People transitioning from prescription opioids to heroin report heroin is cheaper, more available, and provides an intensified euphoric effect.⁵⁴ The potency of illegally manufactured fentanyl, which is often mixed with heroin or cocaine, has also increased opioid overdose deaths related to synthetic opioids, which jumped 264% from 2012 to 2015 alone.⁵⁵
- 3. Insufficient treatment capacity:** One of the most important protocols for treating OUD is the use of three highly effective, FDA-approved medications: buprenorphine, methadone, and naltrexone. However, a recent study of 2,863 residential treatment facilities across the country found that 60% did not offer MOUD, and only 1% offered all three types of MOUD.⁵⁶ Though several states have expanded MOUD access in recent years, restrictive laws and regulations – especially pertaining to methadone facilities – may be closely linked to OUD-related stigma. As Dr. Yngvild Olsen, an addiction physician, noted, “There has been an underlying stigma against methadone for so many years that the industry naturally maintains a low profile... even now access to methadone is highly geographic. It depends on where you live.” This stigma may also contribute to a lack of certified addiction specialist physicians. According to the American Society for Addiction Medicine, there are 4,400 actively practicing certified addiction specialists, well below the estimated need (6,000).⁵⁷ This disparity is especially pronounced in rural areas, as nearly 50% of U.S. counties in 2017 did not have a single physician licensed to prescribe buprenorphine.⁵⁸ Furthermore, many prescribers with a DATA 2000 waiver (the certification process to prescribe buprenorphine) do not prescribe the medication at the amount the waiver allows.⁵⁹

Community stories

“Treatment can be hard to get. Many people are turned away because of inadequate insurance coverage, and that keeps them from seeking the treatment they need.”

Kacey Gibbs-Knight

4. **Gaps in evidence-based treatment:** In addition to limited treatment capacity, there are meaningful gaps – including limited quality measurement, limited reimbursement, and insufficient medical education – that help reinforce the separation of SUD treatment from the mainstream medical system and restrict the availability of evidence-based treatment. Currently, there are very few quality measures available to the public to determine which treatment will be most effective. Furthermore, many health care providers have not received the training required to provide evidence-based treatments for substance use disorders. For example, in a survey of physicians and nurse practitioners, only one in four respondents had received addiction training during medical education, a startling statistic relative to other chronic medical conditions.⁶⁰ Perhaps as a result of limited training, medical trainees and providers often hold negative attitudes toward individuals with SUD.
5. **Criminalization of people with SUD:** Approximately 137,000 people are in state prisons or jails in the United States on any given day for drug possession, often for possessing small quantities of illicit drugs.⁶¹ Yet punitive approaches have not been shown to significantly reduce drug use. Instead, people with OUD involved in the criminal justice system are rarely able to access medically-appropriate care for their disease and are commonly forced into withdrawal.⁶² More than half of those in state prisons and two-thirds of people awaiting sentencing in jail exhibit problematic substance use or meet the criteria for SUD.⁶³ Less than 1% of prisons offer a key medication for OUD (Vivitrol).⁶⁴ Some formerly incarcerated individuals are 40 times more likely to die of an opioid overdose in the first two weeks after release from prison than someone in the general population.⁶⁵ Additionally, harsh penalties for drug use and possession have been in existence for decades, with an especially strong effect on Black and Latinx communities. Racial and ethnic minorities are significantly more likely to be arrested and receive stronger sentences for drug-related offenses.⁶⁶ ⁶⁷ Since laws and judicial proceedings can reflect societal norms, stigma may also contribute to the criminalization of substance use and punitive policies.⁶⁸
6. **Health care coverage:** Historically, most substance use services have been delivered outside of mainstream medical care in the United States. Attitudes and stigma about substance use disorders (e.g., a belief that it is a failure of will rather than a medical condition) may drive this separation, which can be associated with reduced access, coverage, and use of comprehensive approaches to care.⁶⁹ The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) requires health insurance plans to provide the same level of benefits for mental and substance use treatment as they would for physical health care services. Although this has generated change, some insurance companies, health plan issuers, and employers continue to design coverage plans that impose burdensome financial, quantitative, and non-quantitative requirements on SUD treatment relative to other types of health care.⁷⁰ Due to the significant amount of work required to adapt to changes from the implementation of the Affordable Care Act, it has been difficult for organizations to dedicate the needed attention to apply and enforce all areas of the MHPAEA consistently. Further, while not necessarily non-compliant, many state Medicaid programs require prior authorization for some buprenorphine-naloxone medications, a significant barrier inhibiting access.⁷¹ In many states, Medicaid also does not cover residential treatment.⁷² Only 60% of employer-sponsored health plans cover MOUD.⁷³

7. **Shame and social isolation:** Addiction can reduce one's feeling of wholeness. It makes people feel broken and diminishes self-esteem. In a recent survey, fewer than 20% of Americans were willing to associate as a friend, colleague, or neighbor with someone who is addicted to prescription opioids, 44% of respondents believed that OUD indicates a lack of willpower and 32% believed a character defect or bad parenting caused OUD.⁷⁴ Public stigma can be internalized, with a serious impact on an individual's recovery, including treatment dropout and reduced social aptitude.⁷⁵ This self-stigma extends beyond guilt, making people feel deep shame about themselves. Stigmatizing language can perpetuate the social distance between people with OUD and their communities. "Anticipated stigma" also plays a role in shame and social isolation that limits the effectiveness of recovery: people are less likely to want to make new friends, reach out to colleagues, and connect with their family as they believe those people will treat them poorly if they learn of their chronic medical disease.
8. **Individuals not seeking help for their opioid use disorder:** According to the National Survey on Drug Use and Health, though an estimated two million individuals meet the diagnostic criteria for OUD, only 500,000 of those met DSM clinical criteria and received specialized treatment. The actual gap in treatment is potentially more pronounced. One estimate from Milliman suggests as many as four million people have OUD.⁷⁶ This is well below treatment rates for other chronic diseases like hypertension and diabetes, which are near 75%⁷⁷ and 88%⁷⁸, respectively. One of the reasons so few are treated is anticipated stigma. For example, 15% of people who knew they needed treatment, but did not receive it at a specialty facility, felt that getting treatment would cause their neighbors or community to have a negative opinion of them. And approximately 1 in 6 people felt getting treatment would harm their job.⁷⁹
9. **Other societal barriers to recovery:** Individuals with OUD face many barriers and forms of structural stigma that make it more difficult to secure housing, employment, and education when in treatment and recovery.⁸⁰ For example, some federal policies allow housing agencies to prohibit those with a history of drug use from receiving assistance.⁸¹ And, until recently, federal funding for OUD lagged far behind other chronic conditions such as cancer and HIV.⁸²



