

Houston Area HIV Services Ryan White Planning Council

Affected Community Committee Meeting

12 noon, Monday, November 12, 2018

Meeting Location: 2223 West Loop South, Room 240

Houston, TX 77027

AGENDA

- I. Call to Order Rodney Mills and
Tana Pradia, Co-Chairs
 - A. Welcome
 - B. Announce who will be chairing the meeting
 - C. Moment of Reflection
 - D. Adoption of the Agenda
 - E. Approval of the Minutes

- II. Public Comment
(NOTE: If you wish to speak during the Public Comment portion of the meeting, please sign up on the clipboard at the front of the room. No one is required to give his or her name or HIV status. All meetings are audio taped by the Office of Support for use in creating the meeting minutes. The audiotape and the minutes are public record. If you state your name or HIV status it will be on public record. If you would like your health status known, but do not wish to state your name, you can simply say: "I am a person living with HIV", before stating your opinion. If you represent an organization, please state that you are representing an agency and give the name of the organization. If you work for an organization, but are representing yourself, please state that you are attending as an individual and not as an agency representative. Individuals can also submit written comments to a member of the staff who would be happy to read the comments on behalf of the individual at this point in the meeting.)

- III. Old Business Tori Williams
 - A. Update on Standards of Care/Performance Measures
 - B. Updates on Road 2 Success
 - C. Sign up for World AIDS Day Events
 - D. Other Community Events
 - E. Greeters

- IV. New Business Tori Williams
John Poole
 - A. Request from Council: Host some evening meetings in 2019?
 - B. Houston Health Dept. Prevention Marketing Workgroup

- V. Announcements

- VI. Adjourn

- VII. Members meet with committee mentor Allen Murray

Houston Area HIV Services Ryan White Planning Council**Affected Community Committee Meeting**

12 noon, Monday, October 15, 2018

Meeting Location: 2223 West Loop South, Room 416, Houston, TX 77027**MINUTES**

| MEMBERS PRESENT | MEMBERS ABSENT | OTHERS PRESENT |
|------------------------|------------------------|-------------------------------------|
| Tana Pradia, Co-Chair | Ruth Atkinson | Reachelian Ellison, TRG (via phone) |
| Rodney Mills, Co-Chair | Rosalind Belcher | Samantha Bowen, RWGA |
| Skeet Boyle | Herman Finley | |
| Johnny Deal | Arlene Johnson | <i>Office of Support</i> |
| Ronnie Galley | Denis Kelly, excused | Tori Williams |
| Mona Cartwright-Biggs | Allen Murray | Rod Avila |
| Eddie Givens | John Poole | |
| Lionel Pennamon | Isis Torrente | |
| Veria Steptoe | Veronica Ardoin | |
| | Ma'Janae Chambers | |
| | Amber David | |
| | Holly McLean | |
| | Crystal Starr, excused | |
| | Roy Wesley | |

Call to Order: Tana Pradia, Co-Chair, called the meeting to order at 12:09 p.m. and then asked for a moment of reflection.

Adoption of the Agenda: ***Motion #1:*** *it was moved and seconded (Boyle, Pennamon) to adopt the agenda with one addition: Under Old Business add A. Standards of Care and Performance Measures. Motion carried unanimously.*

Approval of the Minutes: ***Motion #3:*** *it was moved and seconded (Boyle, Mills) to approve the September 17, 2018 minutes. Motion carried. Abstentions: Galley, Steptoe, and Deal.*

Public Comment: Ellison (via phone) read her public comment regarding the need to collect documented information regarding consumer concerns about dental care. After members reviewed the public comment and discussed the items that Ellison would like the Committee to help with, it was agreed by consensus to table further discussion until Ellison is available to meet with the committee in person.

New Business

Standards of Care and Performance Measures: Samantha Bowen introduced herself to the committee members as the Project Coordinator of Quality Management for Ryan White Grant Administration. She outlined the current process for reviewing Standards of Care and how

recommendations from Ryan White workgroups are processed by her office moved forward to the Quality Improvement Committee.

Road 2 Success: Emergency Preparedness Training for the HIV Community: Pradia summarized the results of the *Emergency Preparedness Training for the HIV Community*, see attached.

Road 2 Success events in 2019: Williams stated that upcoming Road 2 Success training programs will integrate the Committee's original suggestion of having agencies describe all services available at that particular agency.

Community Events: Committee members signed up to staff booths at community events, see the attached schedule of events. Pradia and Boyle asked for an update on new display materials. Williams stated that she is not sure that there are funds in the budget to provide new display materials in fiscal year 2018, but there are funds available in fiscal year 2019. In the meantime, the Office of Support is putting some ideas together.

Greeters: Members reviewed the 2018 list of greeters at monthly Council meetings, see attached. On November 8, Galley will substitute for Boyle as a greeter.

New Business

Houston Health Department Prevention Marketing Workgroup: Williams informed the committee that Denis Kelly and John Poole are participating in the Houston Health Department Prevention Marketing Workgroup. Since the workgroup has not met, there have been no reports.

Announcements: Boyle reminded the committee that certain Administrative Agency personnel have the authority to review a Ryan White funded consumer's medical record.

Adjourn: Motion #6: *it was moved and seconded (Givens, Boyle) to adjourn the meeting at 1:03 p.m. Motion carried unanimously.*

Submitted by:

Approved by:

Tori Williams, Director

Date

Committee Chair

Date

Response For the Planning Council

How is The Resource Group (TRG) addressing client concerns with dental care?

