Understanding and Addressing Substance Use Disorder Stigma in Clinical Care Settings

John F. Kelly, PhD, ABPP
Opioid Response Network (AAAP/SAMHSA)
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Sponsoring Organizations

RECOVERY RESEARCH INSTITUTE

Opioid Response Network

SAMHSA
Substance Abuse and Mental Health Services Administration
The SAMHSA-funded Opioid Response Network (ORN) assists states, organizations and individuals by providing the resources and technical assistance they need locally to address the opioid crisis and stimulant use.

Technical assistance is available to support the evidence-based prevention, treatment and recovery of opioid use disorders and stimulant use disorders.

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The Opioid Response Network (ORN) provides local, experienced consultants in prevention, treatment and recovery to communities and organizations to help address this opioid crisis and stimulant use.

- ORN accepts requests for education and training.
- Each state/territory has a designated team, led by a regional Technology Transfer Specialist (TTS), who is an expert in implementing evidence-based practices.
Contact the Opioid Response Network

✧ To ask questions or submit a request for technical assistance:

• Visit www.OpioidResponseNetwork.org
• Email orn@aaap.org
• Call 401-270-5900
50 years....
1970-2020
During the past 50 yrs since “War on Drugs” declared, our rhetoric and terminology also has changed... we have moved from “Public Enemy No. 1” to “Top public health problem...”

Rhetoric and terminology has changed along with broad approaches to addressing endemic substance use problems...
The Last 50 Years in U.S. Addiction Laws

1965

Reorganizational Plan No. 2
Creation of the Drug Enforcement Agency (DEA), consolidating a number of different entities to form a single federal agency to enforce government drug control policy.

1970

Controlled Substances Act (CSA):
Part of the larger Comprehensive Drug Abuse Prevention & Control Act of 1970, the CSA established U.S. drug control policy & created 5 schedules (classifications) of drugs to determine the legality of a substance & corresponding legal ramifications.

1973

Charitable Choice
Charitable choice allows direct U.S. government funding of religious organizations to provide substance use prevention & treatment.

1986-1988

Anti-Drug Abuse Act
1986: Act created the policy goal of a drug-free America, created the Office of National Drug Control Policy (ONDCP), changed the federal probation & release system from a rehabilitative to a punitive (punishment-focused) model, enacted minimum mandatory sentencing, & prohibited controlled designer drugs.

2006

Sober Truth on Preventing Underage Drinking Act (STOP Act)
Passed in 2006, the STOP act created a grant program to target underage drinking within communities & establish the federal Interagency Coordinating Committee on the Prevention of Underage Drinking (ICCPUD), with high-level leadership from across 5 federal agencies to coordinate government efforts to address underage drinking.

2010

Fair Sentencing Act
Passed in 2010, the act reduces the sentencing disparity between crack & powder cocaine from 100:1 to an 18:1 ratio.

2016

Comprehensive Addiction & Recovery Act (CARA)
Passed in 2016, CARA increased access to overdose treatment, naloxone (overdose reversal medication), & medication assisted treatments (MAT), reauthorized an opioid treatment program for pregnant & postpartum women, & allocated money for creation of opioid epidemic response plans on the state level.

2017

Mental Health Parity & Addiction Equity Act (MHPAEA)
Enacted in 2008, the MHPAEA closed loopholes in the Mental Health Parity Act of 1996 by requiring insurance companies to offer coverage for mental health & substance use disorders that is equal to the coverage offered for other medical or surgical care (e.g., deductibles, co-pays, out-of-pocket maximums, treatment limitations).

The Patient Protection & Affordable Care Act (ACA)
Healthcare legislation enacted in 2010, declared substance use disorders of the 10 elements of essential health benefits in the U.S., requiring that Medicaid & all insurance plans sold on the Health Insurance Exchange provide services for addiction treatment equal to other medical procedures (closing insurance exemption gaps of the 2008 MHPAEA). Commonly referred to as the Affordable Care Act or "ObamaCare".