The Tragic Gap in Our Nation's Response

Our nation's response

To respond to the opioid epidemic, numerous institutions, including our federal government, state governments, philanthropic institutions, and hundreds – if not thousands – of others have launched efforts to combat the epidemic, including but not limited to the following:

Improved public health surveillance of the epidemic: The Centers for Disease Control and Prevention (CDC) received \$475 million in FY2019 for opioid overdose prevention and surveillance. The CDC's Enhanced State Opioid Overdose Surveillance (ESOOS) program aims to improve how quickly and comprehensively opioid overdoses are reported.⁸³ ESOOS currently funds 32 states and D.C. and has helped states identify patterns in fentanyl and carfentanil deaths.⁸⁴

Increased funding for opioid use disorder research: The National Institutes of Health HEAL Initiative is a trans-agency effort to fund science-based solutions to the opioid epidemic. The National Institute on Drug Abuse is coordinating seven HEAL projects across the country, covering a range of topics that include at-risk adolescents and OUD treatment in criminal justice settings.⁸⁵ Academic institutions are also increasing their research in OUD. For example, the Johns Hopkins Bloomberg School of Public Health's Center for Mental Health and Addiction Policy Research has published widely on opioid use and studies the role of communication in public views about mental illness and substance use disorder.⁸⁶

Increased efforts to reduce the importation of illicit drugs into the U.S.: The U.S. has held discussions with China and Mexico to stem the flow of illegal fentanyl and heroin into the country. Due to these discussions, China expanded its list of controlled synthetic chemicals to include six fentanyl products.⁸⁷ Recent control efforts have also targeted disrupting internet sales and interdiction.⁸⁸ The Department of Justice and Drug Enforcement Administration established Operation Synthetic Opioid Surge to reduce the supply of synthetic opioids in high-impact areas. States and local governments have also increased their efforts. For example, in Ohio, the criminal justice system and the highway patrol have coordinated to intercept drugs and share data on drug-trafficking through the Ohio Incident Based Reporting System.

Creation of prescribing guidelines, policies, and monitoring programs: In 2016, the CDC issued a Guideline for Prescribing Opioids for Chronic Pain, with information for prescribers on safe opioid prescribing. SAMHSA also created the Providers Clinical Support System, a program to train primary care providers in evidence-based practices for OUD through free resources such as webinars. Professional associations like the American Medical Association (AMA) have convened task forces like the AMA Opioid Task Force which have developed policy recommendations for health care professionals and policymakers including the "2019 State Roadmap Response" to the opioid crisis. Several states have enacted anti-"doctor shopping" laws and some states also require that physicians receive postgraduate training in opioid prescribing, SUD, and/or related topics.⁸⁹ As of 2020, most states have a Prescription Drug Monitoring Program, an electronic database tracking controlled substance prescriptions dispensed in a state.⁹⁰ Within the private sector, some workers' compensation and health care insurers have also implemented opioid management initiatives to prevent over-prescribing.

Increased availability of non-opioid alternatives to treat chronic pain: Alternatives to treating chronic pain have long existed but have been underutilized. In 2019, Medicare announced it would be exploring acupuncture coverage for chronic pain. Agencies like SAMHSA have released resources on alternative approaches to chronic pain that include a more holistic approach to health such as physical therapy, therapeutic massage, chiropractic treatment, meditation, and yoga. Research suggests mindfulness may be effective at addressing chronic pain and opioid use, such as the University of Utah's Mindfulness-Oriented Recovery Enhancement program, an eight-week program to ease pain and craving.

Increased access to naloxone and other harm reduction strategies: Naloxone, a lifesaving overdose-reversal medication, is increasingly available across different settings. Points of naloxone distribution and overdose education include community-based organizations, social service agencies, and various health care providers. For example, the City of Philadelphia partners with local nonprofit Prevention Point to distribute free naloxone kits and conduct outreach to communities most affected by drug use. Many states and municipalities also have "blanket" prescriptions, so those wanting naloxone can receive it at their pharmacy at little or no cost. As a result, naloxone prescriptions have increased since 2012, doubling from 2017 to 2018 alone.⁹¹ Naloxone is often provided with other harm reduction services, which reduce the negative outcomes associated with substance use. For example, syringe exchange programs (SEPs), which distribute clean syringes to people who inject drugs, have reduced HIV and Hepatitis C transmission.⁹² States have also passed Good Samaritan Laws to offer legal protection to people seeking emergency help for an overdose.⁹³ Given the scale of the current epidemic, more states have introduced or passed legislation legalizing SEPs. Several others have also considered opening supervised injection facilities, where people can use illicit drugs under medical supervision.

Increased investment in broad efforts and targeted initiatives, including in evidence-based treatment: The last two years have seen a surge in federal funding for OUD, though most funding is short term, non-guaranteed,⁹⁴ and targeted at areas other than stigma. As the primary federal agency providing funds for the epidemic, SAMHSA administers two primary opioid grant programs: State Targeted Response (STR) and State Opioid Response (SOR). No less than 80% of STR funds must fund treatment, and SOR programs must include the entire continuum of care, prevention, treatment, and recovery, as well as incorporate access to medications.⁹⁵ Shatterproof established its National Treatment Quality Initiatives to engage stakeholders across systems to treat SUD with the same efficacy as other chronic diseases. Launching in 2020, ATLAS® is Shatterproof's free web-based platform to help patients and families identify highly-quality SUD treatment. Based on the Shatterproof National Principles of Care, ATLAS® (Addiction Treatment Locator, Analysis, and Standards Tool) assesses SUD treatment facilities across all levels of care and types of treatment. Web-users will be able to compare facilities and filter by select criteria.

