Alignment for Progress:

A Commitment to Stop Stigma

Policy Issue Brief

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The Kennedy Forum

The Kennedy Forum (TKF) seeks systemic transformation for mental health and substance use (MH/SU) prevention, treatment, and care. The organization draws on strong relationships with key leaders and partners to create action around MH/SUD policies and issues, including insurance coverage inequities and the escalating youth mental health crisis.

Co-founded by former Congressman Patrick J. Kennedy and his wife, Amy L. Kennedy, the nonprofit plays a distinct role as a catalyst, creating visibility and connectedness for movements of change.

In 2023, TKF activated the Alignment for Progress movement, a partner-powered coalition working toward a bold vision: By 2033, 90% of the population is screened for MH/SUD, 90% who need it receive quality treatment, and 90% manage symptoms and achieve recovery.

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STOP STIGMA Together

Stop Stigma Together

Stop Stigma Together strives to achieve a world free of stigma by bringing together the nation's largest coalition of partners focused on coalescing information, ideas, and education around stigma and its impact.

Stop Stigma Together provides the nation's only largescale coordination and activation of stakeholders including practitioners, providers, mental health and substance use disorder advocates, business leaders, community organizations, and government agencies.

Our work de-silos the efforts of medical, psychiatric, therapeutic, and social groups to build a landscape of solutions to destigmatize mental health and substance use disorders across disciplines.

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Ten-Year Goal: 90-90-90 by 2033

The Kennedy Forum's strategic initiative, <u>Alignment for Progress</u>, sets forth a <u>ten-year 90-90-90 goal by 2033</u>:

90%

of individuals screened for MH/SUDs

90%

receiving evidencebased treatment 90%

managing symptoms and achieving recovery

One element of the Alignment for Progress is its <u>National Strategy</u> for Mental Health and Substance Use Disorders, a reference for federal policymakers to attain better access to MH/SUD care for all.



The Grand Challenge of Stigma

"There is no health without mental health."

- World Health Organization

Stigma encompasses the range of negative attitudes, beliefs, and behaviors associated with prejudice and discrimination against individuals with mental health conditions and substance use disorders (MH/SUDs).

A legacy of discrimination in the U.S. produces persistent stigma that causes MH/SUD conditions to be treated differently from other health conditions and social challenges. Stigma pervades our society at three levels: structural, including laws and policies; social, including norms and attitudes; and individual, including internalized negative stereotypes.¹

Stigma impacts our nation's ability to achieve the 90-90-90 goals by 2033. Stigma makes MH/SUD screening, treatment, and supports less accessible and creates barriers for people engaging in care. Stigma also intersects with other inequities and social determinants of health to pose additional challenges in recovery, from difficulties with employment to finding community and belonging. These challenges are magnified for those facing other areas of discrimination, such as racism, sexism, and/or ableism.

This policy brief will:

- Introduce the modern conceptualization of stigma;
- Outline the cascading impacts of stigma on our society;
- Elaborate on a framework for policy reform; and
- Elevate key National Strategy recommendations for reform

Stigma is not just a matter of changing individual thoughts and behaviors. As with other forms of oppression, it is reinforced and systematized in law and policy. We must identify and reform these policies to achieve the 90-90-90 goals by 2033. The Kennedy Forum (TKF) and Stop Stigma Together (SST) look forward to collaborating with the broader MH/SUD stakeholder community in seeking solutions for pervasive stigma challenges.

¹ National Academies of Sciences, Engineering, and Medicine (NASEM). 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 [p.5]

Introduction to the Brief

The Huntsman Mental Health Institute at the University of Utah launched a Grand Challenge to eliminate MH/SUD stigma, led by Stop Stigma Together. Given the centrality of stigma reduction to the Alignment for Progress vision, The Kennedy Forum partnered with Stop Stigma Together to elevate the role of policy change in eliminating stigma and advancing the movement toward its 90-90-90 goals by 2033.

In April 2024, Stop Stigma Together and The Kennedy Forum convened premier researchers, organizational leaders, mental health and substance use care providers, and subject matter experts to prioritize policy recommendations that will address mental health and substance use disorder stigma in our country. This convening united TKF's work on Alignment for Progress and the National Strategy, offering a comprehensive approach to policy and advocacy, with Stop Stigma Together's interdisciplinary and multisystem leadership of the Grand Challenge to eliminate MH/SUD stigma.

The convening began with an overview of the Alignment for Progress 90-90-90 by 2033 strategy, the Stigma Grand Challenge, and expert presentations highlighting the ways that stigma manifests at structural, social, and individual levels. Following the presentations, participants divided into large groups to prioritize the policy recommendations that could have the best impact on access to effective interventions, treatment, and support needed to improve mental health and substance use disorder outcomes.

