



Community Engagement 301: HRSA's Ryan White HIV/AIDS Program Community Engagement in Action

2024 National Ryan White Conference on HIV Care and Treatment
August 22, 2024

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HIV/AIDS Bureau (HAB)

Vision: Healthy Communities, Healthy People



Learning Objectives

- Learn how HRSA's HIV/AIDS Bureau is prioritizing community engagement to improve HIV strategies and outcomes.
- Explain how storytelling can change decision-makers' minds about programs and policy.
- Describe effective strategies used by RWHAP recipients to make systems changes that are responsive to community needs.



Presenters



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Bounce to Zero Campaign
New Orleans, LA



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Health Resources and Services Administration (HRSA)

Overview



Supports more than 90 programs that provide health care to people who are geographically isolated, economically or medically challenged



HRSA does this through grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities



Every year, HRSA programs serve tens of millions of people, including people with HIV, pregnant people, mothers and their families, and those otherwise unable to access quality health care

HRSA's HIV/AIDS Bureau Vision and Mission

Vision

Optimal HIV care and treatment for all to end the HIV epidemic in the U.S.

Mission

Provide leadership and resources to advance HIV care and treatment to improve health outcomes and reduce health disparities for people with HIV and affected communities.



HRSA's Ryan White HIV/AIDS Program (RWHAP) Overview

- Provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV.
- Funds grants to states, cities, counties, and local community-based organizations to improve health outcome and reduce HIV transmission.
 - Recipients determine service delivery and funding priorities based on local needs and planning process.
- Provided services to over 566,000 people in 2022—more than half of all people with diagnosed HIV in the United States.
- 89.6% of RWHAP clients receiving HIV medical care were virally suppressed in 2022, exceeding national average of 65.1%ⁱ. This means they cannot sexually transmit HIV to their partners and can live longer and healthier lives.



Why Is Community Engagement Important?

- The voices of people with HIV, their communities, and the greater communities that support people with HIV have been the cornerstone of the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) since its passage by Congress in 1990.
- With a renewed focus on community engagement to meet the goals for Ending the HIV Epidemic in the U.S., our collective success depends on how well communities are involved in the planning, development, and implementation of HIV care and treatment strategies.

Community Engagement Guiding Principles

“voices of the community from beginning to end”



Community Engagement is a dynamic process that engages various stakeholder, partners, groups, communities, institutions, and individuals at various levels and throughout the lifecycle of a program or project.

Community Engagement and the RWHAP

- **Community engagement is part of the existing fabric of the RWHAP.**
- **RWHAP recipients funded through Parts A, B, C, D, and the Ending the HIV Epidemic in the U.S. (EHE) initiative recipients are encouraged and/or required to support activities that:**
 - Facilitate collaboration with community members
 - Work with their communities and public health partners to improve health outcomes across the HIV care continuum
- **In addition, community engagement is a key element of RWHAP Part A and Part B Planning Councils and Planning Bodies, integrated planning efforts, and clinical quality management activities.**



Community Engagement and the RWHAP

- HRSA's RWHAP continues to invest in programs supporting community engagement and building leadership among people with lived experience. This includes:
 - Building Leaders of Color 2.0
 - ELEVATE for All People with HIV
 - ESCALATE: Ending Stigma through Collaboration and Lifting All to Empowerment
 - EHE Systems Coordinating Provider
 - EHE Technical Assistance Provider



Community Engagement Resources

Community Engagement Principles in Action



Community Engagement Principles in Action

- **Intentional.** Recipients and subrecipients plan thoughtfully how to effectively partner with people with HIV and other communities, building on existing strengths that exist in these communities.
 - [Wellness Web 2.0, The Coastal Bend Wellness Foundation, Corpus Christi, TX](#)
- **Committed.** Authentic community engagement means investing in the development of people with HIV and facilitating their access to tools needed to partner and participate effectively. Investments include providing opportunities for training, communications, leadership development, and hiring people with lived experience.
 - [Transgender Health Program Integrated Into HIV Prevention and Care, Rutgers New Jersey Medical School, Newark, NJ.](#)
- **Sustainable.** To meet the goals of ending the HIV epidemic and ensuring that community engagement continually builds and grows, it is important to establish and maintain sustainable strategies.
 - [Co-Locating Care Management Staff and Peers in Medical Clinics, The Alliance for Positive Change, New York, NY](#)



Community Engagement Principles in Action

- **Flexible and Tailored.** Developing innovative strategies for community engagement and input that is broad and allows for flexibility that acknowledges the required time and process for leadership development. Recipients and subrecipients are supported to develop creative strategies that are flexible to meet people where they are.
 - *Navigator Case Management for People Leaving Jail, University of San Francisco, San Francisco, CA*
- **Transformational.** Community engagement is an iterative process that includes ongoing communication and feedback between recipients and subrecipients, providers, community-based organizations, and people with HIV. This shared experience centers on the needs of people with HIV and results in the transformative approaches needed to support engagement in care and achieve the goals of ending the HIV epidemic in the U.S.
 - *Using Advisory Boards to Enhance and Implement Interventions for Black Women, AIDS Foundation of Chicago & Grady Health System*

Community Engagement Resources

- **Best Practices Compilation | TargetHIV:**
<https://targethiv.org/bestpractices>
- **EHE Systems Coordination Provider | TargetHIV:**
<https://targethiv.org/ta-org/ehe-systems-coordination-provider>
- **Community Engagement Learning Series: Successful Strategies for Promotion | TargetHIV:** <https://targethiv.org/library/community-engagement-learning-series-part-three-successful-strategies-promotion>



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Department
of Health

Consumer Affairs & Involvement



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Office of Planning and Community Affairs (OPCA)
New York State Health Department & AIDS Institute

Consumer Affairs is dedicated to empowering, affirming, and implementing consumer voices. Consumer Affairs employs a collaborative approach between providers, consumers, and other community stakeholders to ensure that the quality of care across New York State is efficient, effective, and equitable.

