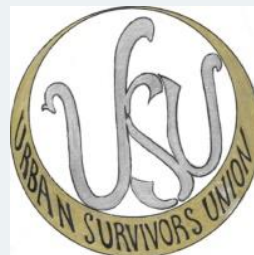


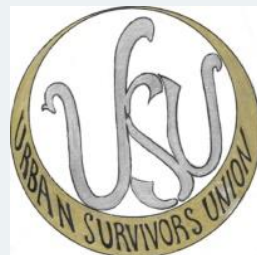
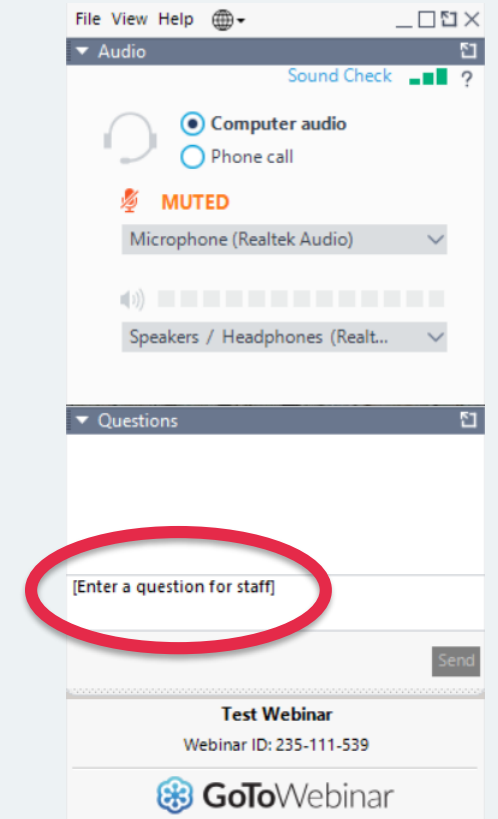
More than Tested, Empowered: Engaging Drug Users to Fight Stigma and Improve Access to Hepatitis C Care

August 8, 2018



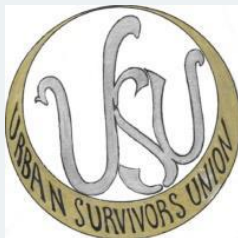
Housekeeping: GoToWebinar

- Slides and a recording of the webinar will be sent to everyone who registered and posted on our website.
- Please use the question box to submit your questions and comments
- The Q&A session will follow the last presentation



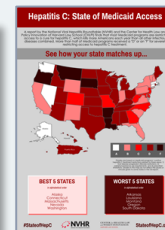
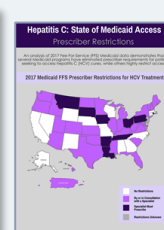
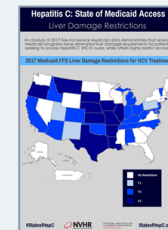
Meaningful Engagement of People who Use Drugs

- Almost every person involved in USU's part of the project identified as a person that uses drugs.
- “Grant Parents” – NVHR considering the harm reduction groups as true partners and providing technical assistance
- Planning, implementing, evaluating the program
- Every person involved in USU's part of the project was paid
 - Focus group facilitators, focus group attendees, interviews, survey participants, video team
- Paying people is about showing people you believe their time is valuable.



Hepatitis C: The State of Medicaid Access - Overview

- One of NVHR's top priorities is **ensuring that public and private payers end all restrictions to treatment access.**
- This project examined Medicaid reimbursement criteria for available direct-acting antivirals (DAAs) for all 50 states, in addition to the District of Columbia and Puerto Rico.
 - **Focuses on liver damage, sobriety and prescriber restrictions.**
 - Highlights successes in access expansion as well as ongoing challenges since 2014.
 - Providing a first-time national assessment of Medicaid Managed Care Organization (MCO) coverage.