This brief is being launched as part of the National Summit to End Stigma in June 2024 with Stop Stigma Together and The Kennedy Forum to guide the movement with policy solutions to mitigate the complex and intersecting effects of stigma.

The Modern Understanding of Stigma

Historically, work on stigma focused predominantly on the attitudes and behaviors of individuals, in isolation from their social, institutional, and policy context. Interventions focused on educating and empowering individuals to change those attitudes or behaviors. While education and self-empowerment remain critical parts of addressing stigma, advancing research in social norms has led to a more nuanced way of understanding MH/SUD stigma.

In 2016, the National Academies of Sciences, Engineering, and Medicine (NASEM) released a consensus study that offered a modern framework for understanding stigma, which guides our work today.² The study brought together the latest research from across disciplines to inform the federal government's approach to the issue. The study explains that stigma is "a dynamic multidimensional, multilevel phenomenon that occurs at three levels of society," existing at three levels:

- Structural: Laws and other policies that institute and perpetuate stigma.
- Public: Social norms, beliefs, and attitudes that promote stigma.
- **Self:** Internalized perspectives that represent stigma.

Understanding stigma in this way, we can see how it impacts the nation's response to MH/SUD. At a structural level, stigma is reinforced in policies that can pose barriers in areas such as housing, education, and employment for those with MH/SUD conditions. Structural stigma also, in part, explains the lack of policies that would increase access to care in schools, workplaces, and within the criminal legal system.

At the social level, stigma appears in discrimination people may experience at work or in attitudes toward individuals with MH/SUD conditions. Social stigma also appears in the lack of buy-in from some school, business, and community leaders in normalizing open and honest discussions of mental health concerns.

At the level of self, stigma can internalize shame and prevent individuals from seeking treatment for their own MH/SUD conditions or supporting loved ones navigating their own MH/SUDs.

Stop Stigma Together's Definition of Stigma



A set of negative and unfair beliefs that a society has about something, resulting in stereotypes, prejudice, and discrimination.³

³ Journal of Adolescence, 66(1), 83-90. Personal and perceived public mental-health stigma as predictors of help-seeking intentions in adolescents (2018). https://doi.org/10.1016/j.adolescence.2018.05.003

The Impacts of Stigma

Stigma disrupts access to mental health care and affects people of all ages and demographics.

A national survey of adolescents ages 12-17 found that young people reported the following reasons for not seeking treatment: 4

55%

Worried about what people would think or say if they got treatment

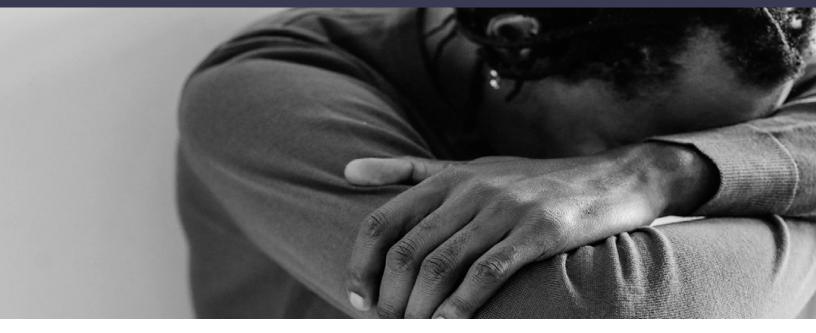
39%

Thought their family, friends, or religious group would not like it if they got treatment

83%

Thought they should have been able to handle their mental health, emotions, or behavior on their own

⁴ Substance Abuse and Mental Health Services Administration. 2022 National Survey on Drug Use and Health. November 13, 2023. https://www.samhsa.gov/data/report/2022-nsduh-detailed-tables



A national survey of adults recovering from significant drug, alcohol, and addiction challenges found high rates of stigmatizing experiences, including people reporting that: ⁵

- **38%** were held to a higher standard
- **35.7%** experienced people avoiding them
- 18.5% were treated unfairly by the police
- 16.2% could not get a job

Although the national dialogue around MH/SUD progresses, young people today continue to face stigma that prevents them from accessing care. In some cases, the belief that they should be able to handle their mental health in their own may exacerbate self-stigma. Among people who have accessed care and are in recovery, stigma continues to impact their daily lives and in some cases their livelihoods. The U.S. must continue concerted efforts to address stigma at all levels.

