

Cultural Competency, Stigma, and Drug User Health: Considerations for Service Providers

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About NASTAD

WHO: A non-profit, non-partisan national association founded in 1992 that represents public health officials who administer HIV and hepatitis programs funded by state and federal governments.

WHERE: All 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, seven local jurisdictions receiving direct funding from the Centers for Disease Control and Prevention (CDC), and the U.S. Pacific Island jurisdictions.

MISSION: NASTAD's mission is to end the intersecting epidemics of HIV, viral hepatitis, and related conditions by strengthening domestic and global governmental public health through advocacy, capacity building, and social justice.

VISION: NASTAD's vision is a world free of HIV and viral hepatitis.

National HIV & Hepatitis Overview

Injection Drug Use accounts for
~9% of new HIV cases ¹
Over 65% of HCV cases ²

Among people who inject drugs
60%-90% have HCV after 5 years
Median time to HCV transmission is ~3 years
And each year ~ 20-30% of PWID acquire HCV ³

Comorbidity

Among PWID and have HIV, 75% also have HCV
Among PLWHIV w/o IDU, 25% have HCV ⁴

**Life time cost of
each HIV infection is
over \$380,000 ⁵**

**Accumulated costs
of HCV care over the
next 20 years on this
trajectory over \$78
billion ⁶**

1. Centers for Disease Control and Prevention, 2017. HIV Surveillance Report, <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>

2. Centers for Disease Control and Prevention, 2016, Surveillance for Viral Hepatitis – United States, 2016. <https://www.cdc.gov/hepatitis/statistics/2016surveillance/index.htm>

3. Grebely, J. et al. 2011. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3072734/>

4. Centers for Disease Control and Prevention, 2017. HIV and Viral Hepatitis. <https://www.cdc.gov/hiv/pdf/library/factsheets/hiv-viral-hepatitis.pdf>

5. Centers for Disease Control and Prevention, 2017. <https://www.cdc.gov/hiv/programresources/guidance/costeffectiveness/index.html>

6. National Academies of Sciences, Engineering, and Medicine, 2017. <https://www.nap.edu/read/24731/chapter/8>

Diseases Associated with Injection Drug Use

- **Viral infections (bloodborne)**
 - **Hepatitis C Virus (HCV)**
 - **Hepatitis B Virus (HBV)**
 - **Hepatitis A Virus (HAV)**
 - **HIV**
- **Bacterial Infections (soft tissue/skin) ⁴**
 - **Septicemia**
 - **Bacteremia**
 - **Cellulitis**
 - **Abscesses (staph, strep)**
 - **Endocarditis**
 - **Necrotizing fasciitis**
 - **Wound botulism**

- Hepatitis C is the leading cause of death among all infectious diseases ¹
- The CDC estimates 41,200 acute HCV cases in the US in 2016 ¹
- Estimated 2.4 million people have HCV in the US (~1% of US pop.) ²
- 85% of HCV infection leads to progresses to chronic infection ¹
- IDU is currently the most common risk factor for HCV in developed countries (60-80% worldwide) ³

1. Centers for Disease Control and Prevention, 2017. <https://www.cdc.gov/hepatitis/hcv/index.htm>

2. Centers for Disease Control and Prevention, 2018. <https://www.cdc.gov/nchhstp/newsroom/2018/hepatitis-c-prevalence-estimates.html>

3. Nelson, et al. 2011. <https://www.ncbi.nlm.nih.gov/pubmed/21802134/>

4. Collier, M., et al. 2018. <https://link.springer.com/article/10.1007%2Fs10900-017-0458-9>

Hepatitis Overview

HEPATITIS A

HOW DO YOU GET IT:



Fecal-oral



Contaminated Food



Household Contact

WHAT DOES IT DO: Most adults experience symptoms

Acute infection, which usually resolves within 2 months

HEPATITIS B

HOW DO YOU GET IT:



Sexual Contact



Infected Blood



Bodily Fluids



Mother to Child

WHAT DOES IT DO: Life-long infection with no cure

Long term infection leads to liver scarring and ultimately liver cancer

Often no symptoms

HEPATITIS C

HOW DO YOU GET IT:



Dirty Works



Infected Blood



Sexual Contact

WHAT DOES IT DO: Virus slowly attacks liver over the course of infection. Often no symptoms.

Long term infection leads to liver scarring and can cause liver cancer

HEPATITIS A

HOW DO YOU STOP IT:



Improve Hygiene



Vaccinate



Access care if infected

HEPATITIS B

HOW DO YOU STOP IT:



Vaccinate



Practice Safe Sex



Manage Your Infection

HEPATITIS C

HOW DO YOU STOP IT:



Use **New Works!**



Practice Safer Sex

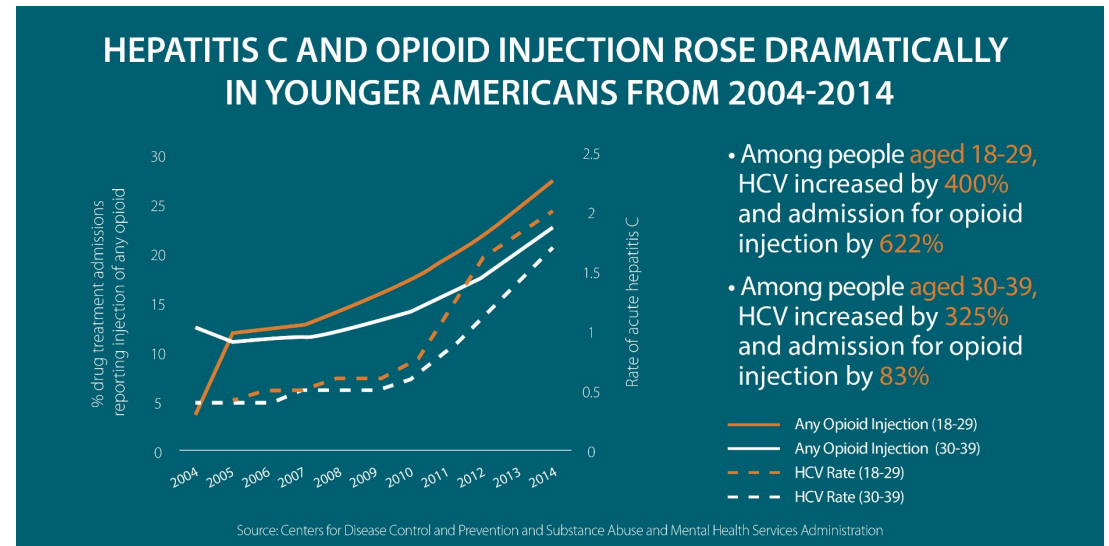


New Treatments are **EASY** and available to **EVERYONE!**

There is a CURE!!!

Huge Increases in HCV Related to Injection Drug Use

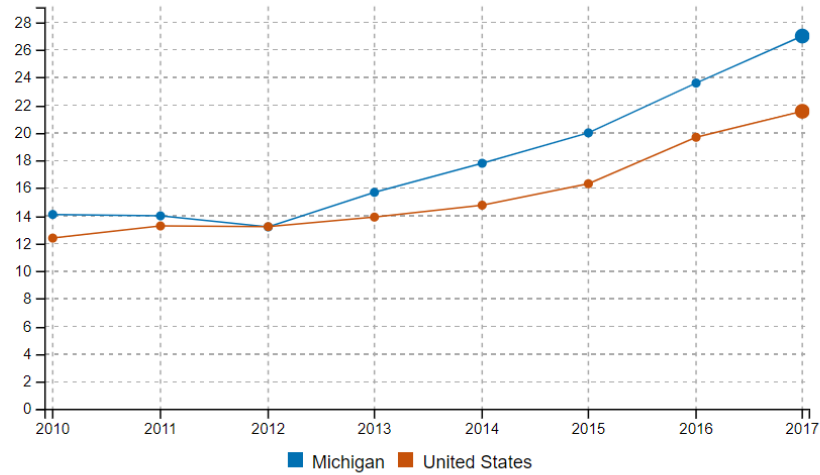
- Among 18- to 29-year-olds, there was a
 - 400 percent increase in acute hepatitis
 - 817 percent increase in admissions for injection of prescription opioids
 - 600 percent increase in admissions for heroin injection
- Among 30- to 39-year-olds, there was a
 - 325 percent increase in acute hepatitis C
 - 169 percent increase in admissions for injection of prescription opioids
 - 77 percent increase in admissions for heroin injection
- There were also sharp increases among whites and among women



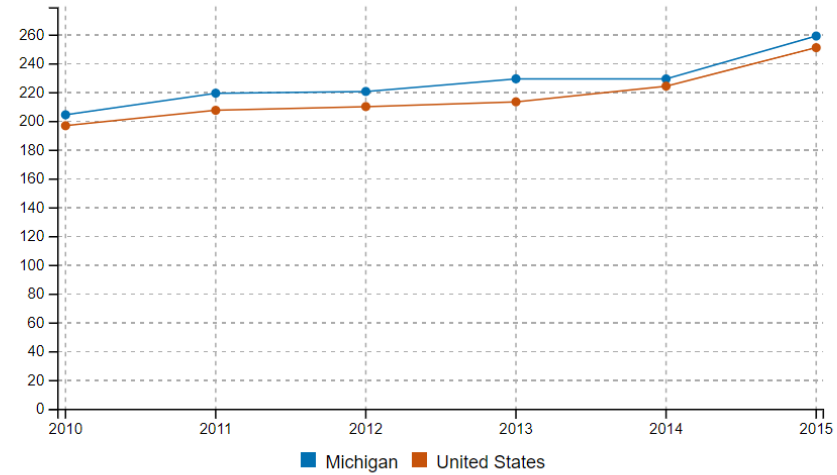
Zibbell, J., et al. 2017. <https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2017.304132>