Hepatitis C: The State of Medicaid Access - Findings

- **Access to HCV treatment has improved, primarily in reduction/elimination of liver damage (fibrosis) restrictions.**
- Access restrictions related to sobriety and prescriber limitations have decreased to a far lesser extent.
- While there are some MCOs with low levels of restrictions, many follow their states' fee-for-service (FFS) Medicaid restrictions, and others impose more restrictions.
- Transparency about criteria has increased dramatically from 2014 to 2018.

Georgia



Grade: C

- Currently, the Georgia Medicaid Fee-for-Service (FFS) system and one Managed Care Organization (MCO) do not have any liver damage requirements. One MCO requires at least severe liver damage (F3 or greater).
- Georgia Medicaid Fee-for-Service (FFS) system and one Managed Care Organization (MCO) require a patient to enroll in a substance use program if the individual is currently using alcohol or intravenous drugs. One MCO considers patients with active substance or alcohol use on a case-by-case basis and in coordination with a substance treatment specialist.
- Georgia Medicaid Fee-for-Service (FFS) system and one Managed Care Organization (MCO) do not have any prescriber requirements. One MCO requires a prescription be written by or in consultation with a specialist.
- Two MCOs do not provide hepatitis C coverage requirements publicly.

North Carolina



Grade: B

- North Carolina Medicaid Fee-for-Service (FFS) system and Primary Care Case Management System (PCCM) do not have liver disease requirements.
- North Carolina Fee-For-Service (FFS) and Primary Care Case Management System (PCCM) require screening and counseling for alcohol and substance use. Patients with a history of substance use in the last year must be enrolled in a treatment program and agree to abstinence during treatment as well as toxicology screening.
- North Carolina Medicaid Fee-for-Service (FFS) system and Primary Care Case Management System (PCCM) do not have any prescriber requirements.

Washington



Grade: A-

- Washington has significantly improved access to hepatitis C medications and removed most barriers to treatment in all three categories of restrictions.
- **As a result of legal action and patient advocacy, Washington Medicaid does not have any liver damage (fibrosis) requirements or sobriety restrictions.**
- Alaska Medicaid requires a prescription be written by or in consultation with a specialist.
- Due to the prescriber restrictions, a “minus” has been added to the state’s “A” grade.

Fighting HCV Criminalization

- Laws criminalizing hepatitis single out people living with viral hepatitis for especially harsh treatment under our criminal legal system. Laws criminalizing viral hepatitis target the same behaviors as HIV criminal laws: sex, exposure to bodily fluids (blood or saliva), and needle-sharing. **Often, the laws include situations where there is no real risk of disease transmission.**
- Just like HIV criminal laws, laws criminalizing hepatitis are unscientific, overly harsh, and discriminatory. Criminalizing someone's health status should never be the solution to a public health challenge.
- 13 states have laws that criminalize hepatitis.
- Opportunity to partner with HIV advocates and harm reduction groups to fight these laws while working to expand access to syringe services.

NVHR Hepatitis C Patient Summit

- Patients not engaged enough in advocacy work
- NVHR is planning a HCV Patient Summit in early 2019 to address need for greater patient engagement and leadership in the HCV field.
 - opportunity for 100 patients recently or currently living with HCV who have not had experience engaged in other advocacy programs to come together to develop shared goals.
 - emphasize recruitment of individuals from disproportionately impacted and marginalized communities to ensure the demographics of attendees are representative of the demographics of the HCV epidemic.
 - <http://nvhr.org/program/PatientSummit>

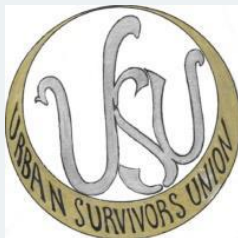
HCV Treatment Barriers Among Drug Users

- **Patient Concerns**

- ❖ Stigma associated with drug use
- ❖ Prior rejection for treatment
- ❖ Lack of knowledge of current HCV treatment options
- ❖ Distrust of health care providers
- ❖ Difficulty navigating through healthcare system

- **Provider Concerns**

- ❖ Not keeping up with appointments/dropping out of care
- ❖ Suboptimal adherence
- ❖ Acquiring drug resistance
- ❖ Getting re-infected

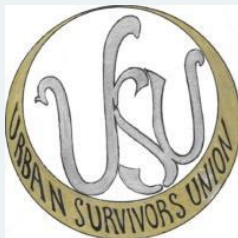


Stigma Associated with Drug Use

“I actually will deny my drug use [to my doctor]. If I tell, the attitude will change and they won't treat.”