Increased efforts to eliminate step therapies, prior authorization, and other utilization management techniques for MOUD: Historically, OUD treatment is provided by specialty programs offering time-limited and largely non-standardized treatment. Most programs are geographically, financially, and culturally separate from the health care system. Accordingly, insurance policies and provisions for treatment for OUD vary from those of other chronic diseases. For example, a prior authorization requirement can prevent a patient from starting treatment, as several days pass between their visit and when their insurance company approves coverage of treatment. During this time, patients "may lose interest, lose access to their doctor... or even die from an overdose."⁹⁶ In 2018, Pennsylvania announced an agreement with seven major health insurance companies to remove prior-authorization requirements for MOUD, prompting the AMA to encourage payers in all states to do the same.⁹⁷

Increased investment in recovery and wrap-around services for those with OUD: Individuals in recovery often struggle to maintain stability in their lives, and social safety nets are often unaccommodating to those with a history of substance use. In 2016, the Department of Health and Human Services was funded via the Comprehensive Addiction and Recovery Act to provide grant funding to states, community recovery organizations, and retailers to expand access to naloxone and other

FDA approved emergency treatments that prevent overdose.⁹⁸ Similar investments are being made by states. For example, in Pennsylvania, the Department of Drug and Alcohol Programs is administering \$15 million to help people with OUD pay rent and other housing-related costs like utilities.⁹⁹ The Laura and John Arnold Foundation's \$800,000 grant to researchers from Brown University and Rhode Island Hospital is supporting the first-ever trial of a peer-based recovery intervention for patients at high risk of overdose.¹⁰⁰

Despite these commendable efforts, our society is falling short of what is needed to combat the crisis effectively. Of the nine drivers of the epidemic, many are at least partially driven or exacerbated by stigma: the criminalization of people with SUD, insufficient treatment capacity, gaps in evidence-based treatment, health insurance coverage disparities, shame and isolation, individuals not seeking help, and social and structural barriers to recovery. Yet, stigma has been largely overlooked. Our nation requires a robust and coordinated national effort to address the stigma surrounding addiction.



Folks often ask me what the biggest killer is out there... is it obesity? Is it smoking? I think the biggest killer out there is stigma. Stigma keeps people in the shadows. Stigma keeps people from coming forward and asking for help. Stigma keeps families from admitting that there is a problem.



VADM Jerome M. Adams, U.S. Surgeon General

Quote from a lecture provided by the Surgeon General at UC Davis Medical School on June 24, 2019

Stigma and the opioid epidemic – the cost in lives and the cost to society

It is difficult to quantify the impact of reducing stigma for OUD. However, to see what might be accomplished, one analog is to look at the outcomes for individuals with other chronic diseases.

In 2019, the American Society of Addiction Medicine redefined their definition of addiction as "...a treatable, chronic medical disease involving complex interactions among brain circuits, genetics, the environment, and an individual's life experiences. People with addiction use substances or engage in behaviors that become compulsive and often continue despite harmful consequences."¹⁰¹ This also makes comparisons between OUD and chronic diseases like diabetes easier to highlight in the following ways:

- **Genetic vulnerabilities and behavioral factors:** Lifestyle and personal choices, as well as environmental factors, contribute to OUD and other chronic diseases. And though estimates of the heritability of chronic diseases range widely, there is a consensus that genetics is also a major contributing factor. OUD is no different, as roughly 40 to 60% of the vulnerability to addiction can be attributed to genetic influence.¹⁰²

- **High rates of co-morbidities:** OUD has high rates of co-morbidities, like many chronic diseases, which makes it complicated to treat. For example, one study found that nearly 40% of adults with hypertension have three or more co-morbidities.¹⁰³ Approximately 60% of those with OUD have at least one other chronic medical condition.¹⁰⁴
- **Managed, not cured, through medication:** Both OUD and chronic diseases (i.e., arthritis) are mostly managed, not cured, in part through medication, and often over long periods. For such diseases, individuals are typically able to live a healthy and productive life when they consistently receive evidence-based treatment.
- **High rates of non-adherence:** Many individuals with OUD struggle to adhere to their medications, even when their treatment plan is evidence-based.¹⁰⁵ But that is also true of other chronic diseases. Research suggests roughly a third of people with diabetes do not adhere to their physician-recommended treatment protocol.¹⁰⁶

Despite these similarities, there is a gap between rates of treatment for OUD compared to other chronic diseases, illustrating the harmful role stigma can play in partially contributing to this gap.



Research and Findings

Recognizing this gap in our nation's response, and the immense societal and economic cost of the epidemic, **Shatterproof, McKinsey and Company, and The Public Good Projects** studied analogous social change movements, along with initiatives taken to reduce the stigma associated with mental illness, to determine whether stigma could be significantly reduced and if so, the most effective ways to do so. In our research, we have:

- **Assessed 11 analogous social-change movements to understand how they shifted behaviors:** tobacco smoking, HIV/AIDS, sexual assault, teenage drug use, gender equality, obesity, mental health, cancer, substance use, intellectual disability, and same-sex marriage
- **Reviewed over 100 publications and reports** related to stigma reduction and social change
- **Held interviews with over 50 experts** in social change, mental health, and SUD, including government officials, private-sector leaders, nonprofit executives, academics/researchers, and communications specialists

From this extensive research, we concluded that a national effort to dramatically reduce stigma is not only vital but can be successful. Despite unfavorable odds, other social movements have achieved meaningful progress with the right resources and engagement.

Six key enabling factors for success

Our review of other social movements identified several factors present in many successful movements. We distilled this list to six, which we believe will have an outsized impact in reducing addiction stigma.

Factor #1: A well-funded, central actor or set of coordinated actors mobilized rapid change

Successful social change efforts can accelerate current momentum by bringing together a wide range of stakeholders across local, state, and national contexts, outlining a list of priority actions, and establishing a strong center of gravity to coordinate efforts and measure impact.