The Consumer Affairs team works collectively to ensure that clients receive the best experiences in HIV care, prevention, and support services by implementing quality management tools and interventions.

The Consumer Affairs Manager liaises between the AIDS Institute and community stakeholders to facilitate clear, transparent, and effective communication while advocating for the consumer's best interest.

About Consumer Affairs

Consumer Affairs Goals

01

Increase consumer involvement in the quality, policy, programmatic making, and implementation process

02

Implement a consumer involvement component for all AIDS Institute, and national Quality of Care Initiatives

03

Provide technical guidance and coaching for local, regional, and state consumer involvement groups/programs

04

Develop and facilitate consumer-focused trainings and discussions



Department
of Health

Strategies

Attend Community
Forums

Local, Regional, &
State Consumer
Advisory Group
Meetings

Facilitate
Consumer
Trainings

Conduct
Community Focus
Groups

Conduct One on
One Interviews and
Discussions

Report back at
AIDS Institute
Meetings

Collaborate with
Consumers and
Health Department
Staff



OPCA

**Office of Planning
and Community
Affairs (OPCA)**

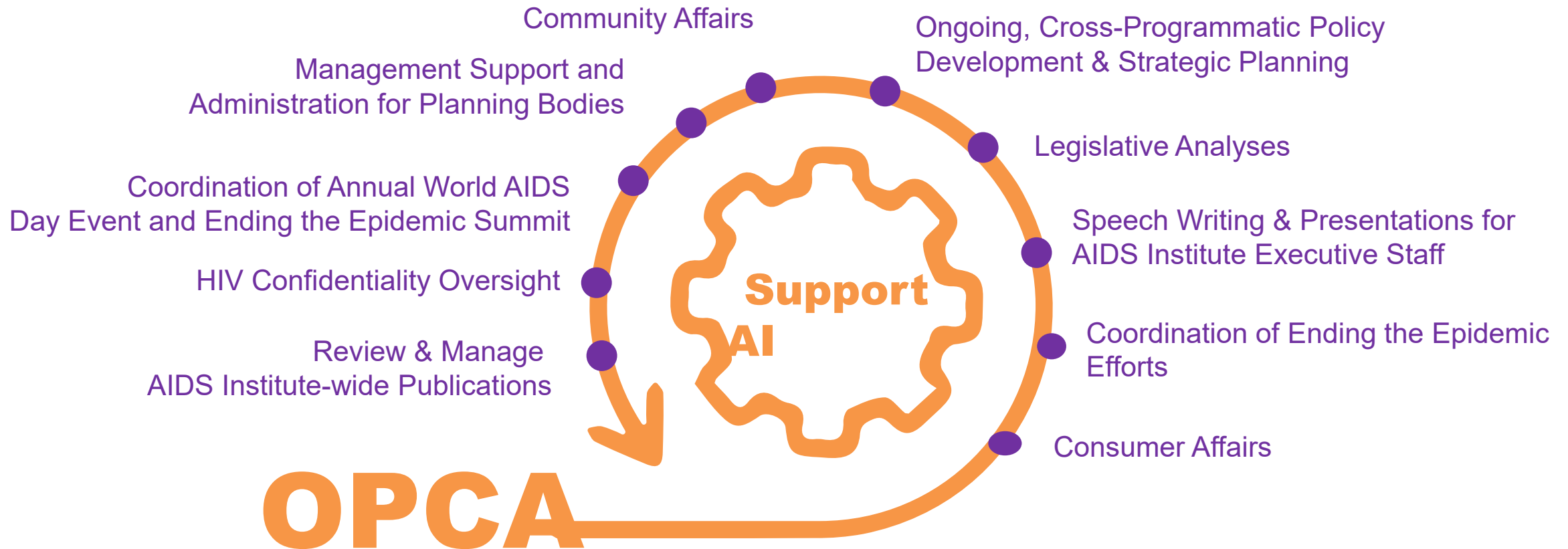


**Department
of Health**

OPCA's Mission

To act as a steward between the AIDS Institute and community members across New York State to facilitate ongoing reciprocal communication and participation in the planning, development, and delivery of AIDS Institute initiatives, with specific emphases on ending the epidemic efforts, to ensure evolving community needs are recognized and addressed.