“If I feel comfortable, I might ask [my doctor] about hepatitis C, but if I am made to feel like a drug user, I won't ask.”

“I inquired about [HCV treatment] and was told that I had to be clean/sober for an extended period of time.”

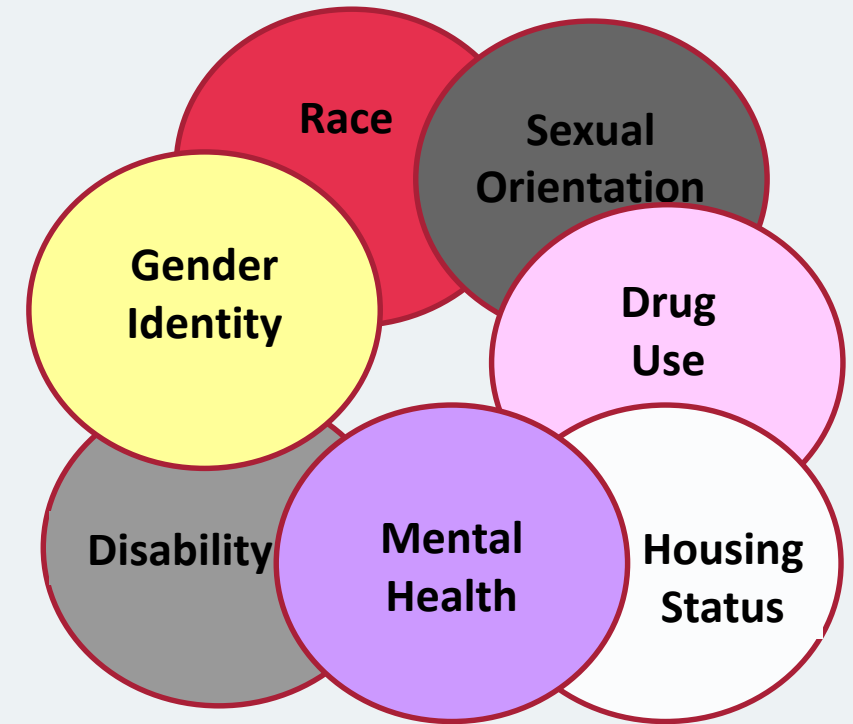


Multiple Stigmatized Identities

- Many people have multiple, stigmatized identities
- An intersectionality framework is important

“I wanted to do the [HCV] treatment but the doctor told me ‘I had to have housing’.”

“Until a migrant trans person who sells sex and uses drugs can be included as one person, rather than being seen through four layers of stigma that might result in being targeted by four services, it’s simply not good enough.”



Another Step Closer

MOJGAN ZARE, MD, MPH

EXECUTIVE DIRECTOR, ATLANTA HARM REDUCTION COALITION

Atlanta Harm Reduction Coalition, Inc.

AHRC is a community based wellness organization committed to promoting health and dignity by reducing the impact of HIV/AIDS, Hepatitis C, STI, and Substance Use within vulnerable communities.