The Resource Group has received client concerns related to the changes in fees and services for oral health care. Clients with concerns should contact the Consumer Relations Coordinator of TRG with further questions or concerns. So far two have resulted in further action. There is confusion related to which service require client contribution and how fees are assessed. TRG staff is currently seeking clarity on the changes. TRG has requested documents which will be review and discussed with the providers of dental service. The goal is to have the providers distribute materials which will outline for clients what changes have occurred and how the clients dental care may or may not be affected. Once materials are available, TRG would like to collaborate with the Office of Support to host a Ryan White Oral Health Service update for Ryan White clients. Client will have the opportunity to ask questions and discuss the changes with the Administrative Agency & provider agencies. A report of the efforts taken to educate client should be available for distribution by April 1, 2019. TRG will also interview clients of dental services thought the annual process. Feedback form the 2017 interviews contributed to a dental specific questions. TRG invites clients to review the dental questions and provide feedback. The annual interview report will be available and ready for distribution for monthly meetings in February 2019.

1.)
2.)
3.)
The Affected Comm. Committee

Reachelian Ellison
The Resource Group

ROAD 2 SUCCESS and CAMINO HACIA TU SALUD

Schedule of Emergency Preparedness Trainings for the HIV Community

In 10 weeks, over 284 individuals have received training in *Emergency Preparedness for the HIV Community*.

CONFIRMED:

Date to be determined

Legacy Community Advisory Board – anticipated attendance: 30+ consumers

COMPLETED:

July 23, 2018, 12 noon

Ryan White Affected Community Committee – 39 attendees and 6 staff

Aug. 1, 2018, 11 am

Transition Summit for HIV-positive youth transitioning from pediatric to adult medical care – 29 attendees (youth, caregivers and case managers) and 4 staff

Aug. 16, 2018, 12 noon

Thomas Street Health Center – 14 consumers and 4 staff

Aug. 20, 2018, 2:00 pm

HIV and Aging Coalition – 15 consumers and 4 staff

Aug. 27, 2018, 5:00 pm

Positive Support Group (Spanish only) - attendance: 26 consumers and 5 staff

Aug. 29, 2018, 10:00 am

Catholic Charities HOPWA Housing Meeting – Two sessions. attendance: 42 attendees and 7 staff (am session in Spanish, pm session in English)

Sept. 20, 2018, 12 noon

Thomas Street Health Center – attendance: 30 consumers

Sept. 21, 2018, 6:30 pm

Living Large, Living Without Limits – attendance: 14 consumers

Sept. 26, 2018, 12 noon

Case Manager Meeting, Legacy Community Health – attendance: 13 case managers.

Oct. 3, 2018, set up 9 am

Legacy Community Health Staff at Montrose Clinic – attendance: 45 case managers and other staff.

Oct. 17, 2018, set up at 9 am

SPRY Montrose Diners – attendance: 15 consumers and 2 staff

TO BE SCHEDULED:

St. Hope Foundation – they want a January date

Rural clinics - The Resource Group would like to work with us to set up presentations in some of their rural clinics.

Affected Community Committee

2018 Community Events (as of 10-24-18)

Point Person (PP): Committee member who picks up display materials and returns them to the Office of Support.

| Day, date, times | Event | Location | Participants |
|--|---|--|---|
| Sunday, March 4 1pm-Walk | AIDS Foundation Houston (AFH) AIDS Walk | Houston Park Downtown 1100 Bagby Street, 77002 | Tana, Allen & Mona – distribute LEAP flyers |
| Sunday, June 3 Before 1 pm start time | Long-Term HIV Survivors Event | 11410 Hempstead Road | <u>Need 10 volunteers (3 for PC booth):</u> Council: Johnny D., Ronnie, Cecilia, Veria, Crystal, Skeet, Herman, and Ma'Janae LEAP: Calvin, Roy, Erika, Felipe, Mel, Prince, Tony |
| Wednesday, June 20 6:00 – 9:00 pm | Pride Month Volunteer Day | Houston Food Bank 535 Portwall Street Contact Person: Mary Bethal – 832 369-9390 x 9251 | <u>Need 3 volunteers: PP: Herman,</u> Crystal, Ma'Janae |
| Saturday, June 23 Noon – 7:00 pm | Pride Festival | Downtown near City Hall | <u>Shift 1 (11:30 am-2 pm): PP: Skeet,</u> Tana, Rod <u>Shift 2 (2-4:30 pm):</u> Allen, Skeet, Tana <u>Shift 3 (4:30-7 pm): PP: Skeet,</u> Allen |
| July 23, 2018 Set up: 11 am | <i>Dress Rehearsal</i> Road 2 Success: Emergency Preparedness for HIV Community | Affected Community Committee 2223 W. Loop South, 77027 | |
| Wed, August 1, 2018 Set up: 10:30 am | Road 2 Success: Emergency Preparedness for HIV Community | Youth Transition Summit | <u>No volunteers needed</u> |
| Thurs, August 16, 2018 Set up: 11 am | Road 2 Success: Emergency Preparedness for HIV Community | Thomas Street Health Center 2015 Thomas Street, 77009 | <u>Need 5 Volunteers:</u> Rosalind, Michael B., Steven |
| Mon, August 20, 2018 Set up: 1:30 pm | Road 2 Success: Emergency Preparedness for HIV Community | HIV and Aging Coalition the Montrose Center 401 Branard St., 77006 | <u>Need 6 Volunteers:</u> Steven, Michael B., Skeet |
| Mon, August 27, 2018 Set up: 4:45 pm | Camino hacia tu Salud: Emergency Preparedness for HIV Community | Positive713 Leonel Castillo Community Center 2101 South Street, 77009 | <u>Need 4 Volunteers:</u> Isis, John P, Steven, Skeet, Johnny, Herman |