Office of Planning and Community Affairs



People with HIV LIVED Experience (PWLHE) Involvement

The New York State Department of Health AIDS Institute incorporates community voices in every aspect of our efforts by employing the tenets of the Community Engagement Continuum:

- Outreach
- Consult
- Involve
- Collaborate
- Shared Leadership



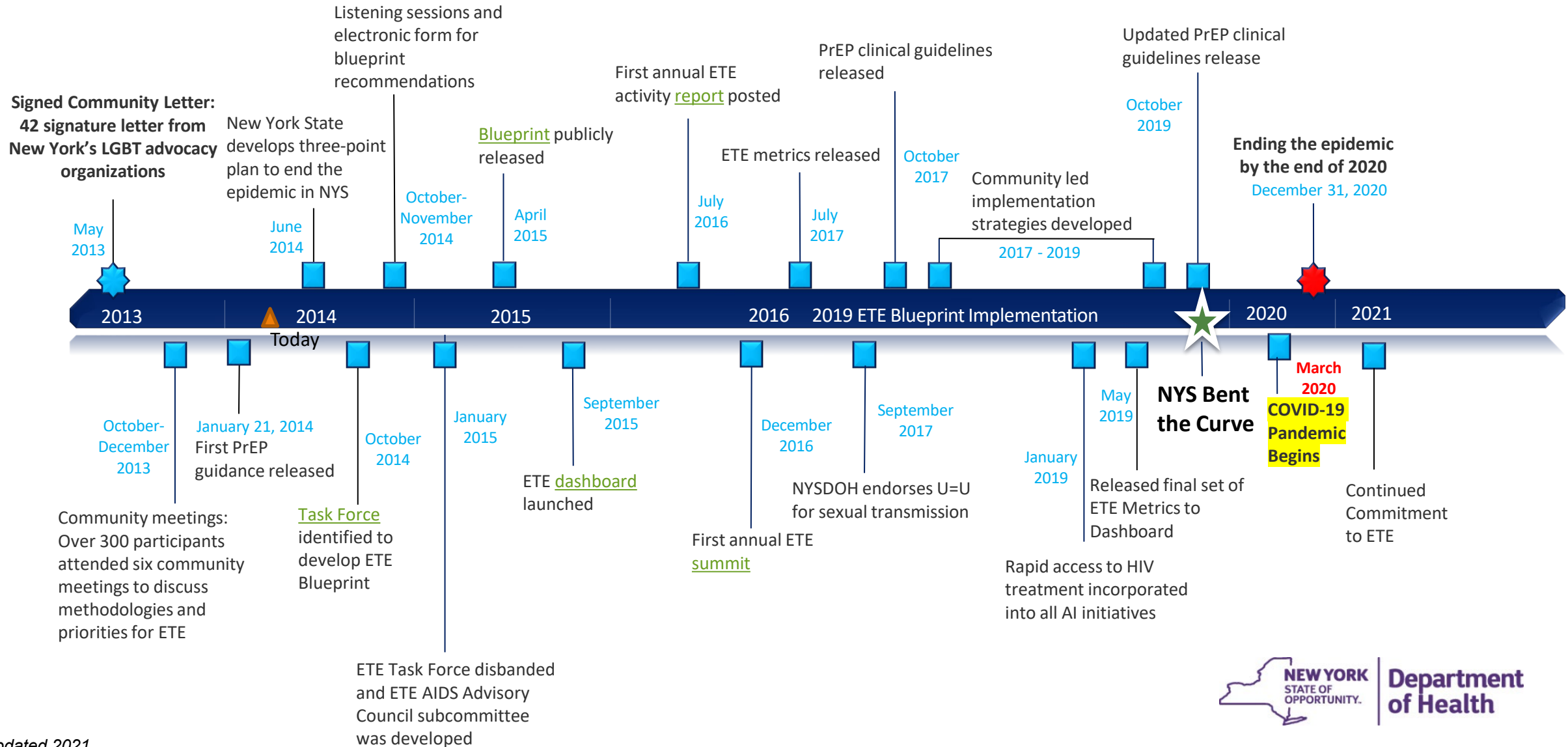
Community Engagement Continuum

Increasing Level of Community Involvement, Impact, Trust & Communication Flow

Outreach	Consult	Involve	Collaborate	Shared Leadership
<p>Some Community Involvement</p> <p>Communication flows from one to the other, to inform</p> <p>Provides community with information</p> <p>Entities coexist.</p> <p>Outcomes: Optimally establishes communication channels for Outreach</p>	<p>More Community Involvement</p> <p>Communication flows to the community and then back, answer seeking</p> <p>Gets information or feedback from the community</p> <p>Outcomes: Develops connections.</p>	<p>Better Community Involvement</p> <p>Communication flows both ways, participatory form communication</p> <p>Involves more participation with community on issues</p> <p>Entities cooperate with each other.</p> <p>Outcomes: Visibility of Partnership established with Increased cooperation</p>	<p>Community Involvement</p> <p>Communication flow is bidirectional</p> <p>Forms partnerships with community on each aspect of project from development to solution</p> <p>Entities form bidirectional communication channels</p> <p>Outcomes: Partnership building, trust building.</p>	<p>Strong Bidirectional Relationship</p> <p>Final decision making is at community level.</p> <p>Entities have formed strong partnership structures.</p> <p>Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</p>

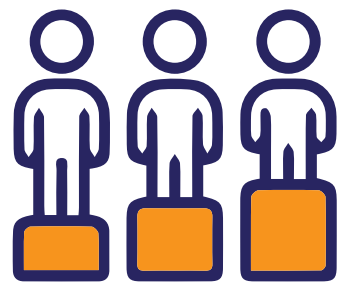
Figure adapted from the International Association for Public Participation and titled "Increasing Level of Community Involvement, Impact, Trust, and Communication Flow."