Laws passed in the past 50 yrs have moved from more punitive ones to public health oriented ones.... increasing availability, accessibility and affordability of treatment..
Criminal justice approaches have begun to shift and embrace clinical and public health emphases in part due to new knowledge....
Public Health Approaches to Addressing Drug-Related Crime: Drug Courts
Public Health Approaches to Law Enforcement

- Chief Campanello
  - Angel Program

“Help not Handcuffs”
United Nations Office on Drugs and Crime

Dedicated to all those affected by drug problems worldwide
Drug problems are preventable and treatable
The “war on drugs” rhetoric reflected a national concerted effort to reduce “supply” but also “demand” that created treatment and public health oriented federal agencies.

The new science emanating from funding from these organizations has informed the shift towards clinical and public health approaches....
Paradigm Shifts
Past 50 yrs since declaration of “War on drugs” led to large-scale federal appropriations and a number of paradigm shifts...
Genetics, Genomics, Pharmacogenetics
Neuroscience: Neural plasticity
## STAGES OF CHANGE

**RELATED TREATMENT & RECOVERY SUPPORT SERVICES**

<table>
<thead>
<tr>
<th>PRECONTEMPLATIVE</th>
<th>CONTEMPLATIVE</th>
<th>PREPARATION</th>
<th>ACTION</th>
<th>MAINTENANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this stage, individuals are not even thinking about changing their behavior. They do not see their addiction as a problem; they often think others who point out the problem are exaggerating.</td>
<td>In this stage people are more aware of the personal consequences of their addiction &amp; spend time thinking about their problem. Although they are able to consider the possibility of changing, they tend to be ambivalent about it.</td>
<td>In this stage, people have made a commitment to make a change. This stage involves information gathering about what they will need to change their behavior.</td>
<td>In this stage, individuals believe they have the ability to change their behavior &amp; actively take steps to change their behavior.</td>
<td>In this stage, individuals maintain their sobriety, successfully avoid temptations &amp; relapse.</td>
</tr>
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### HARM REDUCTION
- Emergency Services (e.g., Narcan)
- Needle Exchanges
- Supervised Injection Sites

### SCREENING & FEEDBACK
- Brief Advice
- Motivational Interventions

### CLINICAL INTERVENTION
- Phases/Levels (e.g., Inpatient, Residential, Outpatient)
- Intervention Types
  - Psychosocial (e.g., Cognitive Behavioral Therapy)
  - Medications: Agonists (e.g., Buprenorphine, Methadone) & Antagonists (Naltrexone)

### NON-CLINICAL INTERVENTION
- Self-Management/Natural Recovery
  - e.g., self-help books; online resources
- Mutual Help Organizations
  - e.g., Alcoholics Anonymous, SMART Recovery, Lifering Secular Recovery
- Community Support Services
  - e.g., Recovery Community Centers, Recovery Ministries, Recovery Employment Assistance

### CONTINUING CARE (3m - 1 year)
- Recovery Management
- Checkups, Telephone Counselling, Mobile Applications, Text Message Interventions

### RECOVERY MONITORING (1-5+ yrs)
- Continued Recovery Management Checkups, therapy visits, Primary Care Provider Visits
What people really need is a good listening to...
“Quitting smoking is easy, I’ve done it dozens of times” –Mark Twain
Swift, certain, modest, consequences shape behavioral choices...
Effective Medications
Harm Reduction Strategies

• Anti-craving/anti-relapse medications ("MAT")
• Overdose reversal medications (Narcan)
• Needle exchange programs
• Heroin prescribing
• Safe Injection Facilities/Safe Consumption sites/Overdose prevention facilities
The clinical course of addiction and achievement of stable recovery can take a long time ... can we speed this up??

- Addiction Onset
- Help Seeking
- Full Sustained Remission
- Reinstatement Risk drops below 15%

- 4-5 years
- 8 years
- 5 years

- Self-initiated cessation attempts
- 4-5 Treatment episodes/mutual-help
- Continuing care/mutual-help

- Recovery Priming
- Recovery Mentoring
- Recovery Monitoring

Stigma & Discrimination
Traditional addiction treatment approach: Burning building analogy

- **Putting out the fire** - good job

- **Preventing it from re-igniting** (RP) - less emphasis

- **Re-building materials** *(recovery capital)* – largely neglected

- **Granting “rebuilding permits”** *(removing barriers)* – largely neglected
Stigma persists despite significant advances...