Michigan Specific Increases

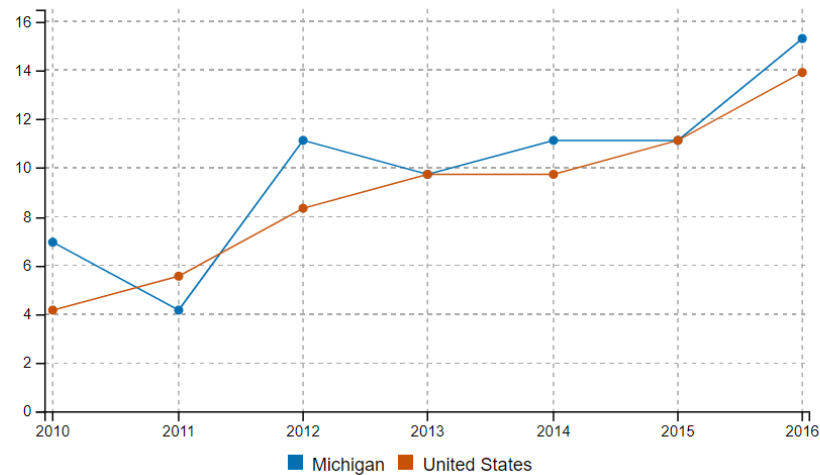
Drug-related Deaths per 100,000 ⓘ



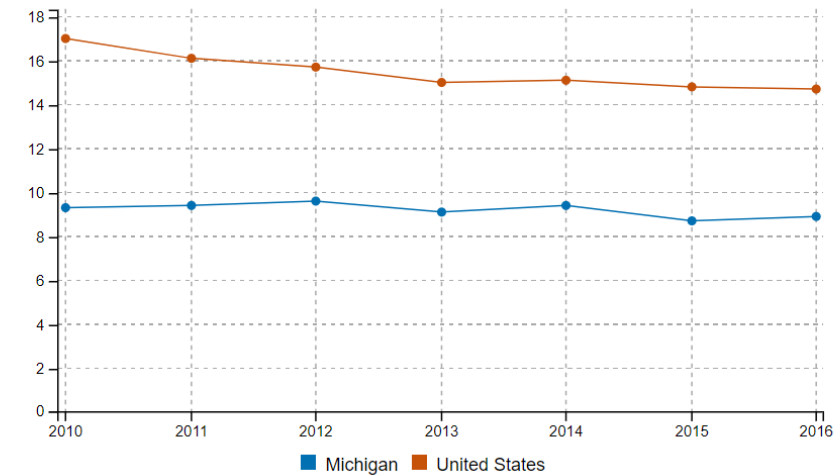
Inpatient Stays Resulting from Opioids per 100,000 ⓘ



Estimated Acute Hepatitis C Cases per 100,000 ⓘ



New HIV Diagnoses per 100,000 ⓘ



Michigan Specific Statistics

Injection Drug Use accounts for:

Approximately 12.8% of all HIV diagnoses among men (IDU+MSM/IDU) and 7% of all new diagnoses

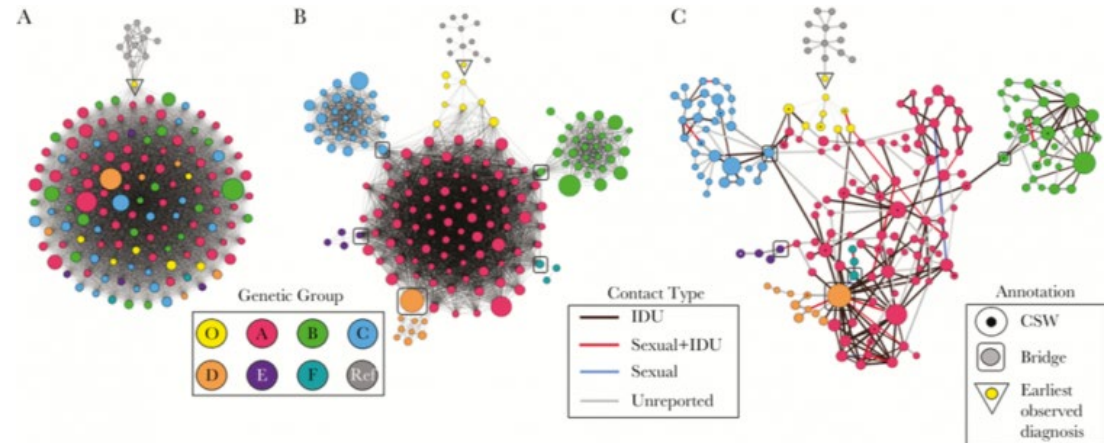
Approximately 21.4% of all HIV diagnoses among women and 20.5% of all new diagnoses

In 2010, an estimated 70,000 people in Michigan had hepatitis C or 910/100,000 (2013-16)

In 2016, there were 415 deaths related to hepatitis C in Michigan or 4/100,000

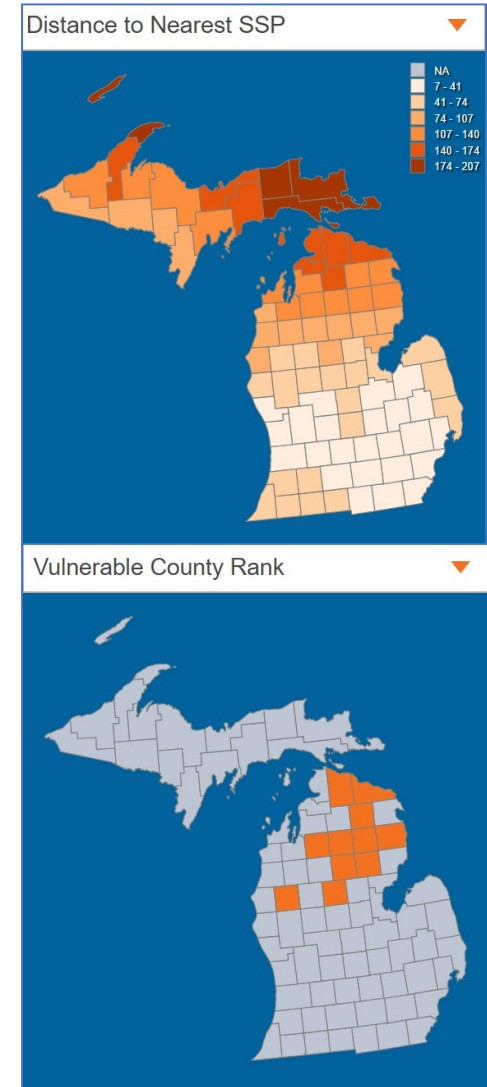
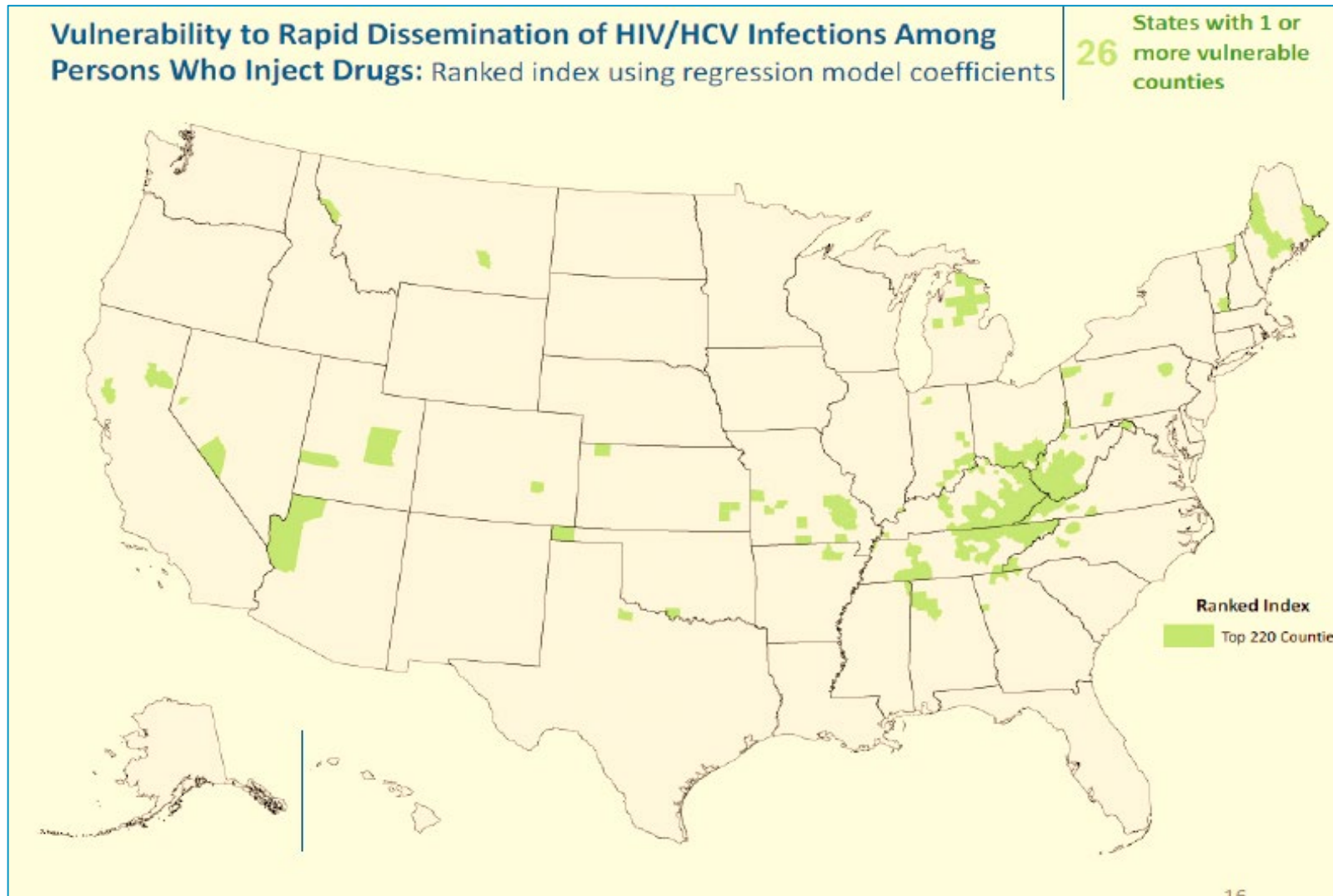
Scott County, Indiana