NYS Ending the Epidemic (ETE) TIMELINE





Past & Current Priorities



Health Equity



Stigma



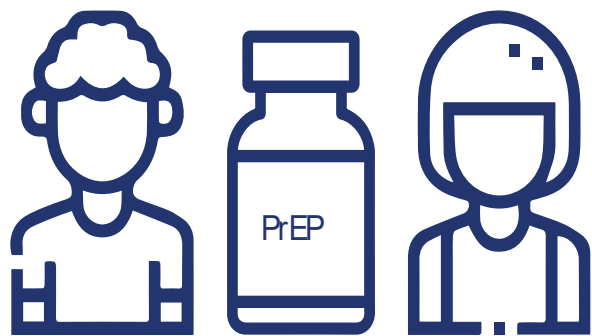
New Metrics that Focus on Health Equity



Status Neutral



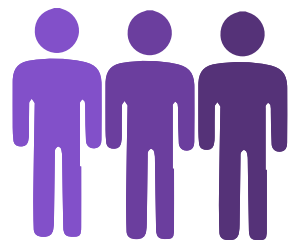
Peer Certification



PrEP Access



People Who Use Drugs



Black Indigenous People Of Color



People Living With HIV 50+



Emerging Issues



Department of Health

Tool	Purpose	Cost
Engage Existing Advisory Groups, Trusted Community Groups – One time basis	Input into response plan of action	Affordable – Can do on Zoom
Regional Listening Sessions	Engage with all communities on emerging needs/challenges	Moderate– Staff Time, potential in-person costs
Develop Regional Community Groups	Community-led prioritization and built in feedback	Moderate to Expensive
Consulting Contracts	Key Population Driven Programming	Affordable/Moderate

Key Takeaways

- Building sustainable partnerships requires flexibility and commitment to the process.
- Stigma & Discrimination is real. Figure out how it impacts your engagement efforts.
- Involve the communities impacted. Identify trusted voices in the community. Remember the Denver Principles.
- HIV prevention partnerships with communities are enhanced by informal relationships.

- **Key Takeaways Continue....**

- Developing HIV prevention partnership with varying communities requires time, trust, patience and financial support.
-
- HIV service providers and consumers need on-going opportunities to hear each other's voices. Maintain on-going communication.
-
- Data, science, community involvement, and compassion have resulted in enormous achievements.
-
- To advance public health policy, critical components needed are political will, funding, community consensus, and a plan.

Questions?



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Community Engagement in Action in New Orleans: The Bounce to Zero Campaign

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Ryan White Services & Resources,
A division of the New Orleans Health
Department



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ON HIV CARE & TREATMENT

Intro Video

https://www.youtube.com/watch?v=M-5_OFxrobg&t=1s



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Project Support

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Disclosures



Daniel Murdock has no relevant financial interests to disclose.

Vatsana Chanthala has no relevant financial interests to disclose.

Background

- No large-scale locally tailored HIV treatment and prevention campaign in New Orleans prior to EHE funding in 2020
 - No central location for local linkage/treatment resources
 - No centrally organized campaign for community engagement
 - Limited availability of locally tailored information and media
- The flexibility of EHE funds allowed activities to address these gaps in developing a community-led social marketing campaign

Community Engagement

- Established an EHE Marketing Committee in 2021
 - Community members
 - Local and state health department staff
 - Planning council members
 - Other stakeholders
- Goal of the Committee was to develop a social marketing campaign that reflects the New Orleans community and addresses EHE Priorities
- Marketing Committee led the campaign development
 - Identified campaign name, strategy & aesthetic
 - Contributed to logo design and campaign creatives

Bounce to Zero Campaign



- Campaign launched in December 2022
- Developed with community input
 - Reflects bounce music culture of New Orleans
 - Intentionally vibrant & upbeat
- Sub-campaigns:
 - Linkage to care
 - PrEP & PEP
 - Testing
 - U=U / HIV stigma
- Campaign website
- PSAs
- Testimonial videos
- Community Engagement activities

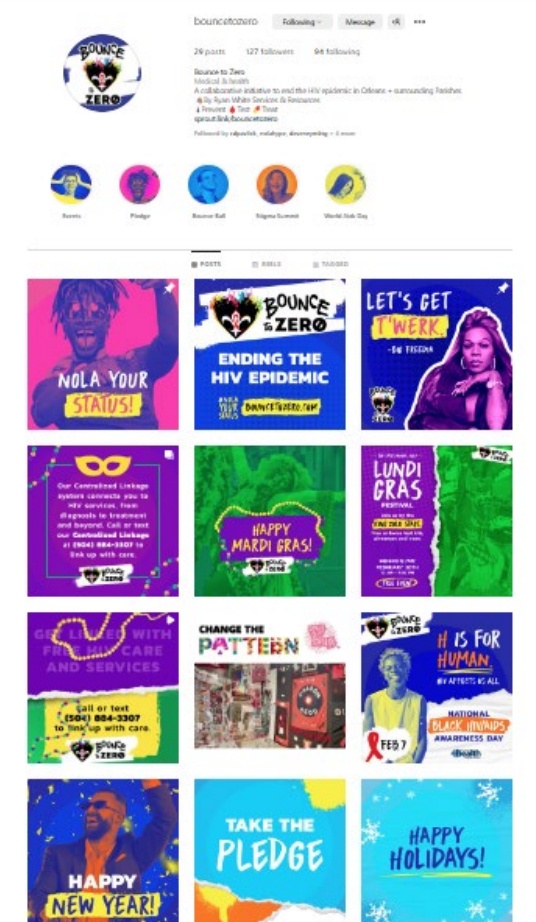
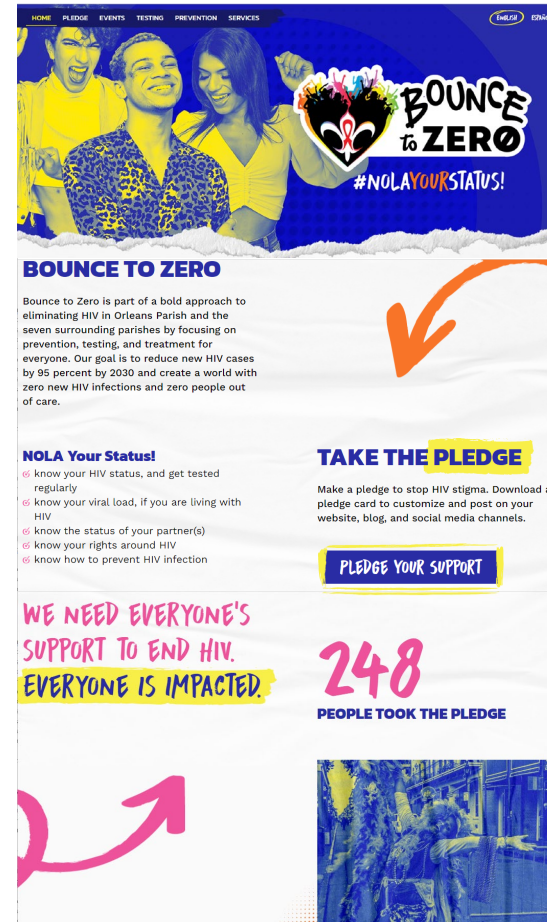
Goals/Purpose