⁵ Vilsaint, C. L., Hoffman, L. A., & Kelly, J. F. (2020). Perceived discrimination in addiction recovery: Assessing the prevalence, nature, and correlates using a novel measure in a U.S. National sample. Drug and alcohol dependence, 206, 107667. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6980305/

Stigma and U.S. Health Care Policy

Mental health and substance use conditions are among the most prevalent health conditions facing individuals in the U.S. For much of the nation's history, though, the U.S. did not support MH/SUD care through policy in any meaningful way. Despite calls for attention to MH/SUDs, stigma prevented substantial policy engagement, while the lack of substantial policy engagement perpetuated stigma.

In 1963, the U.S.'s approach reached a turning point with the Community Mental Health Act, aimed at providing care through local community mental health programming, moving away from the confinement of large institutions. Although largely defunded in subsequent years, leaving many states and counties to build underfunded patchwork systems of care, the Community Mental Health Act represented a shift in what was considered acceptable care for those with mental health conditions.

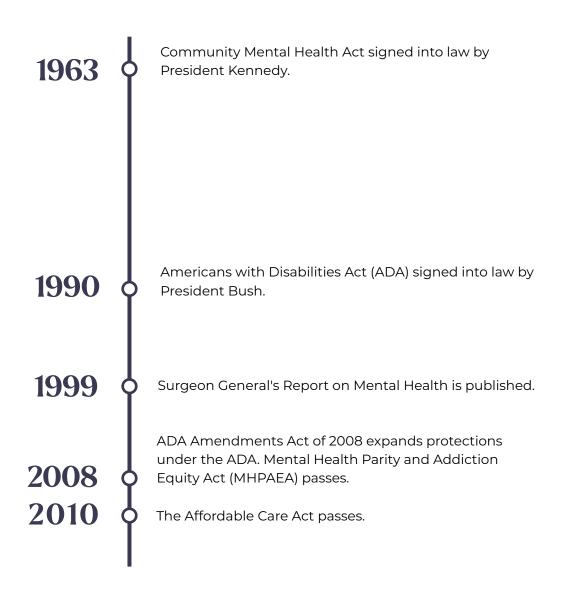
Nearly 30 years later, the passage of the 1990 Americans with Disabilities Act (ADA) signaled yet another change in the rights and dignities of Americans with mental and physical disabilities. The ADA provided that Americans living with disabilities were entitled to protections across numerous facets of life including employment, public accommodations, and access to government programs and services.

In 1999, the Surgeon General's Report on Mental Health was published, underscoring the need to strengthen the nation's mental health systems of care and "fight the stigma associated with mental illness so all Americans can get the treatment and services they need to live full and productive lives." The ADA Amendments Act of 2008 further expanded the protections under the ADA by expanding the definition of disability to include mental health conditions.

⁶ Tipper Gore, President's Advisor on Mental Health, White House Office of the Press Secretary, Release of the Surgeon General's Report on Mental Health, December 13, 1999. https://clintonwhitehouse4.archives.gov/WH/New/html/19991213.html

That same year, the Mental Health Parity and Addiction Equity Act (MHPAEA) passed, with the aim of preventing discrimination in health insurer coverage of mental health and substance use disorder benefits. The Affordable Care Act of 2010 further extended overall health care insurance coverage including the scope of mental health and substance use disorder benefits to all Americans.

Though these laws signal incredible progress in the protections afforded to individuals in the U.S. seeking care of physical and mental health conditions, much headway can still be made to substantively improve the lives of those living with mental health and addiction conditions.



Changing Policy to Reduce MH/SUD Stigma

The ADA and MHPAEA represent two cornerstone laws for addressing structural stigma in the U.S. While the policies are strong and have enjoyed bipartisan support over a number of years, implementation of both remains limited. To realize the vision of equity and address structural stigma, advocates must:

- Further define disability rights for MH/SUD conditions under the ADA and lead efforts to oversee and enforce the law; and
- Support federal and state regulators to oversee MH/SUD parity and expand th MHPAEA protections across Medicare and Medicaid.

While 60 years of structural laws and policies have improved how society thinks about (and how our systems provide) MH/SUD care, individual, social, and continued structural stigmas still persist, exacerbating disparities that keep people from seeking and accessing MH/SUD care.