- HIV Outbreak in Austin, Indiana (pop. 4,200) in 2015
- Over 200 cases of HIV were eventually attributed to injection drug use behavior
- Only had 5 reported cases of HIV in the previous decade
- Within this initial outbreak 115 persons were co-infected with HCV and currently 92% are co-infected ¹

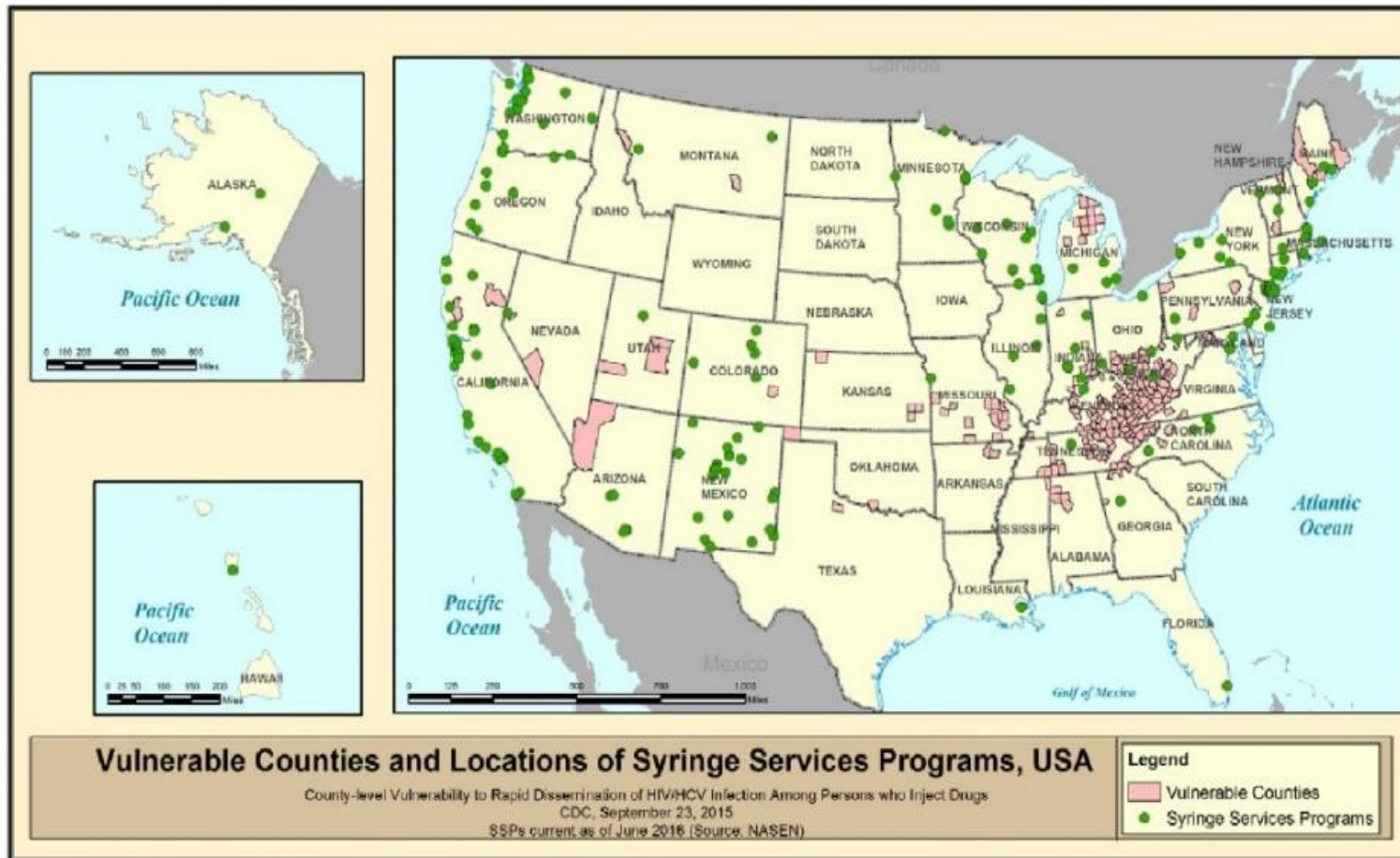


1. Peters, P. et al. 2016. <https://www.nejm.org/doi/full/10.1056/NEJMoa1515195>

HIV/HCV Vulnerable Counties



So What Can Be Done to Decrease HIV/HCV?



Syringe Services Programs

- Most effective way to prevent infectious disease transmission for PWIDs ¹
- Do not increase drug use or crime ²
- SSP participants are 5 times more likely than nonparticipants to enter treatment ³

Source: Van Handel, et al. JAIDS; in press

1. Centers for Disease Control and Prevention, 2016. <https://www.cdc.gov/vitalsigns/hiv-drug-use/index.html>
2. European Monitoring Centre for Drugs and Drug Addiction, 2010. http://www.emcdda.europa.eu/publications/monographs/harm-reduction_en
3. Centers for Disease Control and Prevention, 2017. <https://www.cdc.gov/hiv/pdf/risk/cdchiv-fs-syringe-services.pdf>

Harm Reduction Philosophy

A set of practical, public health, strategies designed to reduce the negative consequences of drug use and promote healthy individuals and communities

Harm Reduction Principles

Health and
Dignity

Participant-
centered

Participant
involvement

Participant
autonomy

Sociocultural
complexity

Pragmatism
and realism

Stages of Change



- Prochaska, DiClemente & Norcross -1992
- Transtheoretical Model
 - Change is gradual
 - Change is cyclical and constant
 - Change is progressive and sequential
 - Change has six basic stages
 - Relapse is likely and still progress
 - Important to meet people at their stage not yours

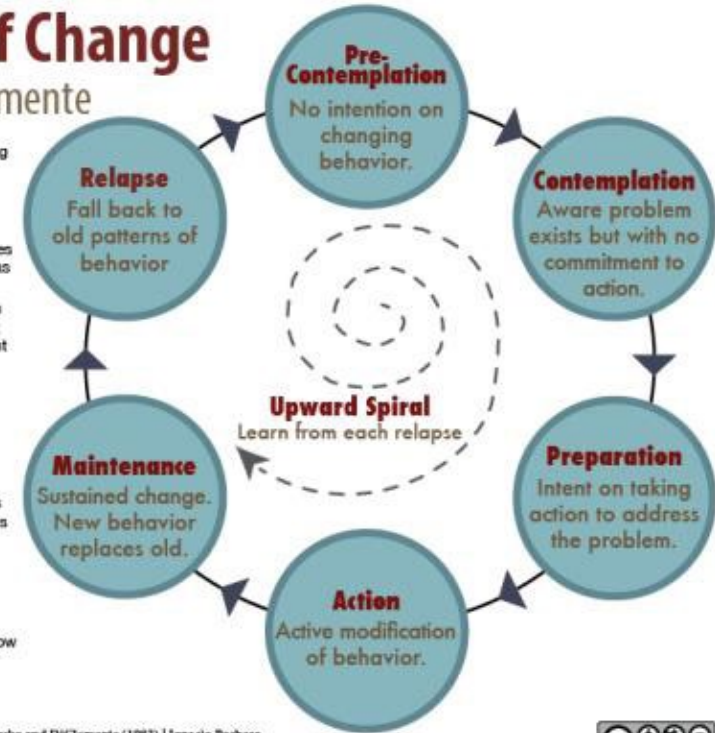
Stages of Change

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance
- Relapse/Recycle

The Cycle of Change

Prochaska & DiClemente

- **Precontemplation:** A logical starting point for the model, where there is no intention of changing behavior; the person may be unaware that a problem exists
- **Contemplation:** The person becomes aware that there is a problem, but has made no commitment to change
- **Preparation:** The person is intent on taking action to correct the problem; usually requires buy-in from the client (i.e. the client is convinced that the change is good) and increased self-efficacy (i.e. the client believes s/he can make change)
- **Action:** The person is in active modification of behavior
- **Maintenance:** Sustained change occurs and new behavior(s) replaces old ones. Per this model, this stage is also transitional
- **Relapse:** The person falls back into old patterns of behavior
- **Upward Spiral:** Each time a person goes through the cycle, they learn from each relapse and (hopefully) grow stronger so that relapse is shorter or less devastating.