- Campaign launched in December 2022
- Establish branch voice/identity for local EHE efforts in the New Orleans area
- Build awareness of Bounce to Zero campaign and EHE initiatives
- Reach priority target demos
 - Individuals out of care
 - LGBTQ+
 - African Americans
 - Teens/Youth
 - Trans
 - Healthcare Providers
 - General Public
- Communicate key messages
 - U=U/Anti-Stigma
 - At-Home Testing
 - PrEP/PEP Prevention
 - Centralized Linkage/Treatment

Building the Foundation

- Establishing the brand identity, voice and key messages
- Building the website and social platforms
- Identifying and training brand ambassadors
- Planning the promotion and outreach strategies
- Developing key promotional materials
- Developing the campaign concepts



Campaigns

- Big Freedia Get T'werk
- Centralized Linkage
- U=U



Campaigns

- PEP
- PrEP
- At-Home Testing



NOT TODAY, HIV!
**HIV EXPOSURE IS
AN EMERGENCY.**

Starting PEP (POST-EXPOSURE PROPHYLAXIS) medication **WITHIN 3 DAYS** of exposure can prevent HIV infection.
Made possible by Grant Number NU62PS924620 from the CDC.

BOUNCE to ZERO
BounceToZero.com



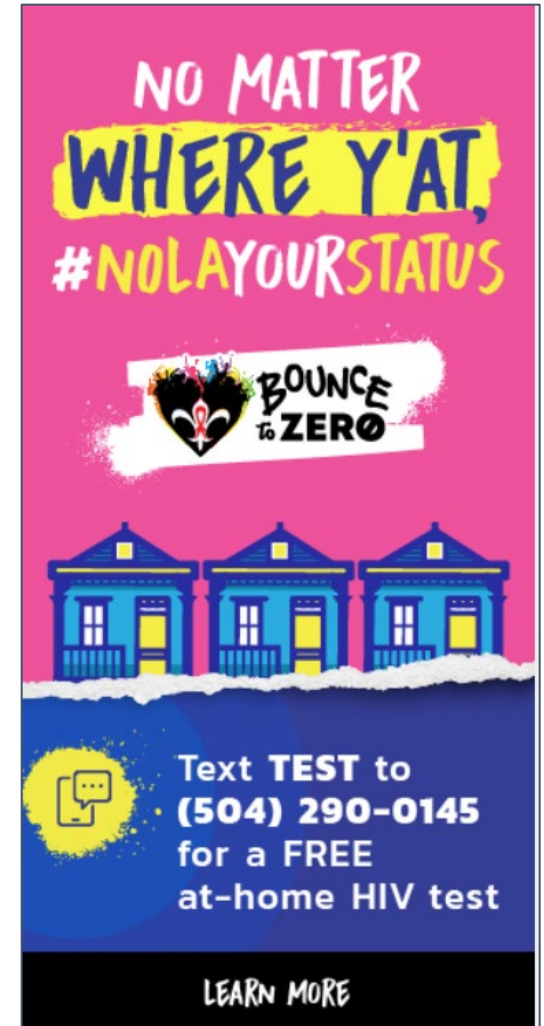
**MORE FRISKY,
LESS RISKY!**

**PREP MEDS
HELP EVERYONE
STAY SAFE
TO PLAY.**

PrEP meds can **reduce** HIV risk **by 99%**
when taken as prescribed.

BOUNCE to ZERO
BounceToZero.com
Made possible by Grant Number H89HA00035 from HRSA.