Implications for strategy:

- Establish a central organization that will coordinate progress nationally
- Design, continuously improve and disseminate Action Plans for stigma reduction
- Mobilize and coordinate institutions and influencers working to reduce stigma
- Conduct research, develop a comprehensive measurement system and regularly report on stigma-related knowledge, attitudes and behaviors
- Focus on sustained, large-scale commitment and resourcing
- Act as a thought leader to gather and assess resources and information

Example: Campaign for Tobacco Free Kids acts as an aggregator and synthesizer of information for the anti-tobacco effort in the U.S. by developing and sharing policy perspectives and action plans with national, state, and local entities. Through coordination and prioritization, the anti-tobacco effort has been able to achieve widespread public education on the danger of smoking, cigarette tax increases, smoke-free policies, and marketing and sales restrictions. Collectively, the impact of the effort has been significant – since the organization was established in 1996, the US has seen a 70% decrease in youth smoking and a 30% decrease in smoking by adults.¹⁰⁷

Factor #2: Key actions taken in three categories: educating, altering language, and changing policies

Stigma reduction efforts are often propelled by public education campaigns. But actions, including those by influential people or institutions, are more powerful in changing how people think and feel. Successful social change campaigns have included the mass adoption of three types of actions: educating individuals, removing stigmatizing language, and modifying policies. The positive link between knowledge, attitudes, and behaviors, including toward stigmatized groups, has been well-studied.¹⁰⁸

- **Education:** Education campaigns can provide information (i.e., treatment is effective) and create an understanding that this disease can occur to any of “us,” not “them.” Previous campaigns were highly effective when the messaging and approach had previously proven to achieve the desired objectives.
- **Language change:** Words influence how we think and act. Research shows that the language we use can cue specific biases toward individuals struggling with substance use. These biases, conscious or subconscious, influence how we behave and the policies we enact. Changing language is critical to changing behavior.
- **Modification of policies:** For policies, those that required change were often outlined in specific action plans, and some movements had a mechanism to measure a change in policies.

Implications for strategy:

- Provide key stakeholders with Action Items to educate, alter their language, and change policies
- Action Items should be supported with easy to implement, “off-the-shelf” implementation tools
- Evaluate the impact of each of the Action Items to continuously improve messaging to ensure it results in the desired changes in knowledge, attitude, and behavior purposely being measured in the **Addiction Stigma Index** for maximum impact
- Coordinate with broader efforts to maximize the impact

Factor #3: Educational initiatives implemented contact-based strategies (messaging between those with a stigmatized condition and those without it) to humanize the disease and emphasize treatment is effective



Further complicating people’s willingness to seek treatment is the stigma that for too long has been attached to SUD. We need to continue to educate the public that addiction is a chronic disease and not the reflection of a personal or family failing. Those we serve need to understand that addiction can be treated; that recovery is possible.



James W. Carroll, Director, White House Office of National Drug Control Policy

“Turning the Tide – Improving Access to Addiction Care and Overcoming Obstacles to Parity” event from September 9, 2019

Example: Special Olympics launched a successful movement to eliminate the use of the terms “retard” or “retarded” for individuals with intellectual disabilities. **Special Olympics** mobilized a language change campaign in response to the 2008 release of the film “Tropic Thunder,” which had a marketing tagline of “Never go full retard.”¹⁰⁹ **Special Olympics** organized protests around the film’s premiere, created a website where individuals could take a personal pledge for language change, and designated a specific day of awareness, Spread the Word to End the Word Day. They began organizing teachable moments, in which high-profile individuals used the negative terminology, publicly addressing and often pulling in the voices of self-advocates who explained how the term(s) impacted their feelings about themselves. Over 200 organizations signed on to support the campaign and advocate for state governments to make official language changes. In subsequent years, several major policy changes were enacted.¹¹⁰

People without stigmatized conditions often have little meaningful contact with those who do, fostering discomfort and fear toward stigmatized groups. By highlighting stories of recovery, effective stigma reduction efforts reduce the shame/judgment towards SUD diagnosis, treatment, and recovery. They also reduce social distance and create positive contact.

Research has demonstrated the efficacy of contact-based education strategies. It has also shown that using personal narratives to engage audiences has the potential to increase public support for policies benefiting people with SUD¹¹¹ and that emphasizing external factors while acknowledging personal responsibility may also reduce stigma around prescription opioid use disorder.¹¹² Such contact can happen in person or via digital channels and are effective when combined with educational interventions.¹¹³ These efforts should also incorporate education on the effectiveness of treatment. For example, studies have found a link between awareness of antiretroviral treatment and the level of stigma, particularly self-stigma, in communities.¹¹⁴ Similar approaches can address the strong stigma against medications for opioid use disorder (MOUD).¹¹⁵

Implications for strategy:

- Use contact-based education efforts to provide context and inform people about the effectiveness of treatment; use tested prompts to promote public health narratives and evaluate their impact on stigma reduction
- Showcase real stories of individuals who struggle with addiction across a range of demographic categories: their hopes and dreams, friends and family, and paths to recovery
- Make recovery stories easily available on a searchable platform for stakeholders to select and share which stories resonate most among their targeted demographic group
- Place individuals and institutions directly impacted by stigma at the center of advocacy and mobilization efforts
- Expand the availability of MOUD and other components of treatment and emphasize the evidence behind their effectiveness

Factor #4: Movements sequenced to first activate influential institutions and ultimately achieve mass adoption by the public

Though successful movements ultimately achieve widespread support from the population, they often begin by targeting a core set of influential actors. Maximizing the impact of their impact can spark a movement and lead to a tipping point, which will then change the attitudes and behaviors of millions of individuals. Influential institutions can either be large and generate their influence via their reach (i.e., major corporations who can change internal policies affecting tens of thousands of people), or they can be effective due to their niche and voice (i.e., advocacy groups with people who have lived experiences).

Example: The Rape, Abuse & Incest National Network (RAINN), a large US anti-sexual violence organization, helped shift public opinion on domestic abuse by communicating, “sexual assault can happen to anyone.”