(Continued on next page)

| Day, date, times | Event | Location | Participants |
|--|---|---|--|
| Wed., August 29, 2018 Set up: 9:15 am | Camino and Road 2 Success: Emergency Preparedness for HIV Community | Catholic Charities Miles Chapel 4315 Lyons Avenue, 77020 | <u>Need 4 Volunteers:</u> Isis, Skeet and Cecilia |
| Thurs, September 20, 2018 Set up: 11 am | Road 2 Success: Emergency Preparedness for HIV Community | Thomas Street Health Center 2015 Thomas Street, 77009 | <u>Need 6 Volunteers:</u> Steven, Isis, Eddie, Crystal, Amber and Cecilia |
| Fri. September 21, 2018 Set up: 6 pm | Road 2 Success: Emergency Preparedness for HIV Community | Living Large Support Group the Montrose Center 401 Branard St., 77006 | <u>Need 5 Volunteers:</u> Crystal, Skeet, Isis, Cecilia and Herman |
| Wed., October 17, 2018 Set up: 9 am | Road 2 Success: Emergency Preparedness for HIV Community | SPRY Montrose Diners the Montrose Center 401 Branard St., 77006 | <u>Need 5 Volunteers:</u> Skeet, Roy, Isis, Mona and Amber |
| October 21, 2018 Set Up: 5:30 pm | MISS UTOPIA | NOTE CHANGE OF VENUE CROWNE PLAZA HOUSTON (Near Reliant - Medical) 8686 Kirby Drive Houston, Texas 77054 | <u>Volunteers:</u> PP: Skeet, Cecilia, Ronnie, Johnny DISTRIBUTE LEAP FLYERS |
| Saturday, December 1 | Change Happens HIV Prevention Community Block Party | Cuney Homes 3260 Truxillo St. Houston, TX 77004 | <u>Volunteers:</u> PP: Skeet, Ronnie, Eddie and Cecilia |
| Saturday, December 1 | World AIDS Day Events | | Most committee members attend events DISTRIBUTE LEAP FLYERS |

Greeters for 2018 Council Meetings

(Revised: 10-24-18)

| 2018 Meeting Dates (Please arrive at 11:45 a.m. Unless otherwise noted, the meetings are held at 2223 W. Loop South)) | Greeter #1 External Member | Greeter #2 | Greeter #3 |
|--|--------------------------------------|-------------------|-------------------|
| Thurs. March 8 | Mona | Skeet | Tana |
| Thurs. April 12 | Eddie | Rodney | Allen |
| Thurs. May 10 CANCELLED | Lionel | Allen | Johnny |
| Thurs. June 14 | Crystal | Tana | Ronnie |
| Thurs. July 12 | Lionel | Allen | Johnny |
| Thurs. August 9 | Tana | Rodney | Allen |
| Thurs. September 13 CANCELLED | Crystal | Herman | Ma'Janae |
| Thurs. October 11 | Eddie or Tana | Skeet | Allen |
| Thurs. November 8 External Committee Member Appreciation | Eddie | Ronnie | Tana |
| Thurs. December 6 | Michael | Rodney | Eddie |



**CONTEST:
WEAR YOUR
CRAZY
HAT**

Houston Area
**HIV & Aging
Coalition**

**FOOD,
PRIZES &
LOTS OF
FUN!**

YOU ARE INVITED TO OUR
2018 HIV & AGING COALITION
Christmas Party

DECEMBER 9TH - 6:00 PM

**MONTROSE CENTER
401 BRANARD STREET, 1ST FLOOR
HOUSTON, TX 77006**

**WE WELCOME ALL WHO
ARE OVER 50 AND HIV+!**



SPONSORED BY





OCT 19 2018

Dear Ryan White HIV/AIDS Program Colleagues,

Several large studies have demonstrated that people living with HIV (PLWH) who have consistent viral suppression do not sexually transmit HIV. This letter outlines recommendations for Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau's (HAB) Ryan White HIV/AIDS Program (RWHAP) recipients and subrecipients as they incorporate messages on the impact viral suppression has on HIV transmission in service delivery settings.

According to recent data from the 2016 Ryan White Services Report (RSR), the RWHAP has made tremendous progress toward ending the HIV epidemic in the U.S. From 2010 to 2016, HIV viral suppression in the RWHAP has increased from 69.5 percent to 84.9 percent, and racial/ethnic, age-based, and regional disparities have decreased.¹ Scientific advances have shown that HIV medication (antiretroviral therapy) preserves the health of people living with HIV (PLWH) and prevents sexual HIV transmission. PLWH who take HIV medication daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner. Such findings underscore the importance of supporting effective interventions for linking PLWH into care, retaining them in care, and helping them adhere to their HIV medication.

HRSA strongly encourages RWHAP recipients, subrecipients, planning bodies, and providers to leverage their expertise and RWHAP infrastructure to incorporate viral suppression messages in service delivery settings where PLWH are engaged (e.g., outpatient ambulatory health services, medical and non-medical case management, health literacy, early intervention services, and treatment adherence discussions). To do this, providers should: 1) involve PLWH in the decision-making process of their HIV treatment and their sexual health; 2) develop a trusting relationship with their patients; 3) assess barriers to treatment adherence; and 4) support PLWH to achieve and maintain healthy outcomes.

HRSA encourages ongoing discussions about the impact of viral suppression for PLWH. Discussions with PLWH should be supported by all staff (e.g., case manager, social worker, medical provider, etc.), use consistent language, and include tailored messages regarding a person's viral suppression and sexual health practices, reinforcing prevention of other sexually transmitted infections.