Treating people who inject drugs and Hepatitis C patients through:

Syringe Exchange Program (1994)

HCV Screening/Linkage (2015)

Harm Reduction Therapy (2017)

Specialty Education (2017)

Specialty Pharmacy (340B) (2017)



Removing Barriers

Step 1: Education

- Patients:
 - Education on the virus, course of disease, complications, and treatment options
- Providers:
 - Education on Harm Reduction, Linkage to Care, and Syringe Exchange Services

Step 2: Case Management/Linkage

- Patients:
 - Removing underlying barriers: Housing/Food/Transportation
 - Active Linkage to Medical Care
 - Linkage to Syringe Service Programs
- Providers:
 - Linkage with Harm Reduction Agencies
 - Linkage to Syringe Service Programs

Step 3: Peer Navigation

- Patients:
 - Education on receiving care and linkage to care through stories from peers who have completed treatment



Achievements at AHRC

2014: Creation of HCV program at AHRC via educational groups

2015: Offering preliminary HCV testing through collaboration with GDPH and Orasure Technologies, and referral to Grady Liver Clinic

2016: Guest Speaker at Harm Reduction Conference

2017: Offering confirmatory HCV testing through collaboration with GDPH, providing education to HCV providers, and becoming 340B participant

2017 Data:

- 535 Preliminary Tests
- 58 Positives identified
- 6 Confirmatory Tests
- 9 Case management and linkage to essential and supportive Services
- 9 Referrals to Grady Liver Clinic
- 25 persons connected to financial resources for treatment
- Training to 16 Hepatitis C providers
- Collaboration with Georgia Department of Public Health, Gilead Sciences, CDC, and SAMHSA

2018: Linkage to Piedmont Hospital, PROMISE, and Provider Guidelines

Linkage

Piedmont Hospital:

- Five patients have been linked to medical care.
- One patient completed treatment.

Grady Liver Clinic:

- Wait list reduced to two weeks

Grady Liver Clinic (Study):

- Priority to active & previous people who inject drugs



PROMISE

Community PROMISE (Peers Reaching Out and Modeling Intervention Strategies) is an effective community-level STD/HIV prevention intervention that relies on role model stories and peers from the target population of intended community. Community PROMISE is successful because it is created anew each time it is implemented in collaboration with a specific community.

Planning and Implementation:

- Completing report by end of August
- Story and supply distribution with help of peers in July: 20 stories distributed



Provider Guidelines

Creation of one page Guidelines

- Method
- Review

Dissemination

- Conferences
- Social Media
- Mass Email
- Training



People's Harm Reduction Alliance (PHRA)

Hepatitis C Project & Engaging People who Use Drugs

VANESSA MCMAHAN, HEPATITIS C CARE ADVOCATE

People's Harm Reduction Alliance (PHRA)

- Peer-run organization promoting harm reduction and safer drug use
- Need-based needle distribution and safer smoking supplies
- Active drug users at all levels
- Fixed and delivery sites
 - Seattle, Everett, Olympia, and Bremerton, WA
 - Portland, OR



PHRA Program: Year 1 (Seattle)

- Needs assessment
 - 20 client interviews
- Provider engagement and client education
- Increased testing
 - 66% increase
- Offered case management

Testing/Treatment	Number (%)
Number screened	166
HCV +	41 (25%)
Returned for confirmatory test	30 (73%)
Confirmed positive	23 (77%)
Linked to treatment	3 (13%)

HCV Program: Year 2

- Case management
 - 4 clients since March
- Expanding testing and linkage to care
 - Kitsap, Olympia, Portland
- Survey of WA providers
 - Opinions & barriers to treating drug users
 - Current knowledge & information needs



Lessons Learned & Key Considerations

- Incorporate testing and linkage to treatment at point of contact
- Collaborate with community partners and providers
- Educate drug users on new treatment options
- Promote activities that decrease stigma
- Engage providers regarding treatment guidelines
- Engage drug users at all levels and compensate them for their time
- Provide case management that helps overcome barriers to treatment (e.g., insurance navigation, transport)



More than Tested Empowered

The Urban Survivors Union
Greensboro Xchange

DO YOU
REALIZE YOU
HAVE RIGHTS
JUST BECAUSE
YOU ARE A
HUMAN?

Stigma effects how we think about our health.
Many of us just give up and give in.