RAINN timed a campaign of survivors sharing stories to coincide with a legislative effort to pass the Debbie Smith Act, which provides government grants to test backlogged DNA samples used to convict sexual assault perpetrators. It was Congressional testimony of Debbie Smith, a sexual assault survivor who found justice through DNA evidence, that helped turned the tide. As one advocate noted, “humanizing the victim, so the public could develop empathy was critical... only once people could put a face on issue that they could empathize with, that is what led them to be outraged.”¹¹⁶

Example: Although cancer has been addressed within mainstream society for decades, historically, it was highly stigmatized. At one point, “patients with cancer often were told that, psychologically, they had caused their own cancer.”¹¹⁷ **The American Cancer Society (ACS)** was founded in 1913 when a cancer diagnosis would result in near-certain death, and patients often did not tell their friends and families of their diagnosis. **The ACS** began by publishing notes directed at professional journals and recruiting doctors to help educate the public. In the 1930s and 1940s, they recruited The Women’s Field Army, which grew from 15,000 people active in cancer control in 1935 to ~150,000 people in 1938.¹¹⁸ In the 1960s and 1970s, with the development of the Surgeon General’s report that linked smoking and cancer and the passage of the National Cancer Act in 1971, the **ACS’s** advocacy expanded to wider audiences.

Implications for strategy:

- Identify critical systems, institutions, and influencers whose actions can spark a movement
- Focus resources on influential individuals and institutions and strategically broaden efforts over several years
- Organize around the notion of “mass adoption” and an eventual “tipping point” by mobilizing a committed minority of enough influence to unlock widespread change

Factor #5: Positive and negative incentives employed to change relevant stakeholder behavior

Acknowledging and rewarding positive behavior is a powerful motivator. However, other successful social change movements have also called out examples of entities and actions that undercut their efforts.

Implications for strategy:

- Commit to transparent and regular reporting on actions taken to address stigma
- Develop a “report card” or certification process recognizing highest performing allies, including distinguishing among different levels of organizational commitment to change
- Publicly highlight negative behavior that contributes to and exacerbates stigma

Example: The Human Rights Campaign (HRC)

Foundation uses the “sticks-and-carrots” approach in its Corporate Equality Index (CEI), which measures LGBTQ+ policies in the workplace and encourages shifts in employer protections from sexual orientation and gender identity discrimination. When the CEI launched in 2002, only 5% of rated businesses included gender identity in their non-discrimination policy; by 2019, that same figure had increased to 97% of rated organizations.¹¹⁹ Each year, the CEI recognizes businesses that earn perfect ratings as the “Best Place to Work for LGBTQ Equality.” As the “stick,” the CEI exerts significant public pressure on poor performers via benchmarking. Over time, **HRC** has also increased requirements for perfect scores, such as those related to transgender-inclusive health care coverage. The CEI grew from assessing 319 companies in 2002 to 1,028 organizations in 2019, including the Fortune 500’s largest publicly traded companies, and has contributed to the implementation of LGBTQ+ friendly policies in workplaces across the country.¹²⁰



Factor #6: Actions mobilized at both the “grassroots” and “grasstops”

Social change movements have coordinated action at the state and national levels, with local communities, including individuals impacted by stigma, playing a critical role in advocacy and mobilization. These movements work across systems to bring together governments, public health experts, faith-based organizations, and others to discuss solutions and serve as messengers for the broader movement.

Implications for strategy:

- Focus resources at the grassroots level to help mobilize local groups behind a unified message
- Invest in community institutions (e.g., recovery organizations, faith-based organizations, and community foundations) as symbols of change and recovery
- Test effectiveness of messaging in the local, state, and national contexts to ensure it resonates with stakeholder groups and does not result in unintended negative consequences

Example: The HIV/AIDS movement in the U.S. operated at the local, state, and national levels to achieve its goals. This included:

- *High levels of civic engagement and community support.* Local leaders garnered support from educators, the medical community, the private sector, and the public. As one social change expert noted, “There was not a single campaign or strategy that brought change... To the extent you can foster inclusion community to community, that is the answer.”
- *Activation of those impacted at a micro-level:* Individuals with HIV/AIDS organized numerous grassroots opportunities across the country where they openly shared their stories. For example, AIDS Walk Boston launched in 1986 and grew to over 12,000 participants grossing \$1 million by 1988.
- *Messaging aligned across stakeholder groups.* The National Association of People with AIDS Speakers Bureau held training for every person with AIDS who was willing to speak out, ensuring consistent messaging aligned with the broader efforts at every level.

Community stories

“Unlike me, who was fortunate enough to have top-notch insurance, most [people] cannot access recovery resources that are helpful or supportive. What’s more, many survivors are stigmatized by society and sometimes their own loved ones for their struggles with substance use. In my field, ‘alcoholic’ or ‘addict’ is often synonymous with ‘abuser.’ I want to work to end that stigma and normalize recovery for these survivors.”

Audrey Comber

Our Evidence-Informed Movement

Key Initiatives and Deliverables

As the central coordinating body, Shatterproof will deliver the following:

I. A stakeholder map within each of the six systems we believe will have the largest impact: employers, health care, government, criminal justice, media and entertainment, and local communities. Those with lived experience and in recovery will be a crucial audience and partner across each of these systems and the stigma initiative as a whole. The maps will depict tiers of institutions based on estimated impact and influence to reducing the stigma identified in the **Addiction Stigma Index**.

High-Level Deliverables:

- ✓ Stakeholder maps by system (employers; health care; government, communities, criminal justice, and media/entertainment) providing the following insight: 1) General guidance on how organizations will be phased into the movement to **End Addiction Stigma** 2) Prioritization of organizations based on system-specific criteria 3) Geographic demonstration of areas that will generate the greatest amount of impact.

Community stories

"I felt so guilty and ashamed of the person I was. It was an uphill battle trying to love myself in the aftermath of all of it. Still, it was necessary for me to try to pick myself up from the ashes."

Vie Oneiro

II. Evidence-informed, implementable Action Plans tailored to each stakeholder in the six targeted systems. Action Plans will include two components: 1) Action Items which are specific activities focused on educating with contact-based strategies, adjusting language, and eliminating harmful policies; and 2) Implementation tools with "off-the-shelf" content to enable each Ally (detailed definition of Allies provided on page 30) to easily incorporate Action Items into their organization. These will include online education, language materials, and prototypes for policy change.