Sharing messages about viral suppression with PLWH may have a profound impact on how they feel about themselves, their life choices, and reducing stigma and discrimination. By reducing HIV-stigma for providers, PLWH, and their family members, these discussions could have a positive impact on linkage to HIV care, retention in care, and HIV viral suppression.

HRSA continues to work with HIV prevention, care, and treatment partners across the U.S. to increase awareness about the importance of HIV treatment and to integrate viral suppression messaging into ongoing discussions with PLWH to reduce HIV transmission. We look forward to continued work with our RWHAP recipients, partners, and stakeholders to improve health outcomes for PLWH and to make continued advancements toward ending the HIV epidemic.

Sincerely,

/Laura W. Cheever/
Laura W. Cheever, M.D., Sc.M.
Associate Administrator
HIV/AIDS Bureau
Health Resources and Services Administration

¹ Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. <http://hab.hrsa.gov/data/data-reports>. Published December 2017. Accessed September 25, 2018.

HIV and the Opioid Epidemic: 5 Key Points

Lindsey Dawson, Jennifer Kates

Background

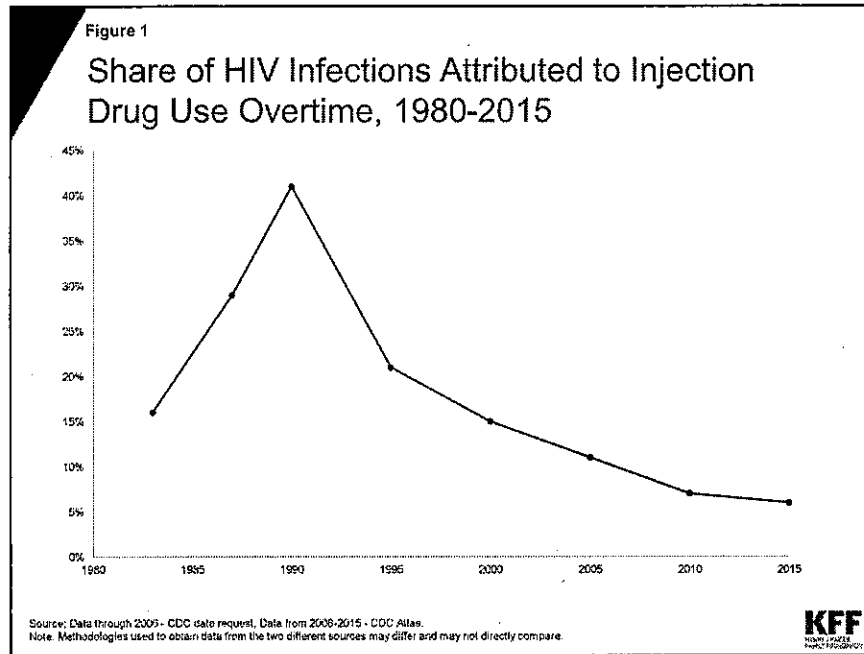
The opioid epidemic represents a significant and worsening public health crisis in the United States. In 2016, 2.1 million Americans were estimated to have an opioid use disorder and nearly 12 million to have misused opioids at some point during the preceding year.¹ Death rates from opioid overdoses doubled between 2012 and 2016, rising from 5.1 to 10.2 per 100,000, and in 2016, an estimated 115 people per day died of an opioid overdose.²

As the opioid epidemic has worsened, there has been growing concern about how injection drug-related opioid use might fuel transmission of infectious disease. Those misusing opioids commonly move from oral use to insufflation to injection use.³ In fact, an estimated 10-20% of people who abuse prescription opioids move on to inject either opioids or heroin.⁴ Injection drug use increases the risk of blood-borne infections including HIV, hepatitis, and bacterial endocarditis, which spread efficiently through needle sharing.

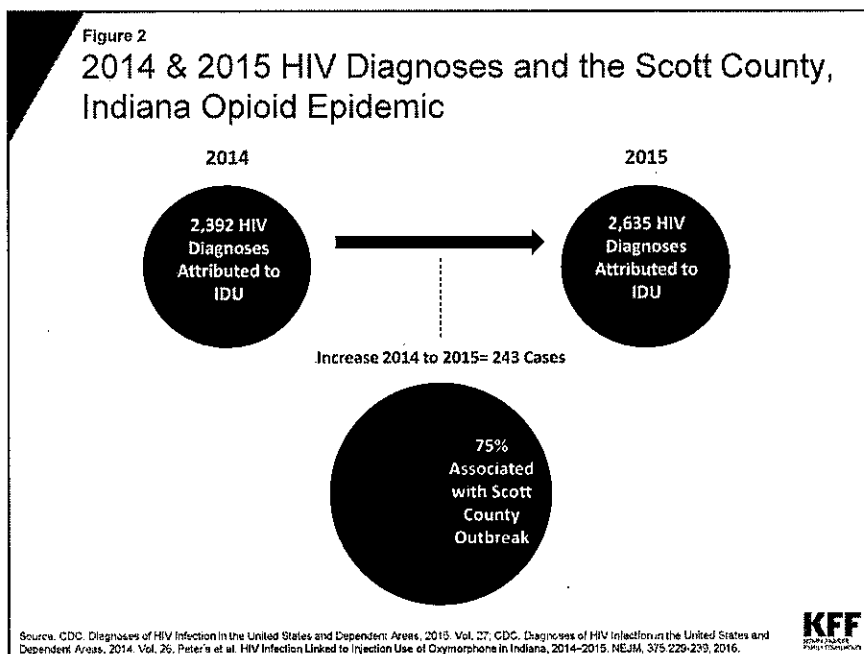
In 2015, opioid use resulted in an HIV outbreak in Scott County, Indiana, with 181 individuals diagnosed with HIV by year-end, most of whom were co-infected with hepatitis C (HCV).^{5,6} In response to this outbreak and the threat posed by the opioid epidemic more broadly, the Centers for Disease Control and Prevention (CDC) identified 220 jurisdictions particularly vulnerable to a similar type of outbreak in an effort to detect and prevent additional events.⁷ Indeed, recent reports suggest new outbreaks may in fact be occurring. In the context of HIV, this has raised particular concerns given that, prior to the opioid epidemic, HIV infections due to injecting drug use had fallen dramatically.