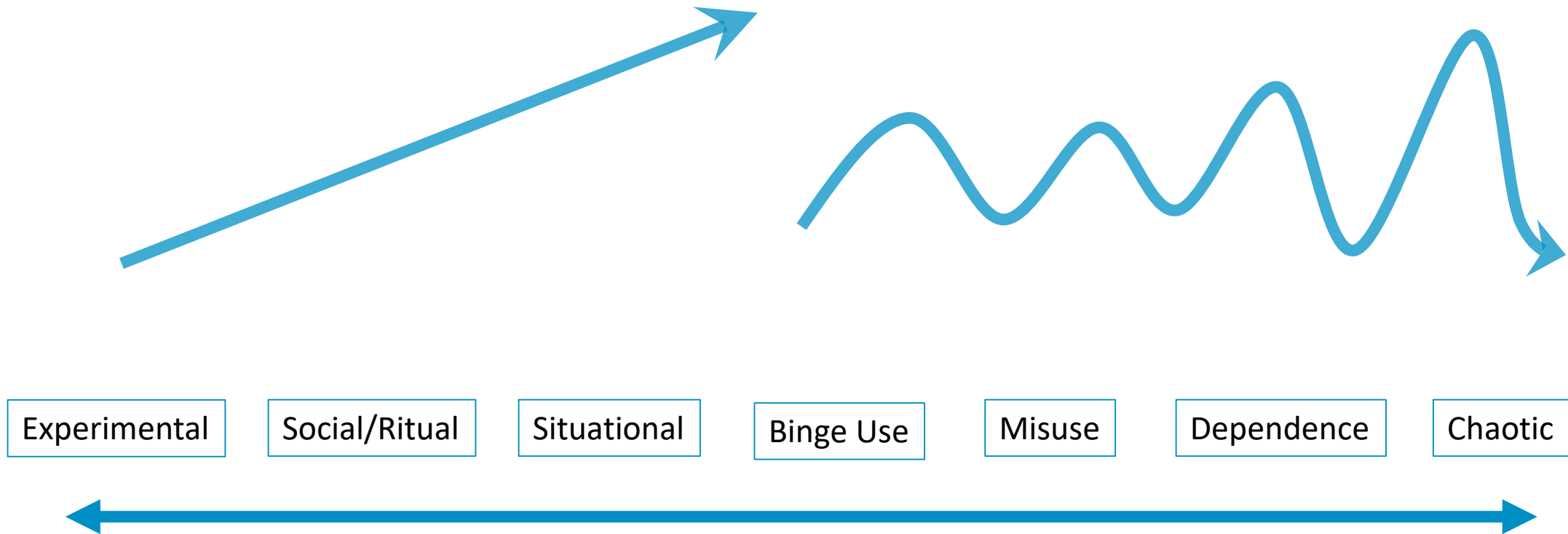


The Cycle of Change
Adapted from a work by Prochaska and DiClemente (1983) | Ignacio Pacheco
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So why do people use drugs?

Continuum of Drug Use



Circumstances of Drug Use

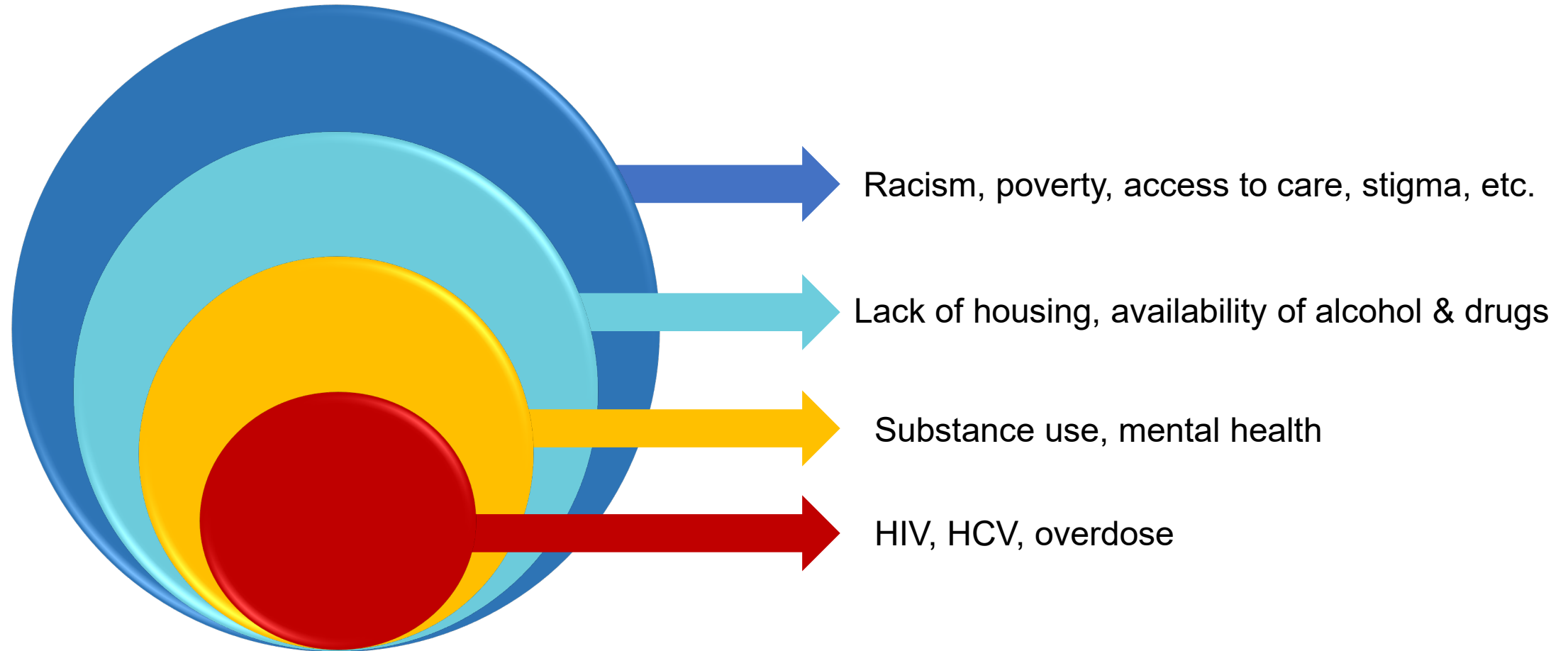
Drug, Set, and Setting - Norman Zinberg, studies between 1972 – 1984

- Found 3 major criteria for what created either benign or chaotic use
 - The Drug – this is the type of drug, the amount, the route of administration, the frequency of use, etc.
 - The Set – refers to the mindset or attitude about use
 - The Setting – this refers to the context of use—basically where the drug is consumed and with whom

The Vietnam Studies – Lee Robbins, 1974

- Examined heroin use among Vietnam Veterans once they completed service
- Found that MOST did not continue use (99%), even though they exhibited physical dependence previously, without obtaining treatment
 - Most cited a change in stress level, change in environment, and family perceptions of drug use

Social Determinants of Drug User Health











So who works with people who use
drugs?