High-Level Deliverables:

- ✓ Action Plans to create evidence-informed change across systems and stakeholders
- ✓ Implementation tools that provide stakeholders i) tailored information on how to incorporate the Action Items into their organization, ii) examples of case studies and best practices, and iii) a list of qualifying actions for certification
- ✓ Interactive, customizable platforms to educate through the sharing of stories
- ✓ Online, self-paced, mobile-enabled educational program (Just Five©)
- ✓ Evidence-based, comprehensive Language Guide
- ✓ Stakeholder-specific content and materials

III. Continual engagement of a core group of Partners and Coalition Members

(roles defined on page 30 of the Appendix) who can generate an outsized impact upon the launch of the movement and help sustain momentum over an extended period by building a national coalition of organizations implementing its evidence-informed Action Plans and reaching a “tipping point” of Action Plan adoption, where thousands of institutions are implementing evidence-informed Action Plans.

High-Level Deliverables:

- ✓ Development of stakeholder map to generate a targeted list of priority Partners and Coalition Members
- ✓ Development of engagement strategy for each stakeholder system
- ✓ List of ongoing, collaborative opportunities (e.g., convenings, webinars) for Partners and Allies to engage with the movement following their initial engagement

IV. Baseline results and recurring publication of an **Addiction Stigma Index**, a first-of-its-kind, comprehensive measurement system to address knowledge, attitudes, and behaviors related to stigma. This Index will measure the levels of public stigma, policy attitudes, and beliefs about addiction as a disease from the general public. It will also capture specific measures of self-stigma.

The Index has been thoughtfully designed to be an indicator of stigma’s role in reducing morbidity, mortality, and societal cost. Shatterproof and experts will analyze the survey results and draft a report that will be widely disseminated. Based on the survey’s results, as well as supplemental survey panels, we will conduct in-depth analyses of the following:

- **Public stigma.** Key stigma indicators such as social distance and feelings towards those using substances.
- **Self-stigma.** The survey will oversample those with lived experience (including those in recovery and those currently misusing substances) to understand the level of the stigma they internalize and how stigma impacts their life.
- **Medications for opioid use disorder (MOUD).** Research has identified stigma around MOUD as a key barrier to its use. The survey has been designed to provide an understanding of the knowledge and attitudes of those with OUD as well as the general public of the effectiveness of different forms of treatment.
- **Geography.** We will compare responses by states to help inform decision-making by stakeholders such as state governments and employers who are in specific regions.

High-Level Deliverables:

- ✓ **Addiction Stigma Index** measuring the current state of stigma and then on a recurring basis.
- ✓ Research plan to inform the continual improvement of the Index.

V. A stakeholder **certification process** to publicly recognize institutions for implementing Action Items and leading innovation around additional actions.

The movement will track the rates of Action Plan adoption for stakeholders who opt into a certification process. The certification process will be conducted annually using a rubric of levels of achievement for stakeholders and processes to enable yearly improvement. Certified organizations will receive recognition signaling to society, employees, and others that they are best-in-class organizations responding to the opioid epidemic. The certification process will balance both positive incentives for joining the program with mechanisms to prevent negative behavior.

This information will be paired with data from the **Addiction Stigma Index** and ongoing research for a 360-degree view of progress against stigma. To give all stakeholders a voice on the movement's progress, supporters will also have ample opportunity to provide feedback on improving the movement through webinars, convenings, and more. The movement will also target additional opportunities for engagement, thought leadership, and research. Opportunities may include partnerships with academic institutions to fund research, publishing white papers, distributing best practices, and speaking or sponsoring convenings related to the study of reducing stigma and its impact on society.

High-Level Deliverables:

- ✓ Annual movement scorecard tracking actions of stakeholders
- ✓ Issuances of press releases and other external communications recognizing leading organizations
- ✓ Public engagement opportunities (i.e., webinars) for leading organizations to share how they are creating change within their community
- ✓ Detailed research plans – and corresponding funding – to evaluate new, innovative stigma reduction interventions

VI. A well-orchestrated **media plan**, executed on national and local levels that promotes the launch of the movement, its progress and impact, and ways for individuals and institutions to get involved.

High-Level Deliverables:

- ✓ White Paper outlining impact of stigma on the drivers of the epidemic to be released during the launch event
- ✓ A well-orchestrated series of launch events publicizing the leadership of the Founding Partners and bringing national attention to the issue of stigma
- ✓ Continual announcements of organizations joining the movement with additional information provided to the public regarding progress (i.e., using results from the **Addiction Stigma Index**)
- ✓ Opinion pieces, webinars, and other reach and relevance opportunities enabling the public to better understand stigma and hear from those with lived experience and experts in the field
- ✓ Outreach and marketing plans including key events

A National Call to Action

With a death from opioid-related overdoses every 11 minutes, the human toll of the opioid crisis is undeniable. The COVID-19 pandemic and ensuing economic downturn is exacerbating this crisis even further, increasing the urgency to act now. Based on extensive interviews, literature reviews, and case studies, we believe that effectively addressing stigma is a critical component of combatting this crisis and reducing the human suffering that results from it — and every individual and institution in the U.S. has an important role to play. The publication of this paper marks an important initial milestone for Shatterproof in our journey to address the stigma surrounding addiction on a national scale. Over the coming months, we will meet with institutions and influencers across the country to share the Action Plans we have developed, with the hope that you will join us in adopting these practices to reduce stigma.

Looking ahead, along with our Founding Partners, we will be announcing the movement to End Addiction Stigma. Shatterproof will play a critical role in coordinating action and measuring impact across the wide variety of efforts that are planned or already underway. **Please join us on this journey.** We hope that this paper will serve to push forward the dialogue among the vast number of stakeholders working to combat the opioid crisis and become the backbone of a national effort to address stigma's role in perpetuating the epidemic.

Acknowledgments

We would like to thank McKinsey & Company for their generous contribution to this project. McKinsey offered pro-bono support from day one and played a critical role in developing the strategy. Their research and logistic support were superb, and this report would not have been possible without their time and energy. They continue to provide ongoing support for our team and full-time staff which has gone well beyond our original expectation for their support.