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ON HIV CARE & TREATMENT



**NO MATTER
WHERE Y'AT,
#NOLAYOURSTATUS**

BOUNCE to ZERO

Text **TEST** to
(504) 290-0145
for a **FREE**
at-home HIV test

LEARN MORE

Bounce to Zero Website

- Bouncetozero.com:
 - Prevention info / PrEP locator tool
 - Testing info / testing locator / test request form
 - Treatment info & U=U
 - Services locator tool
 - Videos
 - Pledge to end HIV stigma
 - HIV & the law
 - Emergency preparedness
 - Future items: Grievances, FAQs (Questions to, and Answers from Clinicians and Case Managers)

Impact to Date

Dec 2022 – Feb 2024

- **Paid Impressions:** 600,823,614

- Outdoor/Transit 585,380,000
- Digital Ads 7,882,275
- Paid Social 7,561,339
 - Instagram/Facebook 3,401,359
 - TikTok 3,665,529
 - YouTube Views 494,451

- **Search Engine Marketing**

- Impressions 144,055
- Clicks 8,248
- CTR (click-through rate) 5.73%

- **Website Metrics:**

- Unique Web Users: 69,136
- Web Page Views: 102,998

- **Pledges to Date:** 1,012

- **Organic Social:** 3,569,713

- Facebook Impressions 2,873,261
- Instagram Impressions 681,165
- Twitter Impressions 15,287

Barriers

- Uphill Battle
- Fear/Stigma
- HIPAA laws make targeting challenging
- Reaching Teens/Youth
- Lack of trust among key demos toward City-run Health Department and medical professionals
- Complicated grant funding parameters
- Slow pace for pledge signing and social media engagement among internal organizations/leaders/individuals and parish leaders
- Texting platform discontinued by service provider

Successess

- 197 people linked to care & supportive services as of June 2024
 - Medical care: 44
 - Supportive Services: 87
 - Prevention: 66
- 579 at home test kits requested as of April 2024

Successes

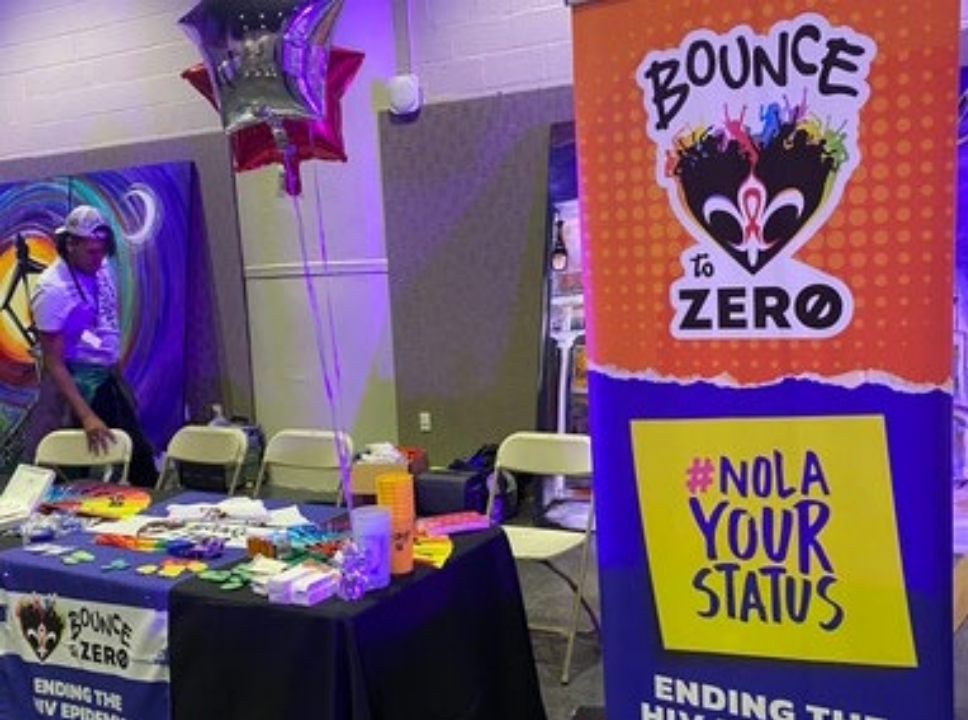


- Strong brand identity
- Well received in the community
- Collaborative process for campaign development
- Partnership with Big Freedia
- Stigma Summit
- Bounce Ball
- Lundi Gras Fest exposures
- Initial Pledges
- Media Trainings
- Centralized Linkage Testimonial Videos
- NORA Planning Council Testimonial Videos
- Coverage of campaign launch on World AIDS Day
- Feature story in *The Louisiana Weekly*
- Coverage on WWL-TV for National African American HIV/AIDS Awareness Day
- Gold American Advertising Award (ADDY) at American Advertising Awards

Lessons Learned & Best Practices



- Community input/engagement is key to success
- Campaigns should be locally tailored
- Set clear plans and metrics for program evaluation early on
- Flexibility of EHE funding allows for greater innovation
- Share information and learn from other jurisdictions



Contact Us



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Preparing 16-24-year-old youth living with HIV to become peer navigator/community health workers

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ON HIV CARE & TREATMENT

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UNLV Health Maternal Child Wellness Program Team

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ON HIV CARE & TREATMENT



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10+ years management experience

A Little History

We are a stand alone Part D Program with a focus on Infants Children and Youth



2007-2017

- Nevada Cares Program
 - Took care of up to 60 infected infants, children and youth