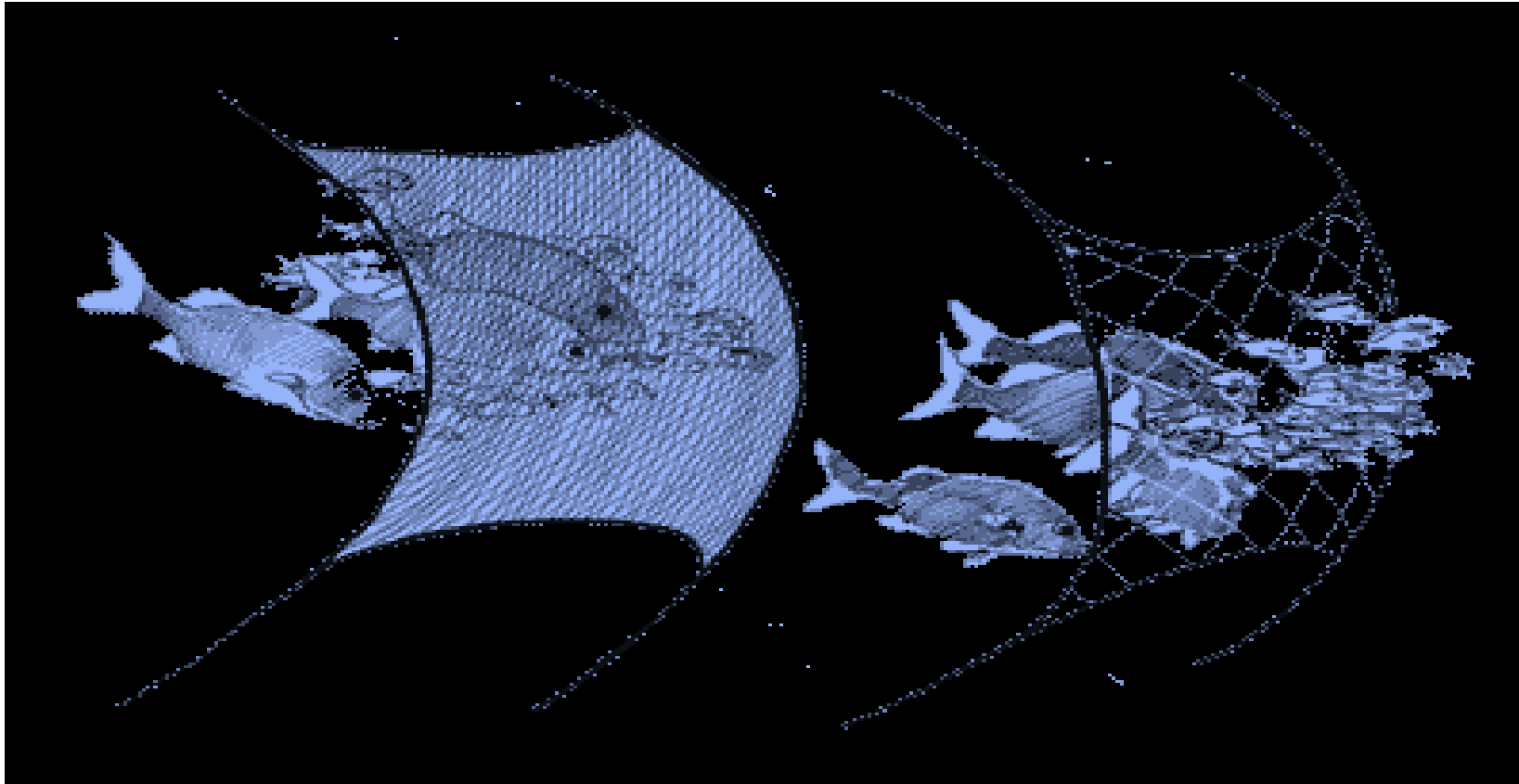
Systems that touch People who use Drugs



Continuum of Drug User Health Services

DRUG USER HEALTH SERVICES CONTINUUM			
SERVICE ENTRY POINT/GATEKEEPER	SERVICES TO PREVENT INFECTIOUS DISEASES	ADDICTION AND OVERDOSE TREATMENT: OUTPATIENT	ADDICTION TREATMENT: INPATIENT
<ul style="list-style-type: none"> Insurance application and enrollment assistance Navigation and linkage of social, housing, and supportive services Navigation and linkage to clinical care 	<ul style="list-style-type: none"> HIV testing HCV testing Syringe and paraphernalia exchange Education on safe injecting practices 	<ul style="list-style-type: none"> MAT Naloxone Outpatient individual and group counseling 	<ul style="list-style-type: none"> Hospital stay Inpatient mental health or SUD treatment
 PROVIDER TYPES Navigator, Certified Application Counselor, case manager, community health worker, peer navigator	 PROVIDER TYPES Case manager, nurse, community health worker, peer navigator	 PROVIDER TYPES Pharmacist, physician, social worker, case manager, peer navigator	 PROVIDER TYPES Physician, psychiatrist
 PRIMARY SETTING Community	 PRIMARY SETTING Community	 PRIMARY SETTING Community and Clinical	 PRIMARY SETTING Clinical

Prevention and Treatment Binary



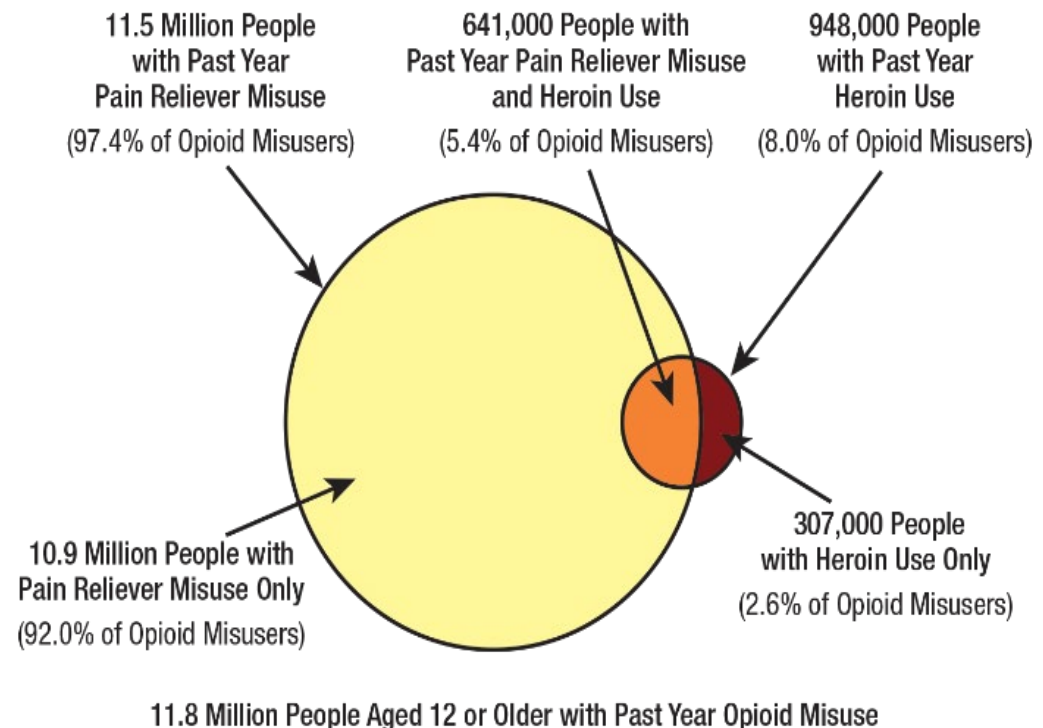
Prevention → → → → Harm Reduction → → → Treatment

Prevention and Treatment Binary

According to the SAMHSA, in 2016:

- Approximately 10% of the US population used illicit substances (past month)
- 11.8 million people over the age of 12 or 4.4% of the US population used prescription pain killers or heroin (past year)

Figure 27. Past Year Opioid Misuse among People Aged 12 or Older: 2016

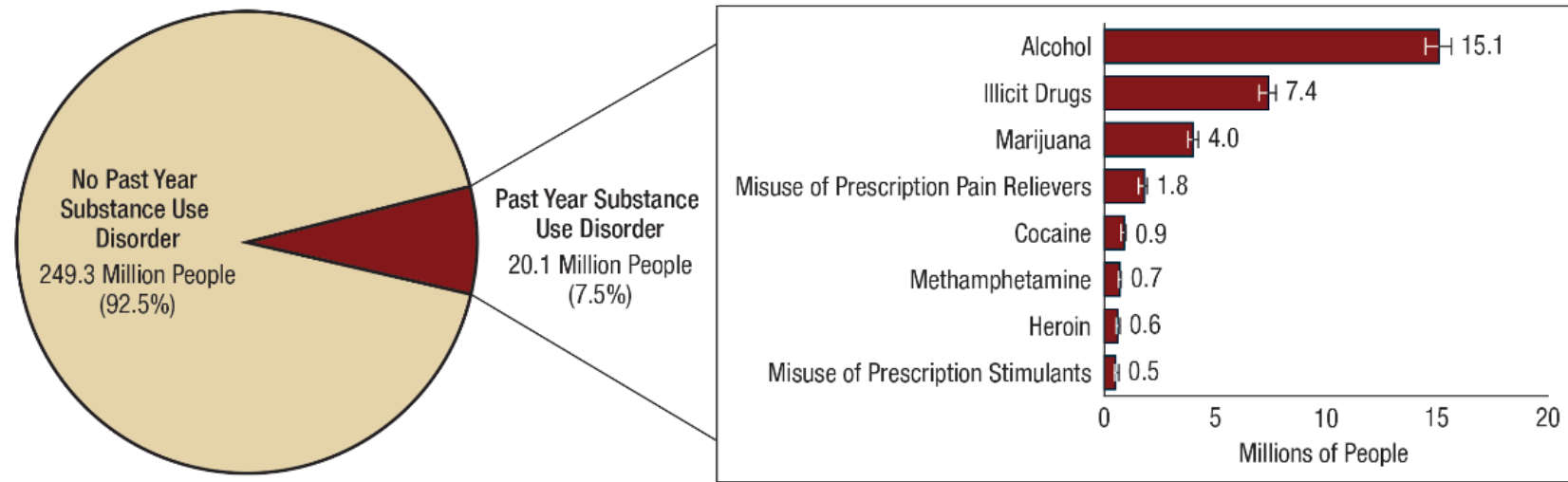


Note: Opioid misuse is defined as heroin use or prescription pain reliever misuse.

Prevention and Treatment Binary

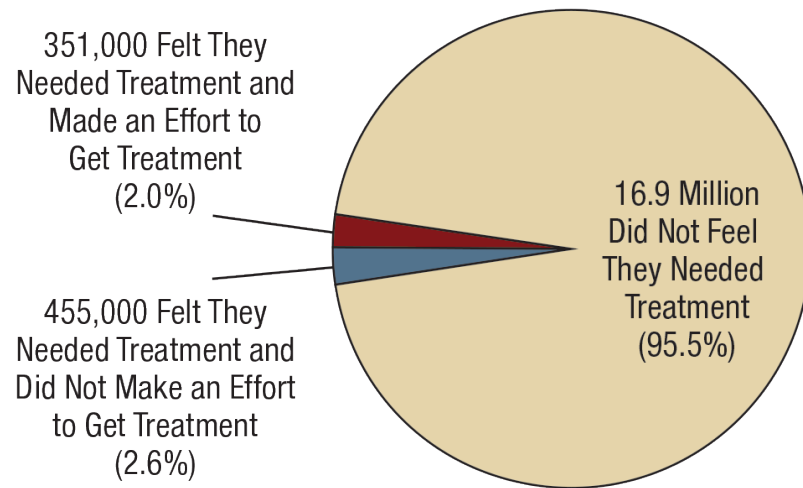
- Within the same data, we can see that a majority of Substance Use Disorders are related to alcohol – not illicit drugs
- Drug User Health/Harm Reduction services are useful for everyone using substances, legal or not