We would like to thank The Public Good Projects for providing crucial thought partnership and expertise on numerous portions of this report. PGP's support in developing this campaign has been exceptional. We appreciate their invaluable guidance in helping us develop and implement our story sharing campaign.

We would also like to acknowledge the generous support and guidance offered by the dozens of experts who answered our questions and offered excellent advice. Their collective knowledge of previous social movements, the opioid epidemic, and stigma more broadly was integral to developing our key learnings and success factors. Their advice significantly altered and guided the development of this plan, and their impact will be felt across the movement to **End Addiction Stigma.**

Acknowledgments – National Academy of Medicine Review

The National Academy of Medicine’s Action Collaborative on Countering the U.S. Opioid Epidemic facilitated a separate, blinded, and academically rigorous peer review of Shatterproof’s “A Movement to **End Addiction Stigma** White Paper” on a pro-bono basis, to provide additional academic rigor for Shatterproof’s national stigma campaign.

Peer reviewers were sourced from two primary pools of experts to conduct this review: members of the NAM’s Action Collaborative, and external subject matter experts sourced from the NAM and National Academies of Sciences, Engineering, and Medicine’s volunteer and expert contacts.

The document was reviewed by representatives from the NAM’s Action Collaborative. These experts represent a wide variety of expertise, including pharmacy, nursing, and clinical care, and are employed by federal agencies, professional organizations, large health care providers, hospitals, and insurance payers. There were also a number of persons with lived experience who reviewed these documents, providing the critical perspective of individuals who have experienced stigma against SUD and OUD firsthand.

The document was also reviewed by two subject matter experts. The subject matter experts represented expertise in stigma research, history of successful social movements, opioid use disorder and/or substance use disorder, and scientific communication.

All peer reviewers were asked to review the document for the following:

- Thoroughness and quality of the analysis presented in the document
- Accuracy of the content and data presented (statements should be backed up by references where possible and/or relevant)
- Quality and robustness of the document’s argument and corresponding plan and tools for implementation
- Clearly defined target audience(s) and realistic goals to reach target audience(s)
- Clearly defined metrics for success and approach to evaluation
- Proposal’s potential for impact to reduce stigma against individuals with OUD

Peer reviews were consolidated and anonymized by NAM staff, so that the peer review process remained single-blind. Once the peer review comments were transmitted from the NAM to Shatterproof, the NAM’s contribution to this process was officially concluded. Incorporation of peer review comments was addressed entirely by Shatterproof staff.

NAM staff and external peer reviewers did not review or approve any of Shatterproof’s final documents, and the final documents are entirely products of Shatterproof and should not be considered endorsed by or products of the National Academy of Medicine, the National Academies of Sciences, Engineering, and Medicine, or the external peer reviewers.

Appendix

Deep-Dive: Stakeholder Ecosystem

Employers: Employers have a compelling incentive to act quickly to address stigma, given the immense economic cost of the opioid epidemic. One study estimated that the epidemic cost \$123.7 billion in lost productivity alone from 2015–2019.¹²¹ In a national survey, 75% of employers reported having been affected in some way by employee use of opioids.¹²² More than 75% of individuals with SUD are in the workforce¹²³ and workers with SUD miss nearly 50% more days than their peers.¹²⁴ There are 5.9 million employers in the U.S. who have daily interactions with ~127 million full-time employees, placing them in a unique position to influence the knowledge, attitudes, and behavior of many Americans. Lastly, since employers set organizational policy, influence language norms, and purchase health care benefits, they can rapidly reduce employer-related stigma.¹²⁵ The movement will start with very large employers (roughly 1,000 firms employ ~40 million, or ~30%, of employees in the U.S.).

Potential of employers to combat stigma



Employers are one of the most credible influencers in peoples' lives.

HIV expert and President of Global Public Affairs at a large communications firm

Health care: Providers and private payers play a central role in identifying and treating individuals with OUD. They are well-positioned to eliminate stigma-related barriers to access, treatment, and recovery. The U.S. provider community — including 6,210 hospitals, ~17 million health care practitioners, and 1,600+ Opioid Treatment Programs — regularly encounter those with OUD. Through training and education, the provider community has immense power to ensure those struggling with OUD do not face stigmatizing language, behavior, or needless barriers to care.

The 900+ health insurance companies in the U.S. cover close to 300 million lives across all lines of business, including commercial, Medicare Advantage, Medicaid, and Managed Care.^{126, 127}

Stigma in the health care setting



The ER (emergency room) setting is most resistant to [the idea that] treatment works. Nurses and front office staff see the same people overdosing, without seeing the backend of people being in recovery successfully and productively contributing to society.

University-based Public Health scientist

Communities: A persistent theme across our interviews is the important role that community-level engagement plays in reducing stigma. The sixth key success factor from previous movements was mobilizing at both “grassroots” and “grasstops,” ensuring change happens at every level. When referring to the community, our interviewees describe the synergistic roles of people in recovery, families, faith leaders, business associations, philanthropic organizations, labor groups, affinity groups, schools and universities, and others. Community organizations and leaders are powerful change agents as they tailor messages to their local contexts, facilitating critical dialogue, enabling peer-to-peer supports, and mobilizing action. For example, schools and universities can play a pivotal role in the path of a person’s life, at a period when they are often the most susceptible to stigma or developing a substance use disorder. Getting schools to support recovery, permit financial aid, provide accommodations, and facilitate access to treatment are critical actions that can limit stigma for someone with an OUD. Similarly, the actions of faith leaders within a community have a significant impact, acting as critical educators within their community, particularly educating the public and communicating hopeful messages.

Criminal justice: The United States’ vast criminal justice system — including the 15,000+ local police departments and sheriffs’ offices, 6,000+ federal and state prisons, local jails, and juvenile correctional facilities, and 870 Federal judges — interacts daily with millions of individuals who already have, or are at high risk for developing an opioid use disorder. In our interviews, the criminal justice system tends to approach OUD as an issue of crime. Yet, there are encouraging examples of criminal justice leaders tackling OUD as a public health issue and working closely with public health leaders to address the crisis. This system will play a critical role in reducing the stigma surrounding OUD, with immense opportunity to shift how OUD is discussed and treated within our nation’s courts, jails, prisons, and other correctional facilities.