• What’s the nature of stigma and discrimination?

• What’s its impact?

• What can be done to address stigma?
WHAT IS STIGMA?

An attribute, behavior, or condition, that is socially discrediting
WHAT IS DISCRIMINATION?

The unfair treatment of individuals with the stigmatized condition/problem
Stigma Consequences: Public and Personal

• Public:
  • Public stigma can lead to:
    • Differential public and political support for treatment policies
    • Differential public and political support for criminal justice preferences
    • Barriers to employment/education/training
    • Reduced housing and social support
    • Increased social distance (social isolation)

• Personal:
  • Internalization of public stigma can lead to:
    • Shame/guilt
    • Lowered self-esteem
    • Rationalization/minimization; lack of problem acknowledgment
    • Delays in help-seeking
    • Less treatment engagement/retention; lowered chance of remission/recovery
**Commonly Studied Dimensions of Stigma**

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Question</th>
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</thead>
<tbody>
<tr>
<td><strong>Blame</strong></td>
<td>are they responsible for causing their problem/disorder?</td>
</tr>
<tr>
<td><strong>Prognostic pessimism/optimism</strong></td>
<td>will they ever recover “be normal”, “trustworthy”?</td>
</tr>
<tr>
<td><strong>Dangerousness</strong></td>
<td>are they unpredictably volatile, a threat to my/others’ safety?</td>
</tr>
<tr>
<td><strong>Social distance</strong></td>
<td>would I have them marry into my family, share an apartment with them, have them as a babysitter?</td>
</tr>
</tbody>
</table>
Addiction may be most stigmatized condition in the US and around the world: Cross-cultural views on stigma

Across 14 countries and 18 of the most stigmatized conditions…

Illicit drug addiction ranked 1st

Alcohol addiction ranked 4th

Stigma, social inequality and alcohol and drug use

ROBIN ROOM

Centre for Social Research on Alcohol and Drugs, Stockholm University, Stockholm, Sweden

• Sample: Informants from 14 countries
• Design: Cross-sectional survey
• Outcome: Reaction to people with different health conditions

Studies have shown that...

- **SUD is more stigmatized** compared to other psychiatric disorders.
- Compared to other psychiatric disorders, people with SUD are perceived as more to blame for their disorder.
- Describing SUD as treatable helps.
- Patients themselves who hold **more stigmatizing beliefs** about SUD are less likely to seek treatment; discontinue sooner.
- **Physicians/clinicians** shown to hold stigmatizing **biases against those with SUD**; view SUD patients as unmotivated, manipulative, dishonest; **SUD-specific education/training helps**.
SO, WHY IS ADDICTION SO STIGMATIZED COMPARED TO OTHER SOCIAL PROBLEMS AND HEALTH CONDITIONS, AND OTHER MENTAL ILLNESSES?
## What Factors Influence Stigma?

<table>
<thead>
<tr>
<th>Cause</th>
<th>Controllability</th>
<th>Stigma</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It’s not their fault”</td>
<td>“They can’t help it”</td>
<td>Decreases</td>
</tr>
<tr>
<td>“It is their fault”</td>
<td>“They really can help it”</td>
<td>Increases</td>
</tr>
</tbody>
</table>
Relation between Cause and Controllability in producing Stigma

Controllability

"Can't help it"

"NOT their own fault"

Extent of Stigma

"IS their own fault"

Cause

"IS their own fault"
If Drugs Are so Pleasurable, Why Aren’t We All Addicted?