This policy brief outlines other critical areas of policy change to address stigma, building on the foundation set by the ADA and MHPAEA. It recommends ways to mainstream anti-stigma structures in the federal government and prioritizes key National Strategy recommendations, along four prongs:

- Eliminating Discriminatory Laws
- Improving Provider Training and Patient Care
- Reaching Diverse Populations
- Improving Public Messaging and Education

Eliminating Discriminatory Laws

Structural stigma exists throughout public, private, and governmental institutions as evidenced by policies both written and understood. Eliminating existing discriminatory laws that perpetuate stigma, create and/or exacerbate mental health conditions, or create barriers to receiving MH/SUD care is critical towards building a better future without stigma. Additionally, consistent training, evaluation, and cross-agency coordination around these types of blatant discrimination will help institutions better detect stigma-creating problems within their own programming.

It is imperative that **federal agencies evaluate and enforce existing laws, policies, and regulations that prevent discrimination against people with MH/SUDs** in all public and private institutions, including legal and justice, business, and education settings. Non-enforcement of anti-discrimination protocols adds additional stigma to those being discriminated against.

A range of federal agencies implement programs to support individuals with MH/SUDs, including the U.S. Departments of Defense, Education, Health and Human Services, Housing and Urban Development, Justice, Labor, Veterans Affairs, and the Social Security Administration. **Coordinating programs using common languages and shared stigma-reduction goals** will reduce duplication, enhance efforts to coordinate across agencies and programs, and augment the effectiveness and reach of these programs.

Eliminating Discriminatory Laws

Policy Recommendations

Ensure fair housing background checks. The Federal Trade Commission (FTC) and the Consumer Financial Protection Bureau (CFPB) should propose rulemaking relating to the use of criminal and eviction records and algorithms in background screening for individuals seeking rental housing.

Source

Ban Sexual Orientation and Gender Identity (SOGI) change efforts. Congress should end harmful and ineffective sexual orientation and gender identity (SOGI) change efforts by passing legislation that bans SOGI change efforts or provides supportive resources. Additionally, licensed MH/SUD providers should be banned from engaging in SOGI change efforts, federal funds should be restricted, and SOGI change efforts should be defined as consumer fraud.

Source

Pass the STRIP Act. Congress should pass the STRIP Act to amend the Controlled Substances Act (CSA) to exempt individuals from punishment for the possession, sale, or purchase of fentanyl drug testing equipment.

Source

Eliminating Discriminatory Laws

Policy Recommendations

(continued)

Limit use of restrictive housing. The Department of Justice (DOJ) should establish policies to ensure the limited use of restrictive housing. Restrictive housing should never be implemented for incarcerated individuals with mental health and substance use disorders (MH/SUD).

Source

Build supportive housing and shelters. Congress should use the Religious Land Use and Institutionalized Persons Act of 2000 (RLUIPA) model to prohibit the use of zoning, landmarking, and other land use laws to prevent the construction of permanent supportive housing and homeless shelters, which are critical to addressing our nation's homelessness crisis.

Source



Explore more of the National Strategy recommendations:

strategy.alignmentforprogress.org



Improving Provider Training and Patient Care

Even as health care providers treat people with MH/SUD conditions, they can unfortunately promote social stigma and may experience self-stigma. Improving competencies of those working in MH/SUD fields is critical for eliminating stigmatizing interactions for those seeking health care and ensuring providers in high-stress positions are able to better identify and seek treatment for their own MH/SUDs. Investing in high-quality training and promoting high standards of care can help disrupt stigma throughout the health care professions.

The federal government must lead the way in developing training content that prepares providers to care effectively and in a non-stigmatizing way for individuals with MH/SUD conditions. In particular, the government must support providers to ensure culturally and linguistically competent care to address stigma that can be amplified by other forms of discrimination.

To ensure uptake of this training, agencies can fund provider training programs or build incentives for training and care standards into existing funding streams. This effort can build on existing work, such as National Institute for Health (NIH) funded research on SUD stigma in MH care that will be incorporated into new training curricula. In some cases, additional funding can ensure that key MH/SUD services are integrated into other aspects of health care, so that individuals have equitable access to MH/SUD care in a non-stigmatizing way.

Improving Provider Training and Patient Care

Policy Recommendations

Improve training for diagnosis and treatment of addiction. All federally supported medical, nursing, and other clinician training programs should be required to incorporate training on the diagnosis and treatment of addiction into curricula.

Source

Develop culturally competent guidelines. The Substance Abuse and Mental Health Services Administration (SAMHSA) should develop culturally competent guidelines for mental health and substance use service providers, particularly those serving predominantly underserved communities — Black/African American; Hispanic/Latino; Asian American, Native Hawaiian, and Pacific Islander; American Indian and Alaska Native; and lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) communities — through inclusive and responsive community engagement.

Source

Require adoption of CLAS standards. The U.S. Department of Health and Human Services (HHS) should require organizations receiving federal funds, including states and local units of government, to adopt HHS's Office of Mental Health's (OMH) Culturally and Linguistically Appropriate Services (CLAS) standards in health and health care settings.