This graphic series highlights key things to know about the intersection of the nation's HIV and opioid epidemics.

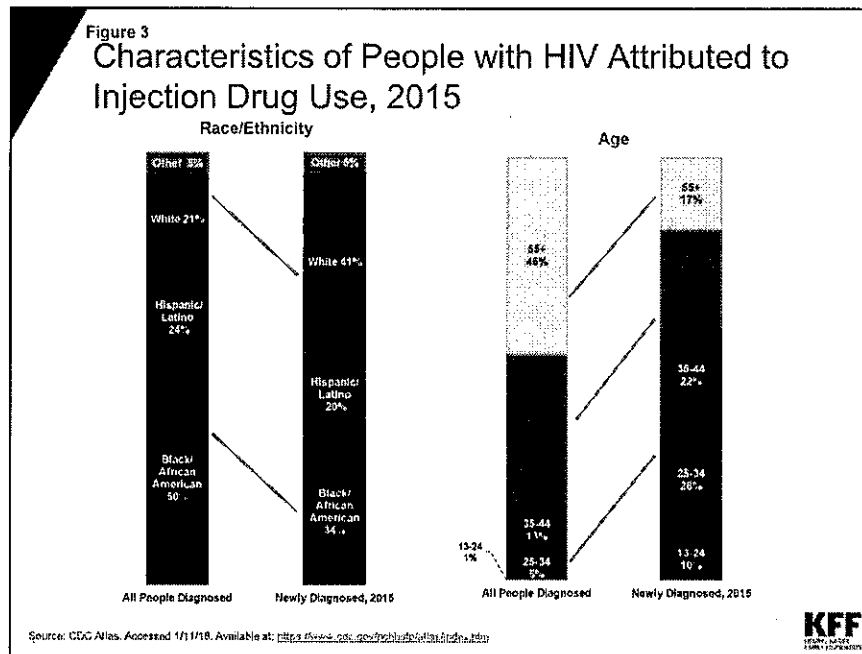
1. The decline in HIV infections associated with injection drug use has been a major success in the fight against HIV in the U.S., with the share of new HIV infections attributed to injection drug use falling from an estimated 40% in 1990 to just 6% in 2015.



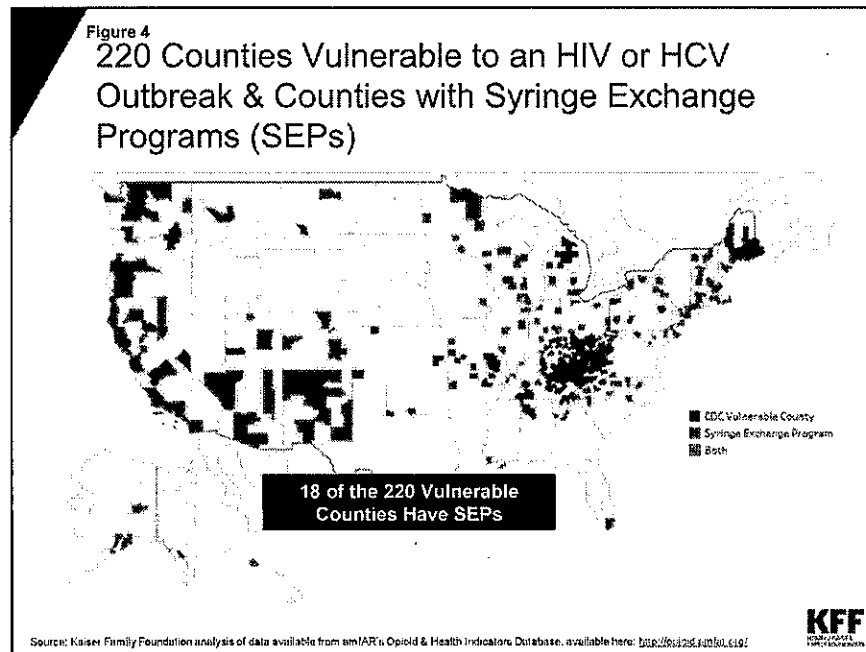
2. However, 2015 marked the first time in two decades where the number of HIV diagnoses attributed to IDU increased, largely associated with the opioid epidemic and subsequent HIV outbreak in Scott County, Indiana. (Early data suggests a decline in 2016, back to 2014 levels, after the peak of this localized outbreak.)⁸