Numbers of People Aged 12 or Older with a Past Year Substance Use Disorder: 2016



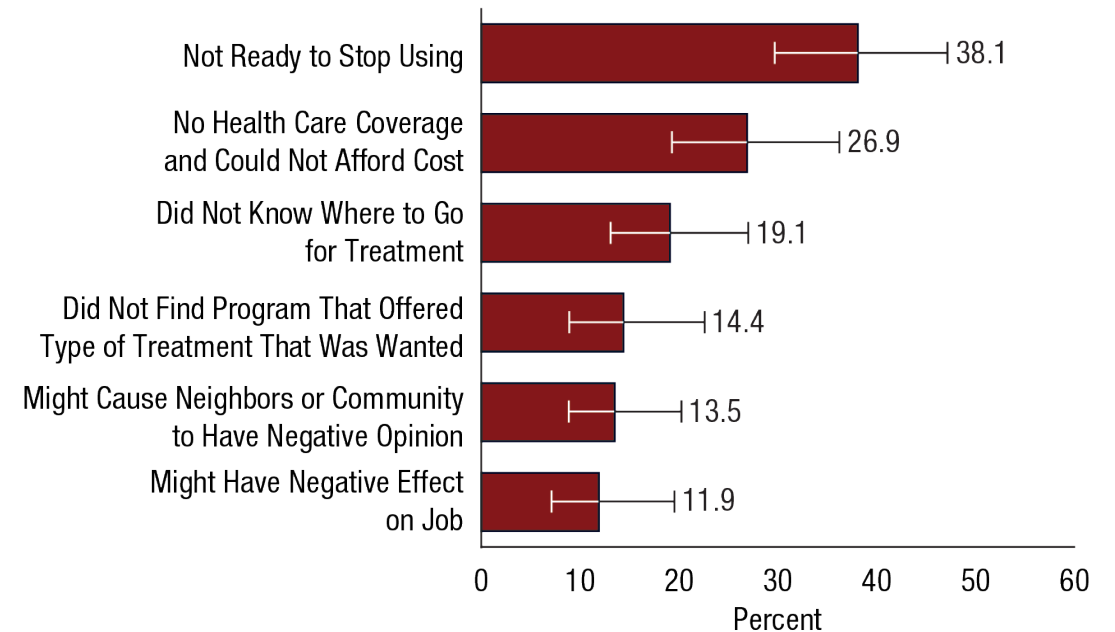
Prevention and Treatment Binary

Perceived Need for Substance Use Treatment among Adults Aged 18 or Older Who Needed but Did Not Receive Substance Use Treatment in the Past Year: 2016



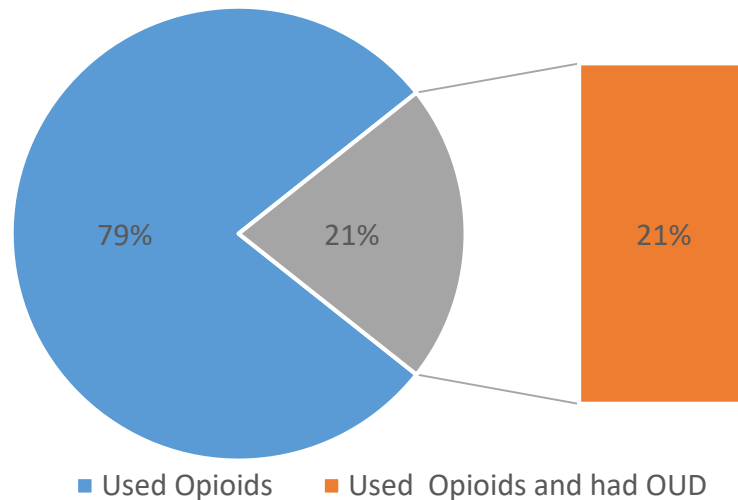
17.7 Million Adults Needed but Did Not Receive Substance Use Treatment

Reasons for Not Receiving Substance Use Treatment in the Past Year among Adults Aged 18 or Older Who Felt They Needed Treatment in the Past Year: Percentages, 2016



Prevention and Treatment Binary

Prescription Drug Misuse and Heroin Use, age >12, 2016



So that means 79% or 9.4 million people who are actively using opioids will not be identified as needing OUD services

- Of the 11.8 million people who used opioids in 2016, only 2.4 million were diagnosed as having an Opioid Use Disorder (OUD) – this is less than 1% of the US population
- Which leaves 9.4 million people using opioids who do not qualify as having an OUD
- Regardless of OUD numbers, some individuals might not ever want or seek treatment
- EVERYONE using drugs needs a range of services to reduce overdose risk, prevent HIV and hepatitis transmission, and reduce collateral consequences related to their substance use

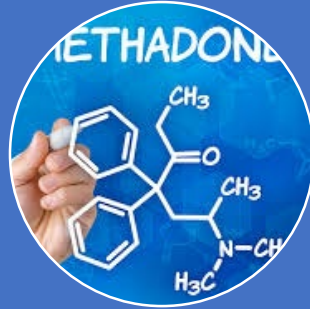
Comprehensive Approach



HCV/HIV
Testing and
Treatment



Mental Health
Services



Medication
Assisted
Treatment



PREP for
PWUDs



Naloxone, SSPs,
and Supervised
Injection
Facilities



Drug User Stigma

Myths and Facts

Myths

- You always know when people are on a drug
- An “addict” will ALWAYS be an “addict”
- Abstinence is the only real recovery
- Using medication as treatment mean you aren’t really recovered
- Drug Users can’t adhere to medication

Facts

- Many people use drugs and you’d never know
- PWUDs will transition from chaotic to benign use
- Recovery can include abstinence but could also look differently
- MAT is evidence-based and considered the gold standard
- PWUDs are just as likely to adhere to medication as others

Stigma

“a set of negative and often unfair beliefs that a society or group of people have about something”

“a mark of shame or discredit---an identifying mark or characteristic; *specifically* : a specific diagnostic sign of a disease”

<https://www.merriam-webster.com/dictionary/stigma>

Stigma

- Based on Social Control Theory – Hobbes, Foucault, Puritans
 - A social process which reinforces relations of power and control
 - Stigma, and the extent to which it is successfully attributed and accepted, should be understood from the unequal (social) power relations from within the context it operates.
- Stigma is Intersectional – multiple stigmatized identities will equal compounded experience of stigma and repression
 - Many groups are stigmatized for the same activity differently
- Stigma takes several forms – individual, institutional, internalized, by association

Stigma

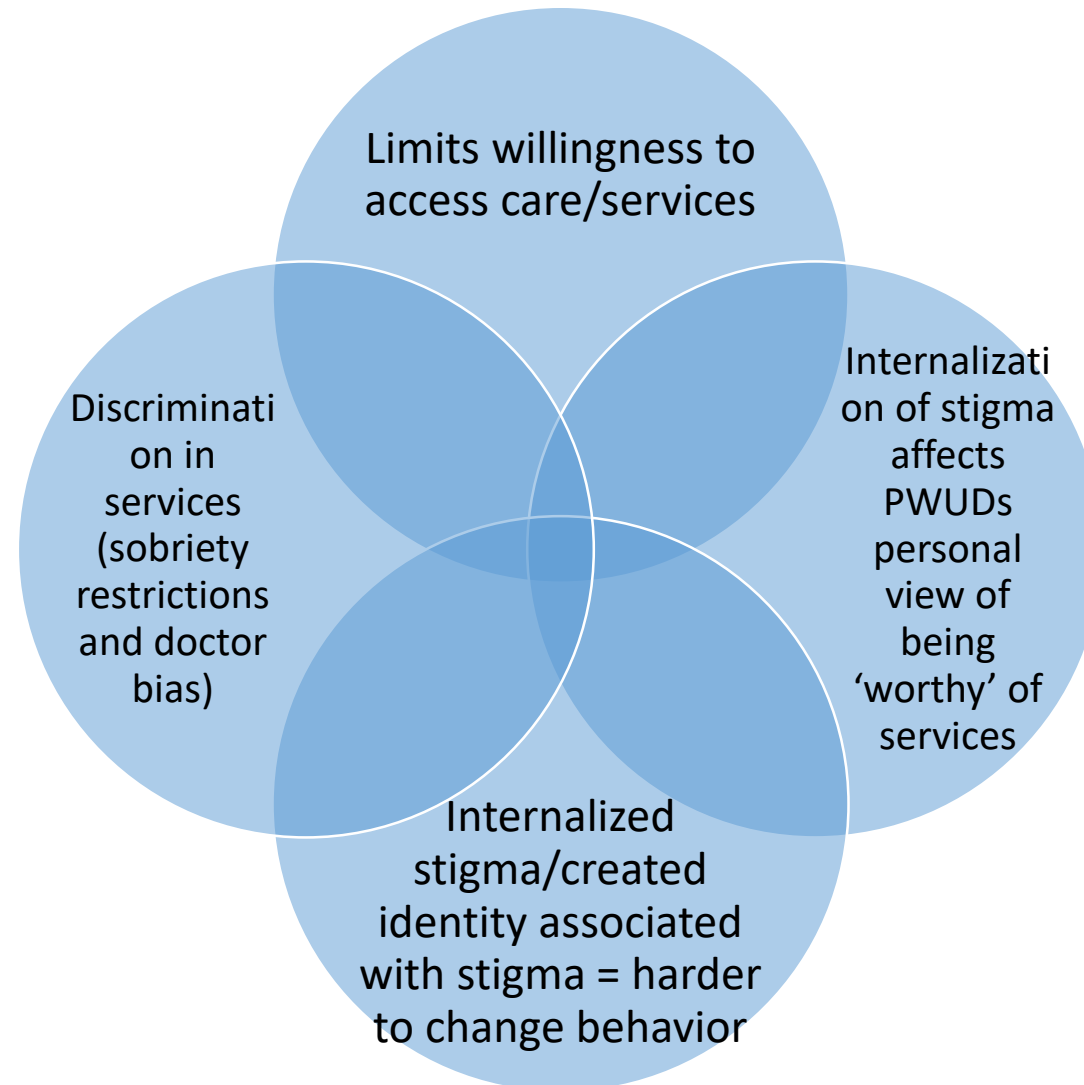
Stigma
Serves
to:

- **Regulate** - Control and enforce behavior
- **Isolate** - Decrease contact with the stigmatized
- **Relegate** - Distinguish the stigmatizer from the stigmatized
- **Discriminate** - Perpetuate/maintain difference

Stages of Stigma




Stigma – Impacts on Health




HCV Treatment

- Direct Acting Antivirals (DAAs) without interferon for HCV came on the market in 2014
- 8-12 week treatment time with a 95% cure rate
- Reinfection occurs in less than 5% of patients
- Cost is high yet constantly decreasing and being negotiated
- The majority of new infections are among PWIDs so we need to treat people as they are actively using to reduce viral load within that community

WORLD HEPATITIS DAY | JULY 28th 

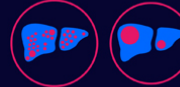
KNOW HEPATITIS ACT NOW

DEMAND TREATMENT!