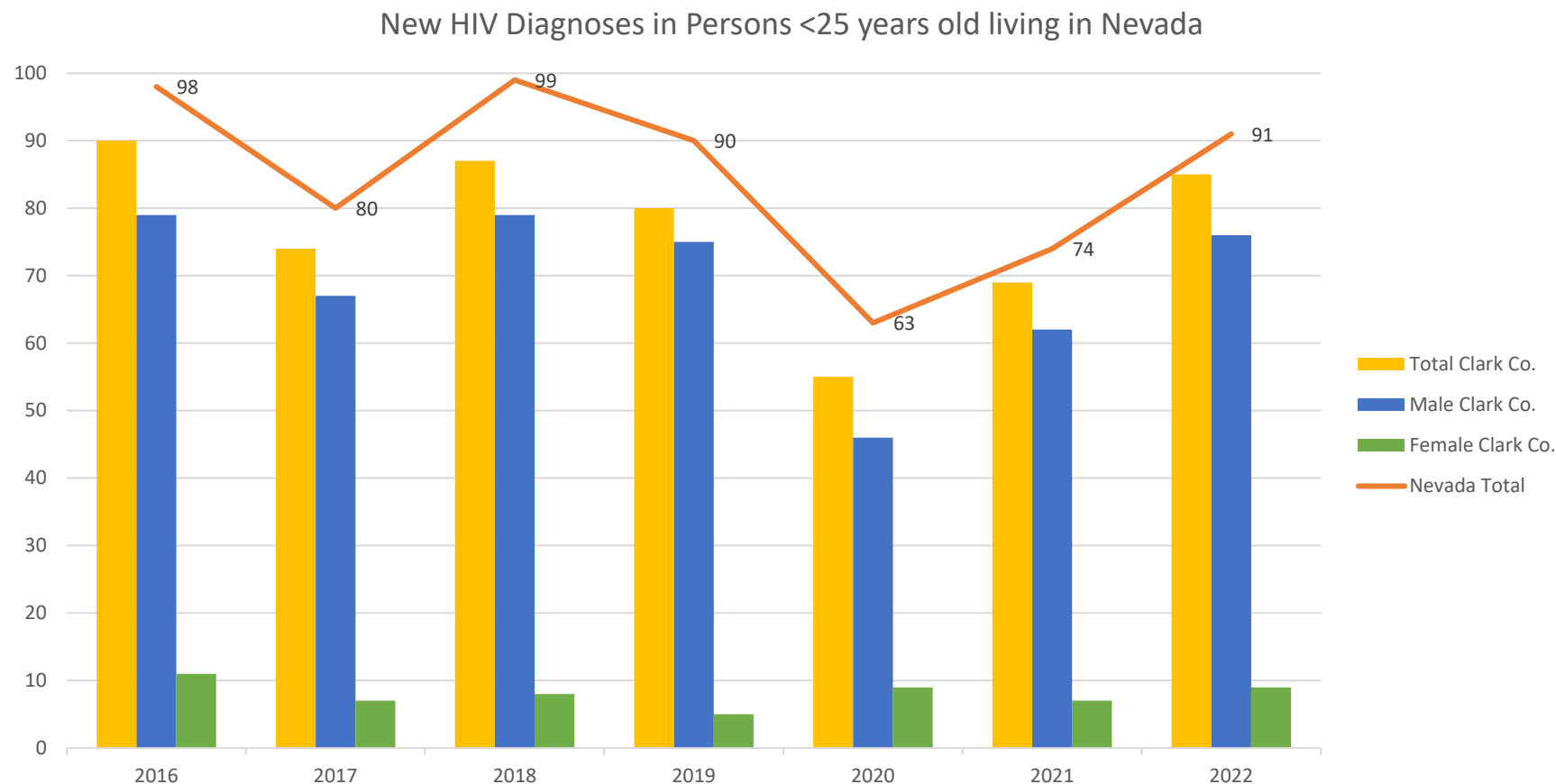
November 2017

- RWHAP Part D Grant for Southern Nevada was assumed from UNR and the Maternal Child Wellness Program begins operations
 - Transition period
 - Assumed care of about 20 infected pediatric patients
 - Diagnosis disclosure discussions

2017-Present

- Established MOU with the Southern Nevada Health District (SNHD) to provide Medical Case Management for WICY population
- Created a Pediatric Medical Home
- Hired a Community Health Worker
- New patients
 - Several infected as teenagers
 - Perinatal infected who were adopted and/or immigrants
 - No new local perinatal infections since 2018

HIV in Nevada



Source: Division of Public and Behavioral Health, enhanced HIV/AIDS Reporting System (eHARS), (2016 - 2023).

New HIV diagnoses are counted in eHARS surveillance statistics and include HIV and HIV Stage 3 (AIDS) cases where resident county at time of diagnosis is Clark County, both living and deceased.

- Over the last 5 years, the number of youth (ages 13-24) in Nevada testing positive for HIV has remained consistently high, ranging from 80-100 persons per year (which is roughly 20% of all new HIV positive diagnoses each year)
- Approximately 90% of those new HIV diagnoses in Nevada can be found in Clark County
- Local data show high rates of new HIV diagnoses among those under 25 years old, especially among males (M).

Community Health Worker / Peer Navigator Program

Provide 16-24 year olds with training necessary to become Community Health Workers

(College of Southern Nevada-CSN)

Provide Youth with accurate meaningful information regarding HIV/AIDS, U = U, and Ending the HIV Epidemic (EHE)

(Project CAATCH – Consumer Access and Adherence to Care for HIV)

Provide youth with Community Experience

Externships
Mentorship
Outreach

Paid externships were provided for anyone that completed the first 2 parts of the program

The Participants

Potential Participants(12)



We were able to secure verbal commitments from twelve (12) of our clients

Eight (8) of those, started the Project CAATCH portion of our training and five (5) completed it.