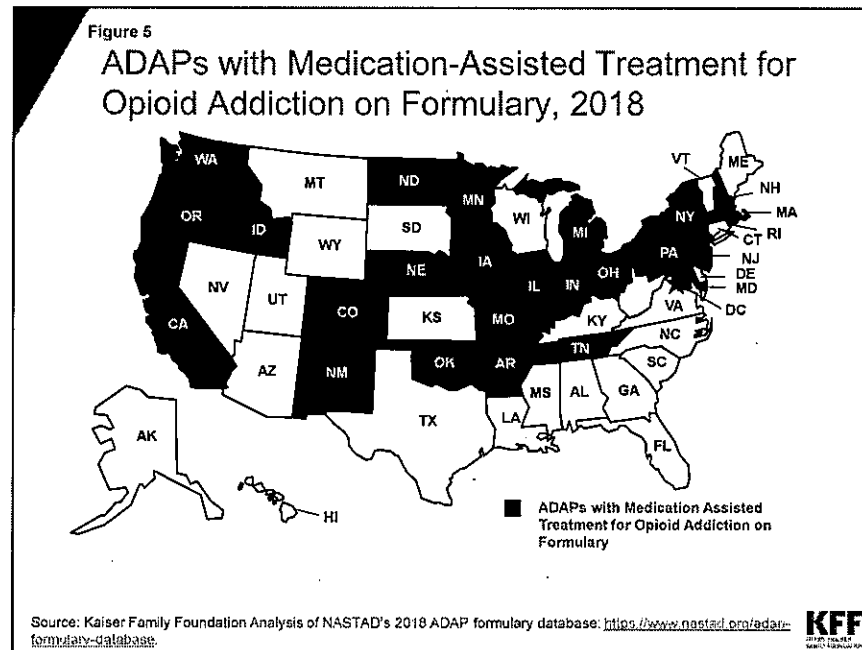
3. The demographics of people with HIV attributed to injection drug are increasingly similar to those most at risk for opioid use and addiction, with greater shares of those newly diagnosed being white and younger, relative to earlier years in the epidemic.



4. While there are several proven strategies available to reduce risk of infectious disease associated with injection drug use, including the provision of Syringe Exchange Programs (SEPs), access varies significantly across the country and does not always align with opioid epidemic epicenters.⁹ Of the 220, mostly rural, counties CDC determined were potentially vulnerable to an HIV or HCV outbreak among people who inject drugs, just 8% have an SEP in place.^{10,11}



5. While all Medicaid programs and some private plans cover Medication-Assisted Treatments (MATs) to address substance use problems, the AIDS Drug Assistance Program (ADAP) of the federal Ryan White HIV/AIDS Program offers an additional source of support for people with HIV with limited or no insurance coverage.^{12,13} However, access varies across the country with just half (26) of state ADAPs covering at least one of the three commonly prescribed MATs for opioid addiction.^{14,15}



Endnotes

¹ SAMHSA. 2016 National Survey on Drug Use and Health. <https://www.samhsa.gov/data/sites/default/files/NSDUH-FFR1-2016/NSDUH-FFR1-2016.pdf>

² Kaiser Family Foundation. State Health Facts. Opioid Overdose Deaths. <https://www.kff.org/other/state-indicator/opioid-overdose-deaths-by-gender/>

³ Peters, P., et al. (2016.) "HIV Infection Linked to Injection Use of Oxymorphone in Indiana, 2014–2015." *New England Journal of Medicine*. 375:229-239.

⁴ Van Handle, M., et al. (2016). "County-level Vulnerability Assessment for Rapid Dissemination of HIV or HCV Infections among Persons who Inject Drugs, United States." *Journal of AIDS*. 73:3, 323-331

⁵ Peters, P., et al. (2016.) "HIV Infection Linked to Injection Use of Oxymorphone in Indiana, 2014–2015." *New England Journal of Medicine*. 375:229-239.

⁶ See for example; Zibell, J., et al. (2018). "Increases in Acute Hepatitis C Virus Infection Related to a Growing Opioid Epidemic and Associated Injection Drug Use, United States, 2004 to 2014." *AJPH: Hepatitis C and Opioids*. 108:2,175-181 and Van Handle, M., et al. (2016). "County-level Vulnerability Assessment for Rapid Dissemination of HIV or HCV Infections among Persons who Inject Drugs, United States." *Journal of AIDS*. 73:3, 323-331.

⁷ Van Handle, M., et al. (2016). "County-level Vulnerability Assessment for Rapid Dissemination of HIV or HCV Infections among Persons who Inject Drugs, United States." *Journal of AIDS*. 73:3, 323-331.

⁸ Centers for Disease Control and Prevention. NCHHSTP AtlasPlus. Updated 2017.
<https://www.cdc.gov/nchhstp/atlas/index.htm>. Accessed February 2018.

⁹ Wejnert, et al. (2016). *MMWR*. "Vital signs: Trends in HIV Diagnoses, Risk Behaviors. And Prevention Among Persons Who Inject Drugs –United States." 65:47,1336-1342.

¹⁰ Kaiser Family Foundation analysis of data available from amfAR's Opioid & Health Indicators Database. Maps from amfAR database, available here: <http://opioid.amfar.org/>. 220 Vulnerable Counties originally identified in Van Handle, M., et al. (2016). "County-level Vulnerability Assessment for Rapid Dissemination of HIV or HCV Infections among Persons who Inject Drugs, United States." *Journal of AIDS*. 73:3, 323-331.

¹¹ The original article identifying these counties also notes that 43% of the counties did not have a buprenorphine-waivered physician (another indicator of limited capacity to respond to an emerging opioid epidemic).

¹² Kaiser Family Foundation. 2018. Medicaid's Role in Addressing Opioid Addiction.
<https://www.kff.org/infographic/medicaids-role-in-addressing-opioid-epidemic/>

¹³ Peters, R. Wengle, E. 2016. The Urban Institute. Coverage of Substance-Use Disorder Treatments in Marketplace Plans in Six Cities. <https://www.urban.org/sites/default/files/publication/81856/2000838-Coverage-of-Substance-Use-Disorder-Treatments-in-Marketplace-Plans-in-Six-Cities.pdf>

¹⁴ The three common MATs are buprenorphine; Methadone, and Naltrexone.