Genetically mediated response, metabolism, reward sensitivity…

- Genetics substantially influence addiction risk
- Genetic differences affect subjective preference and degree of reward from different substances/activities

In terms of cause... Biogenetics

In terms of controllability... Neurobiology

Neural Circuits Involved in Substance Use Disorders

...all of these brain regions must be considered in developing strategies to effectively treat addiction

Axial magnetic resonance images from a healthy 57-year-old man (left) and a 57-year-old man with a history of alcoholism (right). D. Pfefferbaum
What can we do about stigma and discrimination in addiction?

**Education** about essential nature of these conditions

**Personal witness** (putting a face and voice on recovery)

**Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
What can we do about stigma and discrimination in addiction?

- **Education** about essential nature of these conditions
- **Personal witness** (putting a face and voice on recovery)
- **Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
MIGHT GREATER BIOMEDICAL EMPHASIS AND EXPLANATIONS (E.G., BIOGENETIC AND/OR NEUROBIOLOGICAL) HELP REDUCE STIGMA?
Biogenetic explanations as ways to reduce stigma...

- Meta-analysis of 28 experimental studies found biogenetic explanations:
  - Reduced blame, but increased...
  - Social distance
  - Dangerousness
  - Prognostic Pessimism

The ‘side effects’ of medicalization: A meta-analytic review of how biogenetic explanations affect stigma

Erkend P. Kvaale, Nick Haslam, William H. Gotttdiener

Melbourne School of Psychological Sciences, University of Melbourne, Parkville, Australia
Department of Psychology, John Jay College of Criminal Justice, City University of New York, NY, USA

HIGHLIGHTS

- Biomedical perspectives shape contemporary thinking about psychological problems.
- We quantitatively reviewed how biogenetic explanations affect stigma.
- Biogenetic explanations reduce blame, but induce pessimism about recovery.
- Biogenetic explanations do not affect desire for distance.
- Medicalization is no cure for stigma and may create barriers to recovery.

ABSTRACT

Reducing stigma is crucial for facilitating recovery from psychological problems. Viewing these problems biomedically may reduce the tendency to blame affected persons, but critics have cautioned that it could also increase other facets of stigma. We report on the first meta-analytic review of the effects of biogenetic explanations on stigma. A comprehensive search yielded 28 eligible experimental studies. Four separate meta-analyses (N = 1207-3468) assessed the effects of biogenetic explanations on blame, perceived dangerousness, social distance, and prognostic pessimism. We found that biogenetic explanations reduce blame (Hedges g = -0.324) but induce pessimism (Hedges g = 0.263). We also found that biogenetic explanations increase endorsement of the stereotype that people with psychological problems are dangerous (Hedges g = 0.198), although this result could reflect publication bias. Finally, we found that biogenetic explanations do not typically affect social distance. Promoting biogenetic explanations to alleviate blame may induce pessimism and set the stage for self-fulfilling prophecies that could hamper recovery from psychological problems.
Neurobiological explanations as ways to reduce stigma...

Neurobiological explanation studies found they increased:

- Social distance
- Dangerousness
- Prognostic pessimism
- had no effect on reducing blame
What about ways of describing drug-related impairment, specifically?

A Randomized Study on Different Addiction Terminology in a Nationally Representative sample of the U.S. Adult Population

Terminology: What’s the best way to describe drug-related impairment to reduce stigma/discrimination?

- Chronically relapsing brain disease
- Brain disease
- Disease
- Illness
- Disorder
- Problem

Design

• N=3,635
• Randomly assigned to receive one of 12 vignettes which described someone with opioid-related impairment in one of six different ways, as a(n):

  • Chronically relapsing brain disease
  • Brain disease
  • Disease
  • Illness
  • Disorder
  • Problem

“Alex was having serious trouble at home and work because of (his/her) increasing opioid use. (He/She) is now in a treatment program where (he/she) is learning from staff that (his/her) drug use is best understood as a (TERM) that often impacts multiple areas of one’s life. Alex is committed to doing all that (he/she) can to ensure success following treatment. In the meantime, (he/she) has been asked by (his/her) counselor to think about what (he/she) has learned with regard to understanding (his/her) opioid use as a (TERM).”