OVER 90%

of people with Hep C can be completely cured of the virus within 3-6 months

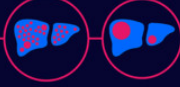
Treatment of Hep B & C can prevent life-threatening cirrhosis & liver cancer 

KNOW HEPATITIS **GET TESTED** **DEMAND TREATMENT**

KNOW HEPATITIS DEMAND TREATMENT!




OVER 90% of people with Hep C can be completely cured of the virus within 3-6 months


Treatment of Hep B & C can prevent life-threatening cirrhosis & liver cancer 

KNOW HEPATITIS ACT NOW


ARE YOU AT RISK?

GET TESTED! **DEMAND TREATMENT!**

WORLD HEPATITIS DAY | JULY 28th 

 **ACCESS TO HEPATITIS C TREATMENT 2016**

Of **80 million** people infected - over **1 million** had access to Hep C treatment



We have a long way to go

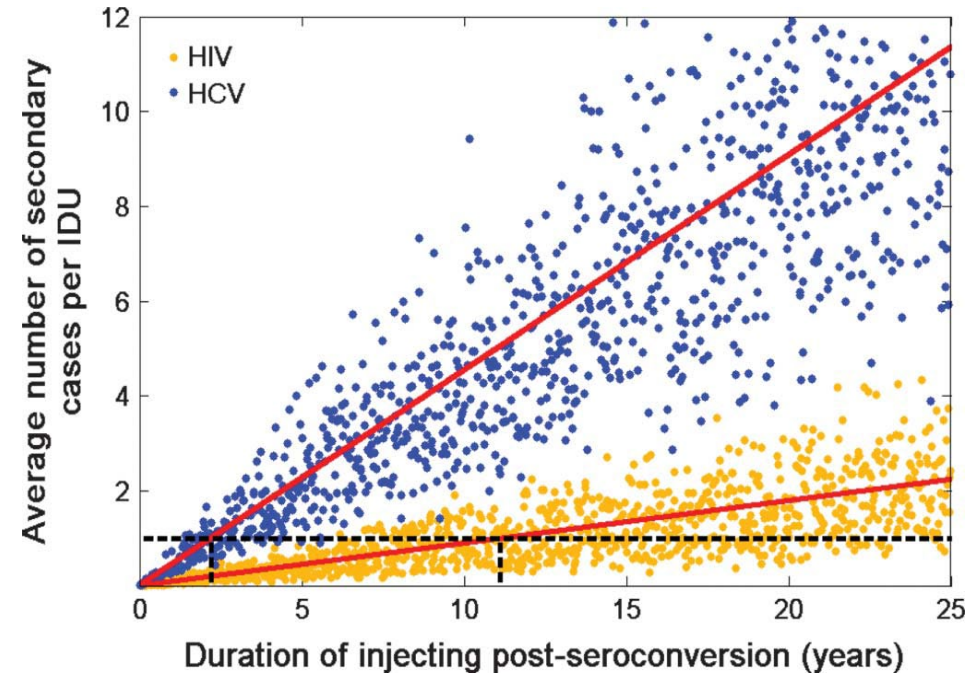
THE NEW HEP C TREATMENTS

TALK TO YOUR DOCTOR, NURSE OR CLINIC ABOUT GETTING READY FOR TREATMENT

SINGLE PILL MADE UP OF SOFOBUVIR AND LEDIPASVIR	SOFOBUVIR PILL AND DAASAVIR PILL	SOFOBUVIR PILL AND DAACLATASVIR PILL	PARITAPREVIRITONAVIR/OMBITASVIR PILL AND DASABUVIR PILL
HARVONI	SOVALDI & IBAVYR	SOVALDI & DAKLINZA	VIEKIRA PAK (SOMETIMES WITH SOVALDI)
FOR GENOTYPE 1	FOR GENOTYPE 2	FOR GENOTYPES 1 & 3	FOR GENOTYPE 1
95% OF PEOPLE CURED*	95% OF PEOPLE CURED*	95% OF PEOPLE CURED*	95% OF PEOPLE CURED*
8, 12 OR 24 WEEKS*	12 WEEKS*	12 OR 24 WEEKS*	12 OR 24 WEEKS*

HCV Screening and Treatment as Prevention

- Curative HCV treatment has been shown to decrease the presence of the viral load and reduce transmission rates overall
- Recent studies suggest that just being aware of HCV infection increased the likelihood of changing substance use behavior



Nelson PK, Lancet 2011, Hagan et al. 2010; Garfein et al. 1998; Armstrong et al. 2006, Amon et al. 2008; Klevens et al. 2013; Daniels et al. 2007; Amon et al. 2008; Weissing L, PlosOne 2014; Grebely PLOS ONE 2014; Clatts MC, J Urban health 2010; Page Clin infect dis, 2013

Sobriety/Fibrosis Restrictions and HCV Treatment

Discriminatory State Medicaid Restrictions Include:

Liver Disease Progression

Requiring that patients reach a certain stage of fibrosis (liver disease), which can be irreversible and cause cancer.

Bans on Former Substance Users

Barring patients with a history of alcohol or substance use.

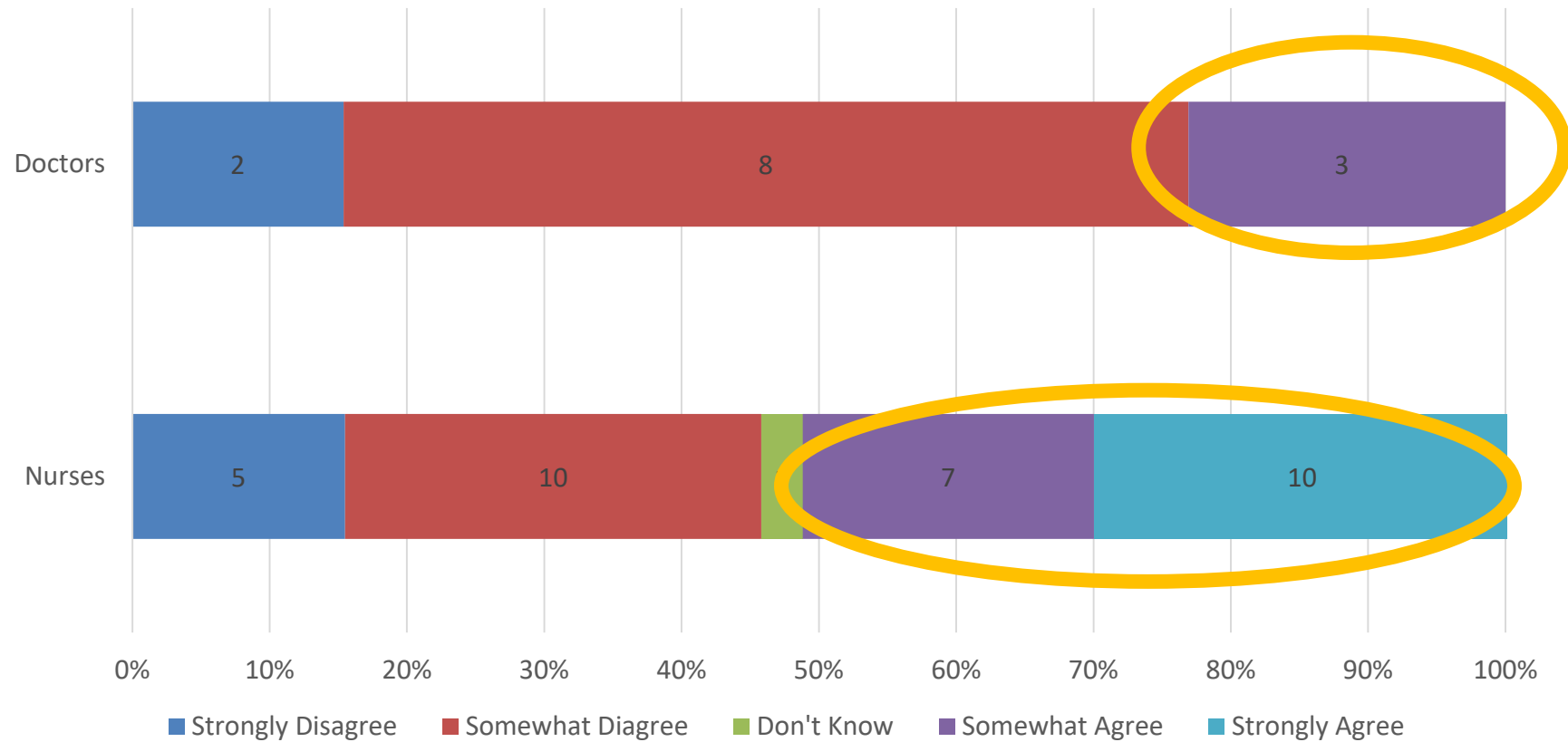
Prescriber Restrictions

Only allowing certain specialists, who can be difficult to find, to prescribe a cure.