¹⁵ 23 ADAP formularies include buprenorphine, 16 include Methadone, and 20 cover Naltrexone. NASTAD's 2018 ADAP formulary database: <https://www.nastad.org/adap-formulary-database>.



Trauma-Informed Care — Reflections of a Primary Care Doctor in the Week of the Kavanaugh Hearing

Today, it was my third patient of the morning: a woman with a history of childhood sexual abuse and an abusive marriage. She shared with me her distress, her escalating nightmares and

onated deeply and brought back memories of their own experiences.

providers and staff about the growing field of trauma-informed care. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), a trauma-informed organization or practice acknowledges the widespread impact of trauma and understands potential paths toward recovery; recognizes the signs and symptoms of trauma in both patients and staff; responds by fully integrating knowledge about trauma into policies, procedures, and practices; and actively resists retraumatization.²

SAMHSA has defined six principles of trauma-informed care: safety; trustworthiness and transparency; peer support and mutual self-help; collaboration and mutuality; empowerment, voice, and choice; and consideration of cultural, historical, and gender issues. As we reflect on the ongoing national conversation about sexual assault and the ways in which, over the past year, the #MeToo

movement has brought to light the prevalence of sexual abuse and harassment and has diminished the stigma associated with disclosure of such experiences, trauma-informed care offers guidelines for response by those of us in health care. Health care services, with an inherent power differential between patient and physician, and which often include physical touch, removal of clothing, lack of privacy, and personal questions, can be retraumatizing for survivors. In order to improve patients' resilience and engagement with their health care, we can draw on the principles of trauma-informed care. We can offer patients choice ("Would you like the door open or closed while you wait for the doctor?") and control — by explaining what we will do, how we will do it, and why it is necessary ("Is it okay if I examine your neck so that I can feel your thyroid gland?" and "What can I do to help you be more comfortable?"). As primary care doctors who have longitudinal connections with patients, we can offer a consistent, honest, and compassionate rela-

tionship within which healing from trauma can take place.

Sitting with my patients as they share their stories takes a toll. It can use up my emotional resources and leave not a lot of room for my family, friends, and community. Like everyone working in health care, I am vulnerable to the effects of vicarious trauma, the weight of witnessing my patients' suffering. Vicarious trauma can lead to compassion fatigue and burnout, especially when it resonates with a provider's own prior traumatic experiences or occurs in a setting that lacks opportunities for support and discussion of the work. But this week has also led me to think about resilience, about the comfort I gain from the partnerships I develop with my patients, about how inspired and motivated I am by their incredible strength and willingness to trust. I am reminded that in order to be able to provide patient-centered and compassionate care for trauma survivors, it is important for us to acknowledge our own needs, our own sources of resilience and support.

In this time of increased awareness of the prevalence and impact of trauma, and as we are inundated with news about abuse, health care providers have an opportunity and responsibility to dig deep into ourselves and commit to actively resisting retraumatization, to develop the resources to support survivors, and to support each other as we do this work. We can strive to make our organizations trauma-informed places of healing.

Disclosure forms provided by the author are available at NEJM.org.

From the Fish Center for Women's Health, Brigham and Women's Hospital, Chestnut Hill, MA.

This article was published on October 10, 2018, at NEJM.org.

1. Breiding MJ, Smith SG, Basile KC, Walters ML, Chen J, Merrick MT. Prevalence and characteristics of sexual violence, stalking, and intimate partner violence victimization — national intimate partner and sexual violence survey, United States, 2011. *MMWR Surveill Summ* 2014;63(8):1-18.
2. Substance Abuse and Mental Health Services Administration. SAMHSA's concept of trauma and guidance for a trauma-informed approach. HHS publication no. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.

DOI: 10.1056/NEJMp1813497

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MEANINGFUL INVOLVEMENT OF PEOPLE WHO USE DRUGS

NOTHING ABOUT US WITHOUT US

Meaningful involvement of people who use drugs ensures the leadership and decision-making power of people with lived experience of drug use in the response to the intersecting crises of drug use, viral hepatitis, and HIV.

The principle of meaningful involvement of people who use drugs is one of the core principles of harm reduction.¹ It was first articulated by the Rotterdam Junkie Union in the Netherlands in 1977 and reinforced by a global community of people who use drugs in the Vancouver Declaration in 2006. It is closely linked to the “nothing about us without us” ethic of the Denver Principles, which outline the meaningful involvement of people living with HIV.² Meaningful involvement is also supported by Centers for Disease Control and Prevention, which has acknowledged that overdose prevention strategies must involve those most at risk for overdose.³

WHY MEANINGFUL INVOLVEMENT?

People who use drugs are intimately familiar with their communities’ needs, cultures, and barriers to services and health. Their expertise is essential to building effective services and trusted spaces where people who use drugs can access services and be treated with respect and dignity.

Meaningful involvement of people who use drugs can increase support for harm reduction policy and advocacy efforts; challenge myths related to drug use, HIV, and viral hepatitis; and reframe the narrative supporting criminalization. Opportunities for job training and employment are in themselves an important component of harm reduction in communities of people who use drugs. In fact, hiring people with prior convictions lowers rates of unemployment, crime, and recidivism.⁴

MECHANISMS FOR INVOLVEMENT

People who use drugs have the capacity to educate and be educated; form organizations; manage funding; serve in consultations, decision making, policy making and advisory structures; and be employed in a variety of roles.⁵ Yet people who use drugs face many challenges that restrict their ability to engage with public health professionals and policy makers, including persistently high levels of stigma and discrimination.⁶

Support for people who use drugs and their organizations must include explicit recognition of their unique value and perspective by both public health agencies and local governments. It must also include capacity building support and financial backing for innovative projects and programs that embody the principles of meaningful involvement.