Government: The federal, state, and 3,000-plus county governments have enormous power in shaping policy, the treatment and research landscape, and public opinion. Public policy can help ensure system change and incentivize societal change. The federal government is also the largest funder of SUD treatment and research. In addition to acting as a critical influencer of all the systems mentioned above, the government also functions as the largest employer in the U.S., placing it in a unique position to combat stigma. Achieving meaningful change will require a commitment to changing how structures operate, embedding change within these institutions and their routines to ensure it sticks over time.

Media and Entertainment: From news to sports to entertainment, the media touches the daily lives of Americans and shapes public knowledge, attitudes, and behaviors. The five major television networks (ABC, NBC, CBS, FOX, and CW) reach millions of viewers daily. The five largest sports leagues (NFL, MLB, NHL, NBA, MLS) attract millions of fans. And the largest social media platforms (Facebook, YouTube, Instagram) have over 1 billion active monthly users each. As one addiction expert noted, “Sympathetic media responses are also a big deal. In many cases in the media, addiction is framed in a criminal context or as a choice... it is startling how popular media frames how we talk about addiction.” Changing public perception will require media companies to adopt certain standards, including style guides on using appropriate language, and to create empowering content that shows recovery is probable. Media companies can also guide viewers to quality help including educational tools and treatment options. Often news sources cover negative news, such as alarming overdose death rates and criminal activity, but in order to make a change, they need to balance these pieces with stories about treatment and recovery.

Deep-Dive: Action Plans

While the specific commitments will vary by the system (e.g., health care) and the specific sub-system in which an institution operates (e.g., hospitals), all institutions should commit to the following changes:

- Educate through empowerment: Examples include launching an educational campaign within your organization, sharing stories of executives in recovery, and promoting your organization's commitment to supporting individuals with a substance use disorder; using contact-based strategies while showing that treatment is effective are especially important success factors identified when building these Action Plans.
- Affirm through language and action: An example includes eliminating stigmatizing language from all internal and external communications.

Academic studies have looked at the impact stigmatizing language has on behavior.¹²⁸ Terms like "addict" and "junkie" imply an affected individual causes his or her illness. One example is a 2010 study conducted with 500+ trained mental health and addiction clinicians to understand whether referring to someone as a "substance abuser" rather than "an individual with a substance use disorder" led to different behavior. The study found that respondents exposed to the term "an individual with substance use disorder" were less likely to say the patient was personally responsible for their illness and should receive punitive, rather than therapeutic, action.¹²⁹

- Support through policy: Examples include harmonizing policies with those of other chronic illnesses and creating a community that supports individuals with a substance use disorder in living full lives. As part of our initial work, we have developed Action Plans that identify key actions to be taken across sub-systems within employers, health care, criminal justice, communities, media and entertainment, and government. Shatterproof will incentivize stakeholders through public recognition and assessment regularly and will be responsible for tracking the rates of Action Plan adoption for stakeholders who opt-in to a Shatterproof managed certification process. .

Successful movements through the past three decades have conducted similar efforts, such as the American Lung Association's "State Rankings" and the Human Rights Campaign's "Corporate Equality Index." Applying lessons from these examples, Shatterproof has crafted a certification process customized to the challenges of responding to the addiction crisis. Certified organizations will receive recognition signaling to society, employees, and others that they are best-in-class organizations in their efforts and attitudes towards the opioid epidemic. To ensure organizations can easily create change, Shatterproof has drafted customized implementation tools that will be available "off-the-shelf." These tools will provide ready-to-use content, suggestions on the most effective way to deliver the intervention and contact information for technical assistance.

Deep-Dive: Partner Engagement Plan

Organizations will be able to engage in this movement in one of three ways: Partner, Ally, and Coalition Member. The core responsibilities of each are outlined below:

- **Partners:** Implement Action Items, recruit Partners and Allies to help establish mass adoption of Action Plans and support with funding.
- **Allies:** Implement evidence-informed Action Plans. Allies will often be leaders, influencers, or decision-makers within their stakeholder system.
- **Coalition Members:** Recruit Partners and Allies to establish the adoption of Action Plans; thought leadership Coalition Members can include nonprofits, academia, associations, community organizations, etc.

Shatterproof will also create and manage an Advisory Board of stigma reduction experts as well as leadership from the above organizations to advise on key strategic decisions of the movement.

Deep-Dive: Addiction Stigma Index

Shatterproof believes stigma is a key leading indicator for 1) the **percentage of people receiving treatment** (public, self, structural, and stigma against MOUD) 2) **the quality of their treatment** (structural and stigma against MOUD), and 3) **likelihood of staying in active recovery** (self-stigma). To increase the amount of data available to inform our strategy to address each of these variables, Shatterproof will consistently and comprehensively measure public and self-stigma through an **Addiction Stigma Index**. Based on the **Addiction Stigma Index** survey results, as well as supplemental survey panels, we will also conduct in-depth analyses of the following: 1) **Public stigma**, 2) **Self-stigma** 3) **MOUD**, and 4) **Geography**.

We will ultimately pair analysis of survey results with two other forms of measurement – (1) best practice adoption rates by institutions (i.e., the amount in which they have completed Action Items); and (2) publicly available data on outcomes related to treatment rates, treatment quality, and recovery rates. These measures will hold us accountable for results and serve as a managerial tool to prioritize systems through refined Action Plans, recruitment of additional Partners, and other targeted interventions.

The frequent publication of the **Addiction Stigma Index** will allow for ongoing evaluation of the movement. Because it is difficult to accurately measure the current level of self-stigma and structural stigma without the **Addiction Stigma Index**, these estimates will be further refined when results from the Index are delivered. Presumably, results will suggest the number of lives saved and the estimated cost savings will be significantly higher. Rigorous and ongoing measurement of stigma will help us better understand which actions address it, hold ourselves collectively accountable for outcomes of this effort, and inspire those engaged in this movement. These measurements will directly inform Shatterproof's performance and the movement's strategic plan.

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