- Numerous studies have shown that adherence among PWUDs is just as high as those who do not use drugs (92-97% adherence overall among PWUDs)
- Treating new HCV infections is cost saving compared to waiting until patients have high fibrosis scores
- It is discriminatory and unethical to not treat based on sobriety or because of financial limitations

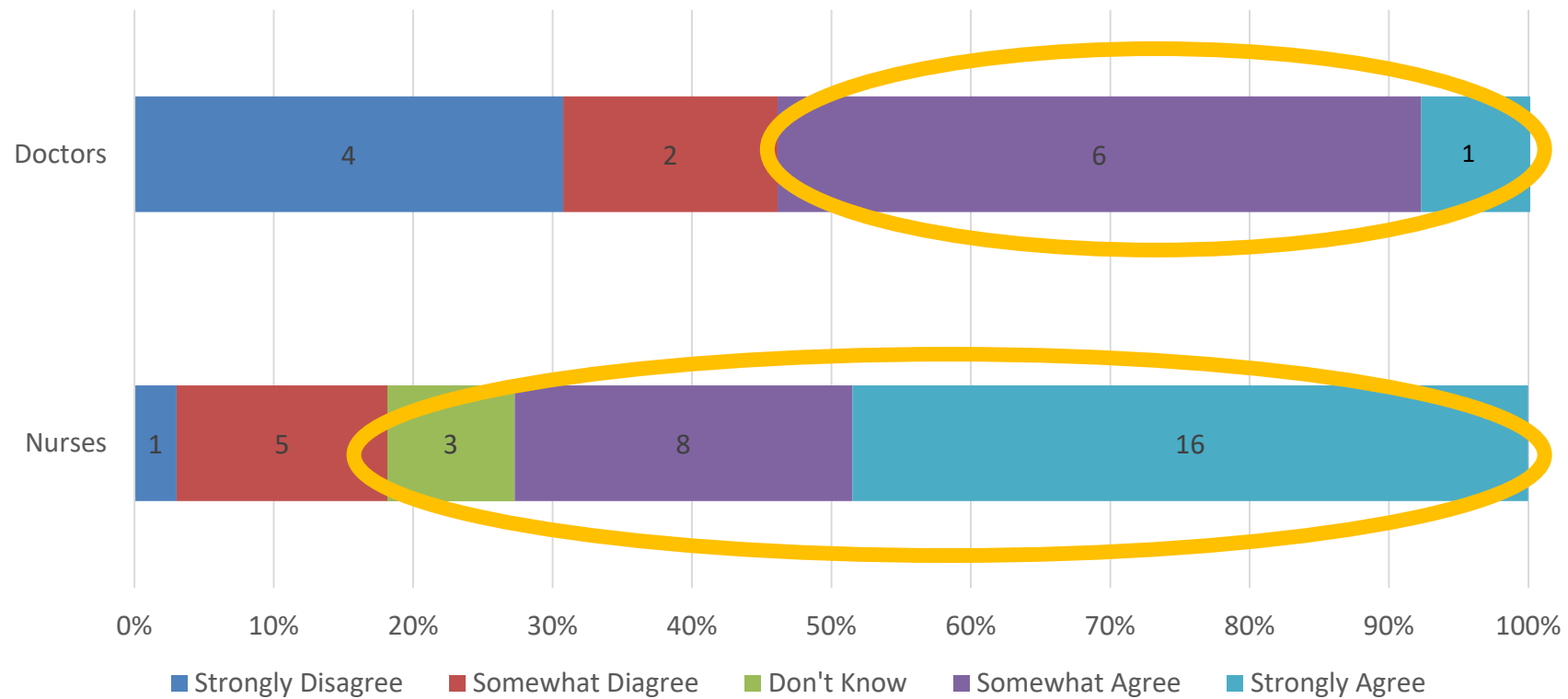
Provider Survey in Louisiana

PWUD are unlikely to adhere to HCV medication regimens



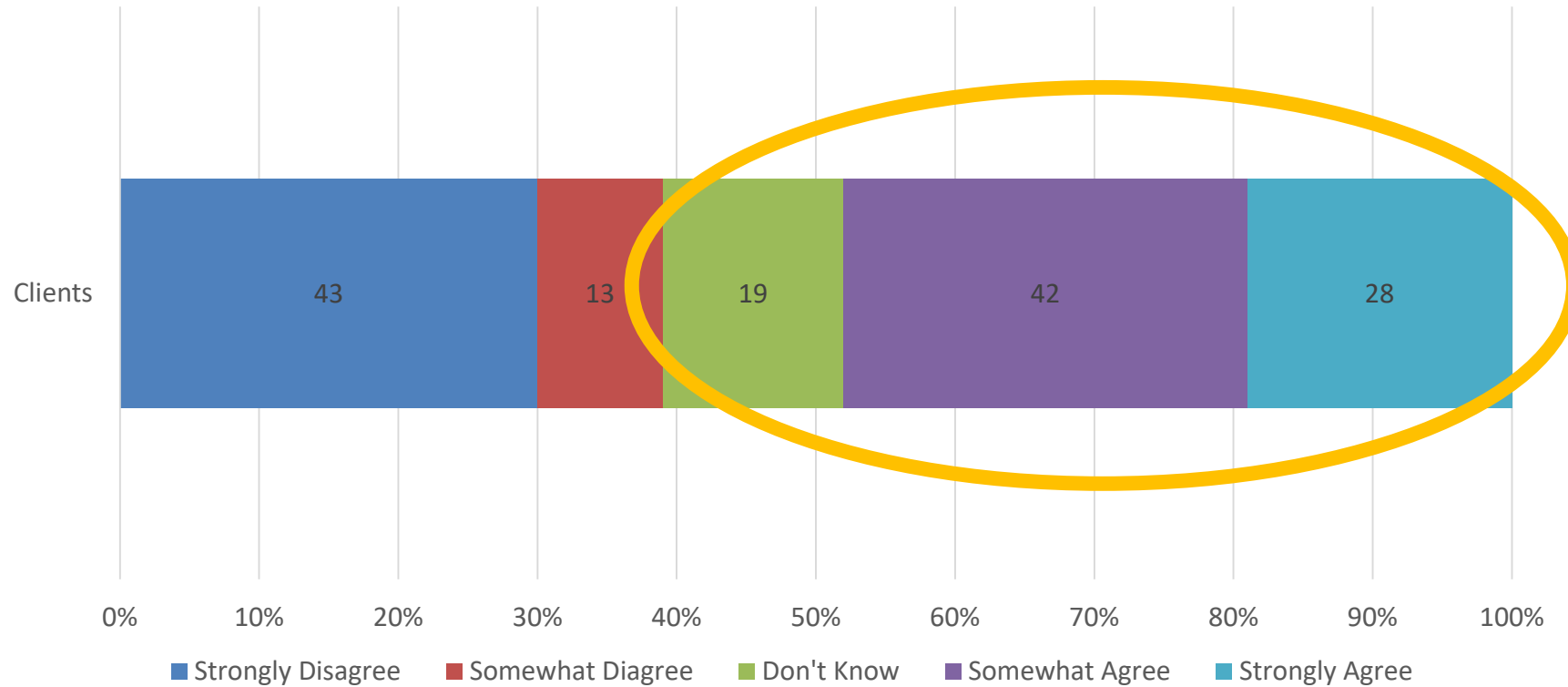
Provider Survey in Louisiana

It is recommended that substance users have a period of 6 month abstinence before beginning HCV treatment



Provider Survey in Louisiana

People have been treated poorly or unfairly by doctors or health care workers because of their substance use.



Strategies for Challenging Stigma

Individual Level

- Language
- Relationships, honesty & authenticity
- Disclosure and dialogue
- Education and personal development

Organizational Level

- Training and education
- Outlets for feedback
- Assessment of practices
- Hiring drug users

Community Level

- Participant Advisory Boards
- Awareness campaigns
- Policy and advocacy
- Events

Person-Centered Language

Linguistic prescription to avoid marginalization and dehumanization regarding a health issue or disability

Best practices:

- Don't describe people by their illness/disability/drug use (addict, alcoholic, epileptic, psychotic)
- Recognize the complexity/many identities people have
- Don't use morally-loaded descriptions when describing someone (dirty, clean, junkie)
- Avoid using group/illness/disability language to describe negative states (gypped, retarded, crazy, spaz)
- Value the preferences of the person, rather than your opinion (addict as self-identification vs. label)
- Language is powerful – it can build bridges or marginalize



Personal Autonomy

An individual's capacity for self determination or self-governance.

Working with people who use drugs requires respect for the choices of the people with whom you are working. It may not be the choice you would make but it is ESSENTIAL you respect the choices of the person as their right.

Recognize that most often, people are making the best choices they can with the tools and resources they have

Radical Neutrality

Providing Harm Reduction services requires a willingness to:

“practice radical neutrality; grapple with ethical gray areas; tolerate, accept, and understand difficult behaviors; be taught by our clients; relinquish the role of authority, judge, or expert; [and] partner with clients”.

-Pat Denning and Jeannie Little

Co-Founders of the Center for Harm Reduction Therapy

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www.nastad.org