Organizational policies and practices may need to be reconceptualized, or overhauled completely, in order to meaningfully involve people who use or formerly used drugs, people affected by police surveillance and the criminal-legal system, young people, people of trans experience, and people of color.

PEOPLE WHO USE DRUGS MUST BE ENGAGED IN SHAPING POLICY AGENDAS AND SHIFTING SOCIAL ATTITUDES TOWARD THEIR OWN COMMUNITIES.



Meaningful Involvement of People Who Use Drugs Self-Assessment

Ask yourself...

Input and Engagement

- Do you compensate people who use drugs for their participation in meetings and advisory boards?
- Do you offer training and support for people who use drugs?
- How do you include people who use drugs in your services, consultative processes, advisory boards, and research?
- Do you involve people who use drugs in program development and evaluation?

In the Workplace

- What policies exist around hiring and recruiting people who use drugs and/or with an arrest or criminal record?
- How are work-related problems for employees who use drugs resolved?
- To what extent are job advancements made available to employees who use drugs?
- How does organizational leadership reflect the communities you serve?

In the Movement for Social Justice

- Have you engaged in workshops to reduce drug-related stigma and discrimination? Do you share such resources with others?
- How do you support organizations or coalitions of people who use drugs and syringe services programs in your region?

MEANINGFUL INVOLVEMENT OF PEOPLE WHO USE DRUGS

Community-based organizations should involve people who use drugs at all levels to identify, develop, implement, and evaluate interventions necessary to reduce harm associated with drug use, including opioid overdose education and naloxone distribution, safer drug use interventions and education, and support meetings.

Listed below are practices that can be put in place to reinforce meaningful involvement of people who use drugs.

HIRE PEOPLE WHO USE DRUGS



DO:

- ✓ Learn about harm reduction policies for the workplace.⁷
- ✓ Focus on workforce development and provide trainings and employment opportunities, or partner with an organization that does.
- ✓ Communicate with organizations of people who use drugs about the barriers and challenges they face and act on opportunities to partner, share resources, and compensate them for their efforts.

DO NOT:

- ✗ Impose a blanket ban on employees with an arrest or criminal record.
- ✗ Overlook a frontline employee, like a peer outreach worker, for career promotion.

HOLD ACCOMMODATING MEETINGS



DO:

- ✓ Be flexible about meeting times, location, agenda, and level of participation.
- ✓ Prepare new attendees with training and a support person.
- ✓ Learn from people who use drugs how to make the meeting more inclusive.
- ✓ Acknowledge gaps in your own experience and address any discomfort or unfamiliarity openly and respectfully.

DO NOT:

- ✗ Put the burden of preparing for and integrating into meetings on people who use drugs.
- ✗ Assume that you cannot learn how to integrate people who use drugs into your meetings.



INVITE PEOPLE WHO USE DRUGS TO THE TABLE

DO:

- ✓ Invite several people who use drugs – not just one – to meetings.
- ✓ Share who else will be attending – especially when meetings include law enforcement, parole officers, or city officials – and how people who use drugs are expected to contribute.
- ✓ Designate a minimum percentage of seats on an advisory board or in organizational leadership for people who use drugs.
- ✓ Guarantee and protect confidentiality and ask about preferred contact methods.
- ✓ Provide financial support for participation in meetings, such as travel stipends, honoraria, and per diems.
- ✓ If travel is involved, help arrange identification, credit cards, and healthcare, especially access to medication-assisted treatment.

DO NOT:

- ✗ Require disclosure of personal information, such as HIV, health status, or exposure to trauma.
- ✗ Tokenize people who use drugs.
- ✗ Invite only people who formerly used drugs or the same person you are comfortable with every time.



ADDITIONAL RESOURCES

Access free resources, training, and technical assistance @ aidsunited.org



1) Harm Reduction Coalition (2018). Principles of Harm Reduction. Available at: <https://harmreduction.org/about-us/principles-of-harm-reduction> 2) AIDS United, The US People Living with HIV Caucus (2017). Meaningful Involvement of People with HIV/AIDS. Available at: <https://www.aidsunited.org/resources> 3) Centers for Disease Control and Prevention (2018). Evidence-Based Strategies for Preventing Opioid Overdose: What's Working in the United States. Available at: <https://www.cdc.gov/drugoverdose/pdf/pubs/2018-evidence-based-strategies.pdf> 4) National Employment Law Project, Safer Foundation (2016). A Healthcare Employer Guide to Hiring People with Arrest and Conviction Records: Seizing the Opportunity to Tap a Large, Diverse Workforce. 2016. Available at <https://www.nelp.org/wp-content/uploads/NELP-Safer-Toolkit-Healthcare-Employer-Guide-Hiring-People-with-Arrest-Conviction-Records.pdf> 5) Canadian HIV/AIDS Legal Network, the Open Society Institute Public Health Program, and the International HIV/AIDS Alliance (2008). Nothing About Us Without Us: A manifesto by people who use illegal drugs. Available at: <https://www.opensocietyfoundations.org/reports/nothing-about-us-without-us> 6) Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: A review of the literature. Substance Abuse Treatment, Prevention, and Policy, 7, 47. 7) Open Society Foundations (2010). Harm Reduction at Work: A Guide for Organizations Employing People Who Use Drugs. Available at: <https://www.opensocietyfoundations.org/reports/harm-reduction-work>