• There does not appear to be one single medical term for opioid-related impairment that can meet all desirable clinical and public health goals

• To reduce stigmatizing blame, biomedical ‘chronically relapsing brain disease’ terminology may be optimal

• To increase prognostic optimism and decrease perceived danger/social exclusion use of non-medical terminology (e.g. ‘opioid problem’) may be optimal

What can we do about stigma and discrimination in addiction?

- **Education** about essential nature of these conditions
- **Personal witness** (putting a face and voice on recovery)
- **Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
TERMINOLOGY
Confusing array of terms Describing the Construct and Spectrum of Substance-Related Problems
Array of Terms Describing the Person using or suffering from compulsive substance use

- Addict
- Substance Abuser
- Crackhead
- Junkie
- Drunk
- Substance Misuser
- Alcoholic
- Problem User
- Smackhead
- Alkie
People with eating-related conditions are always referred to as “having an eating disorder”, never as “food abusers”.

So why are people with substance-related conditions referred to as “substance abusers” and not as “having a substance use disorder”? 
Does it matter?

Much ado about nothing?

“Political correctness”?

Mere “semantics”? 
Two Commonly Used Terms…

➢ Referring to someone as…

- “a substance abuser” – implies willful misconduct (it is their fault and they can help it)
- “having a substance use disorder” – implies a medical malfunction (it’s not their fault and they cannot help it)
- But, does it really matter how we refer to people with these (highly stigmatized) conditions?
- Can’t we just dismiss this as a well-meaning point, but merely “semantics” and “political correctness”?
Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms

John F. Kelly, Cassandra M. Westerhoff

*International Journal of Drug Policy*

How we talk and write about these conditions and individuals suffering them does matter
“Substance Abuser”

Mr. Williams is a substance abuser and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…

“Substance Use Disorder”

Mr. Williams has a substance use disorder and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…

Compared to those in “substance use disorder” condition, those in “substance abuser” condition agreed more with idea that individual was personally culpable, needed punishment
Substance-related terminology is often a contentious topic because terms may convey meanings that have stigmatizing consequences and present a barrier to treatment. Chief among these are the labels, “abuse” and “abuser.”
Implications

➢ Even well-trained clinicians judged same individual differently and more punitively depending on which term exposed to

➢ Use of “abuser” term may activate implicit cognitive bias perpetuating stigmatizing attitudes—could have broad effects (e.g., treatment/funding)

➢ Let’s learn from allied disorders: people with “eating-related conditions” uniformly described as “having an eating disorder” NEVER as “food abusers”

➢ Referring to individuals as having “substance use disorder” may reduce stigma, may enhance treatment and recovery

The American Journal of Medicine

EDITORIAL

Stop Talking ‘Dirty’: Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States

A patient with diabetes has “an elevated glucose” level. A patient with cardiovascular disease has “a positive exercise tolerance test” result. A clinician within the health care setting addresses the results. An “addict” is not “clean”—he has been “abusing” drugs and has a “dirty” urine sample. Someone outside the system that cares for all other health conditions addresses the results. In the worst case, the drug use is addressed by incarceration.

Despite harmful consequences, stigma is alive and well. Use of the more mediusable terms such as “substance use disorder” and “treatment” will help move the discussion away from the extreme terms like “abuser” and “addict” and toward an understanding that drug use is a health condition that requires intervention.

• Avoid “dirty,” “clean,” “abuser” language

• Negative urine test for drugs

http://www.amjmed.com/article/S0002-9343(14)00770-0/abstract

Recommended language examples…

Don’t say…

• “drug abuser”

• “alcoholic”

• “dirty urine”

• “heroin addict”

Instead, say…

• “Person/individual/patient with a substance use disorder”

• “Person/individual/patient with an alcohol use disorder”

• “The urine was positive/negative for….”

• “Person/individual/patient with an opioid use disorder”
ADDICTION-ARY

IF WE WANT ADDICTION DESTIGMATIZED, WE NEED A LANGUAGE THAT'S UNIFIED.