<u>Source</u>

Fund NICUs to provide care for infants with NAS. Congress should utilize tax credits and grant programs to fund new (or existing) neonatal intensive care units in all hospitals to provide specialized care for infants with neonatal abstinence syndrome (NAS) and to ensure mothers and their children remain in close proximity with each other after birth.

Source

Reaching Diverse Populations

MH/SUD conditions cut across diverse populations with intersecting needs and identities. Failing to reach different populations not only leads to poorer MH/SUD outcomes for that population, but also perpetuates stigma. **Targeted funding towards programming for MH/SUD programs that are unique to the particular needs of those being served is critical for ensuring often overlooked and highly stigmatized populations receive appropriate and tailored MH/SUD care.**

Peer support can be an important tool for reaching different populations. Peers are individuals who share key aspects of identity or experience with those they serve. Peer support specialists receive training in leveraging those commonalities to engage distinct populations or communities. **The federal government should continue to support the recruitment, training, and effective and sustainable deployment of peer support specialists,** as a cornerstone of breaking stigma with populations facing intersecting needs or challenges.

Intersecting challenges around stigma become most acute in the context of crisis care, where stigma and intersecting discrimination can be dangerous for individuals in need of a safe and effective MH/SUD response. The federal government launched the 988 Suicide and Crisis Lifeline nationwide as a resource that makes accessing MH/SUD emergency care as simple as accessing physical health emergency care with 911. The federal government must continue to build awareness of 988 and ensure that access is linked to providers who can deliver culturally and linguistically responsive care that disrupts stigma across populations.

Reaching Diverse Populations

Policy Recommendations

Promote uptake of youth peer support services. The Centers for Medicaid & Medicare Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA) should offer learning collaboratives and technical assistance to states on peer support and billing best practices.

Source

Fully implement the 988 Suicide and Crisis Lifeline. SAMHSA should continue to fully implement the 988 number, with responses driven by health care systems, not public safety systems. Enhanced training should be provided to counselors answering 988 calls, and coordination should be strengthened between 988, 911, and all services within the continuum. Clinically staffed crisis response should be integrated within 911, and training provided to 911 operators in identifying mental health needs and linking callers to mental health crisis response services.

Source

Fund drug court programs and mental health courts. Congress should increase appropriations for drug court programs (34 U.S.C. § 10611) and mental health courts (34 U.S.C. §10471). Additionally, the federal cap on grant funding for mental health courts should be removed.

Source

Reaching Diverse Populations

Policy Recommendations

(continued)

Pass the Farmers First Act. Congress should pass the Farmers First Act of 2023 to reauthorize the Farm and Ranch Stress Assistance Network (FRSAN), which would increase funding for the program, authorizing \$15 million per year for the program for the next five years, up from \$10 million.

Source

Fund the Residential Substance Abuse Treatment program. Congress should increase appropriations for the Residential Substance Abuse Treatment (RSAT) program established by 34 U.S.C. § 10421 and amend 34 U.S.C. § 10422 so grant awards are contingent upon the use of medication-assisted treatment (MAT).

Source

Improving Public Messaging and Education

Self-stigma and social stigma can be influenced — positively and negatively — by public discourse. Public awareness campaigns may help reduce stigma by dispelling stereotypes or misinformation with fact and by providing opportunities for people with MH/SUD to share and normalize the ubiquity of their experiences with others.

Self-stigmatization often discourages individuals from disclosing needs or seeking help for MH/SUD conditions, especially when it intersects with other forms of discrimination, such as racism. Existing programs should proactively address individuals within these specific populations with intersecting identities and experiences that place them at risk for greater stigma. **Culturally competent messaging can open the door for those who historically may have been denied access and are hesitant to seek care for themselves, their family, or community.**

To help stop the perpetuation and spread of stigma, public figures, including those in the media, should be trained on how to discuss mental health issues and avoid discriminatory language. Despite existing resources educating the media about individuals with MH/SUDs, negative stereotypes still exist and are propagated through media. The federal government should continue to disseminate and make available trainings for media, public figures, and other leaders in breaking the stigma around MH and SUD.





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About

Co-founded by former Congressman Patrick J. Kennedy and his wife, Amy L. Kennedy, The Kennedy Forum (TKF) is creating a future where all people can access effective prevention and treatment of mental health and substance use disorders (MH/SUD).

TKF uniquely cultivates relationships with key leaders to advance sweeping change for major MH/SUD issues, including inequity in insurance coverage and the escalating youth mental health crisis.