Here is a Preview of our Health Diary:

<https://drive.google.com/file/d/1uymK0h1xpk388Cdp-DTgNubCLqsPcGmR/view?ts=5b67c3e8>

COMMUNITY SYSTEMS

Evidence supports Community Systems for reducing HCV

1 **ADVOCACY**

2 **COMMUNITY
LED SERVICES**

3 **PARTICIPATORY
RESEARCH**

4 **COMMUNITY
FINANCING**

We know that community responses to HCV are the cornerstone of effective, equitable and sustainable programs. They mobilize communities to demand services and exercise their rights; they also deliver services, support health systems and reach those most vulnerable to Hepatitis C where state / government health departments and traditional groups are unable to connect, Community Led groups

YEAR ONE: More Than Tested Cured Nothing About Us, Without Us!

Tools of Discovery:

- SURVEYS
- FOCUS GROUPS
- INDIVIDUAL INTERVIEWS
- SOCIAL MARKETING MATERIALS
- VIDEO/ WEB info
- PROCESS VS. PRODUCT

Main focus group findings:

- Syringe exchange is vital for well being
- Confusion over HCV transmission & treatment
- Distrust of medical system
- Effects of unemployment & underinsurance
- Most have untreated mental health issues

Women

- Lack of control over injection supplies and drugs
- Concern regarding welfare of children

Stimulant users

- Lack of understanding that staying awake for days could negatively impact health
- Increased sex & associated risks

Importance of drug user involvement

“To be part of Planning, implementing and evaluating a program in partnership with other groups with similar missions created a learning environment unlike I have experienced.”

“Being employed, being seen, being truly listened to has given me a reason to keep living and fighting, I love USU”

THE USU SITE WITH OUR WORK

<https://sites.google.com/urbansurvivorsunion.org/usucampaigntoendhcv/home?authuser=0>

YEAR 2

**A true examination of barriers to care.
We are utilizing a rights based approach
to educate around Hepatitis C and
health while exploring how access to
health care and previous trauma with
the medical system creates barriers
beyond the obvious.**

**The Health Diary Video Project /
Participatory Video
Led By USU Participants.**

**Barriers Beyond the
Obvious...**

CHANGE THE FRAMEWORK

“A RIGHTS BASED APPROACH”

We As Humans Have A Right To Health



A Necessary Look at Women's Health

**Exploration of Barriers to Care with women who use
drugs (mothers / pregnant women) who have HCV or are
at risk for HCV. We will explore the barriers to health
care related to Hepatitis C.**

PATICIPATORY RESEARCH: Injection drug users, Pill Injectors, Women who Inject

Regarding needed research, treatment, and preventive services for women who use drugs. To address these needs, we advocate for women-specific thinking and approaches that considers the social, micro, and macro contexts of women's lives.

1

**Participatory community
based approaches**

2

**Health Diary
Paticipatory Video
Focus Groups
Instructional Video
Website:**

3

Rights Based Approach

**Works on outcomes and
process goals**

Emphasizing rights

**Rights always imply
obligations of the state**

4

**Empowerment education
theory:** Paolo Freire
emphasised that sustainable
change is only possible if poor
and deprived communities are
engaged in dialogue, ideas,
and experiences are
exchanged, and they are
empowered to take action to
improve their own health
([Freire, 1970](#))

POWERLESS NO MORE

User Involvement

Moving from Peer to Professional

Daily pay vs. Project Pay

Process vs. Product

Invest in the community

YES it costs more!

Sounds Good

BUT HOW DO WE ACTUALLY DO
THIS???

Drug users should be involved in all prevention efforts related to Hepatitis C. We cannot eliminate without our expertise and knowledge.

Drug Users have been taking care of their health and running effective programs for the last 3 decades.

User unions have implemented syringe exchanges worldwide and safe injection facilities

User Unions are Powerful.

Do You Support Your Local User Union?

Invest in your participants- computers, software.
Provide Resources and access to training

Questions?

Please submit questions for any of the presenters via the webinar question function or send an email to tbroder@nvhr.org

Slides and a recording of the webinar will be sent to everyone who registered and posted on our website. [www.nvhr.org/programs/more than tested cured](http://www.nvhr.org/programs/more_than_tested_cured)