The words we use matter. Caution needs to be taken, especially when the disorders concerned are heavily stigmatized as in substance use disorders.
Together, recovery is possible.
g.co/recovertogether
Anyone can support the recovery movement

With your words

The leaders of the modern recovery movement ask us all to be thoughtful with the words we use around addiction and recovery. Some common terms, even those historically used by those in recovery, can reinforce stigma and even discourage people struggling with addiction from seeking treatment. Here are some that label people or inadvertently pass judgment, with advice on how to replace them with objective descriptions of symptoms or behaviors.

<table>
<thead>
<tr>
<th>Old Term</th>
<th>Replace with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addict/Alcoholic/Junkie</td>
<td>a person with, or suffering from, addiction or substance use disorder.</td>
</tr>
<tr>
<td>Lapse/Relapse/Slip</td>
<td>neutral terms such as “resumed,” or experienced a “recurrence” of symptoms.</td>
</tr>
<tr>
<td>Clean</td>
<td>terms like “in remission or recovery”</td>
</tr>
<tr>
<td>Dirty</td>
<td>a person having positive test results or exhibiting symptoms of substance use disorder</td>
</tr>
</tbody>
</table>

Visit the Addictionary from the Recovery Research Institute for more terminology and guidance.
Addictionary

February 08, 2019

The Recovery Research Institute at Massachusetts General Hospital and Harvard Medical School has developed the Addictionary, a very useful tool when writing or discussing addiction and people with addiction and in recovery. According to the site, “The words we use matter. Caution needs to be taken, especially when the disorders concerned are heavily stigmatized as in substance use disorders.”
ISAJE editors adopted consensus statement advocating against use of stigmatizing language like “abuse” “abuser” “dirty,” “clean” in addiction science in 2015

http://www.parint.org/isajewebsite/terminology.htm
Impact around the U.S. and world…

- ONDCP – White House Office of National Drug Control Policy - efforts to change SUD terminology to reduce stigma
- NIH, SAMHSA, website/literature changes; SGR (2016)
- U.S. Associated Press (AP) style guide update on SUD
- World Federation for the Treatment of Opioid Dependence
- The European Pain Federation EFIC
- International Association for Hospice and Palliative Care
- International Doctors for Healthier Drug Policies
- Swiss Romany College for Addiction Medicine
- Swiss Society of Addiction Medicine
- … Also, called on medical journals to ensure that authors always use terminology that is neutral, precise, and respectful in relation to the use of psychoactive substances.
Our national institutes on addiction have “abuse” embedded in their names... This needs to change
The words that we use matter. Stigma has been identified as a barrier to treatment and recovery among individuals with addiction. Research shows that the commonly used term, "abuse", increases stigma.

Now is the time to tell Congress that national government agencies with words like "abuse" must undergo a NAME CHANGE (e.g., National Institute on Drug Abuse [NIDA], National Institute on Alcohol Abuse and Alcoholism [NIAAA], and Substance Abuse and Mental Health Services Administration [SAMHSA]).

Addiction is a disease. Using words such as "abuse" or "abuser" implies that addiction is a character flaw. It takes an act of congress to change a government agency name, so support is needed at all levels.

This petition was prompted by the recent brief authored by Dr. John Kelly and Valerie Earnshaw, PhD, and published by the Society of Behavioral Medicine. The brief, entitled "End the Fatal Paradox: Change the Names of our Federal Institutes on Addiction" (attached).
Reducing Stigma in Clinical Settings

Prescribe, model and reinforce, universal clinical use of appropriate, person-first, non-stigmatizing terminology pertaining to alcohol/drug use disorders and related problems

Provide continuing education on the nature (causes and impacts) of substance use to clinical leadership, practitioners, and all staff, on the importance of addressing substance use disorders on clinical, ethical, humanitarian, compassionate care grounds, as well as health economics grounds

Provide regular opportunity for interaction and exposure to recovering persons to help dismantle stereotypes and disabuse staff of faulty beliefs

Create a “recovery friendly” workplace that openly and continually supports treatment and recovery for employees suffering form SUD including employing individuals with SUD histories
Thank you for your attention!

Enhancing Recovery Through Science

recoveryanswers.org

Recovery Research Institute

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