Interested Participants(8)



Completed the Program(6)



- Six (6) people completed both Project CAATCH and the CHW Training

Project CAATCH

- We adapted Project CAATCH to fit our needs
- We utilized the curriculum in a group setting vs. one on one
- We reviewed each video and handout for age appropriateness



Project CAATCH was presented at the 2020 Ryan White National Conference on HIV Care and Treatment
Project CAATCH is considered a best practice by HRSA

Project CAATCH

Competencies to be demonstrated

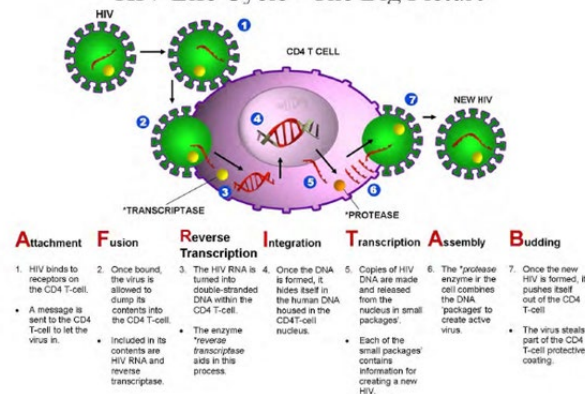
After this session, the client will be able to

- Describe HIV, the routes of HIV transmission and the stages of infection
- Explain the HIV Viral Life Cycle—(AFRITAB) Steps that occur for HIV to replicate inside the body
- Explain what are the stages of HIV Infection
- Discuss 2 ways medications work in the body
- Explain what a CD 4 cell is? What Viral Load is?
- Explain the goal for people with HIV.

Contents

Introduction	1
About MassCARE and Project CAATCH	1
About This Guide	4
Key Components of CAATCH	4
Introduction and Assessment	9
Session 1: HIV Viral Life Cycle and Medications at Work	11
Materials	11
Competencies to be demonstrated	12
Session 2: Treatment Adherence and Communication with Your Provider	17
Materials	17
Competencies to be demonstrated	18
Session 3: Understanding Lab Values	24
Materials	24
Competencies to be demonstrated	25
Session 4: Managing Stigma & Disclosure	30
Materials	30
Optional Materials	30
Working with Transgender Clients	31
Competencies to be demonstrated	32
Session 5: Substance Use Disorders and Harm Reduction	37
Materials	37
Competencies to be demonstrated	37
Session 6: HIV and Wellbeing	41
Materials	41
Competencies to be demonstrated	41

HIV Life Cycle - The Big Picture



Decision-making

Healthy life choices



Distance Use



Session 2: Treatment Adherence and Communication with Your Provider

Materials

Handouts

- Handout 4: How to Prepare for a Visit with your Doctor
- Handout 5: Symptoms Log
- Handout 6: Assessing Adherence
- Handout 7: Tips for Remembering to Take Medications
- Handout 8: Managing Side Effects Through Diet
- Handout 9: Managing Drug Side Effects
- HIV Drug Chart (online only): https://www.poz.com/drug_charts/hiv-drug-chart

Videos

- Speak Up: Tips for Talking to your Doctor
<https://www.youtube.com/watch?v=rEt8xfQ9r1U>
- Empowered: Jen
https://www.youtube.com/watch?v=yUyV10_vR10
- Being Open with Your Healthcare Provider
<https://youtu.be/8vj68G2fW4>
- Clear Communication with Your Provider
<https://youtu.be/YBN0tvADAPY> – English
<https://youtu.be/EK-xPfkqHG8> – Spanish
- HIV: Treat to Prevent
<https://www.youtube.com/watch?v=65KKqTMhT2s>

Each session was followed by a 2 part, 5 item, Likert scale survey to enable us to collect data and make adjustments to the program

Part 1 was general questions about the session
The program scored 4.58 / 5 overall average

Please provide feedback on this session
1. The Information presented this session was appropriate for the topics discussed
2. I feel that I learn new information during this session
3. The material was presented in an interesting way
4. This session was easy to follow
5. Training goals and objectives were clearly stated before starting this session
6. The Facilitator displayed a thorough knowledge of the session content
7. I felt comfortable asking questions and participating in the discussions
8. I believe I achieved the overall learning goals
9. The overall course delivery was appropriate
10. The overall course content was appropriate
11. I would recommend this course to someone else
12. Do you have any suggestions that would make this course better?

KEY	
Strongly Disagree	1
Disagree	2
Neutral	3
Agree	4
Strongly Agree	5

Part 2 was questions about the specific videos used for the session
The videos scored 4.41 / 5 overall average

Please provide feedback on the videos used in during this Session
The content of this video was informative
The information in the video was explained so I could understand it
I would recommend using this video for classes in the future
1. Medication Adherence
2. Speak Up: Tips for Talking to your Doctor
3. Five Reasons to Adhere to HIV Treatment
4. Empowered: Jen
5. Being Open with Your Healthcare Provider
6. Clear Communication with Your Provider
7. HIV: It's Called Treatment as Prevention
Do you have any suggestions for improvement regarding the videos used during this session?

Example of videos used and rated by participants

Community Health Worker Training

We partnered with the College of Southern Nevada
To provide the Community Health Worker Training



They reviewed and adapted their program to ensure all material was age appropriate
CPR and Mental Health First Aid were added to the program curriculum
They provided the classes on site at our clinic location
And on the day and time chosen by the youth involved to accommodate school and other
commitments (Saturday 9 am - 1 pm)

Community Partners

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ON HIV CARE & TREATMENT



NEVADA CANCER
COALITION



College of
Southern Nevada

Investing in Our Future. Students First.



Trac-B Exchange



CCSS
OFFICE OF HIV





Young Adult CHW Curriculum



The Standard Package

The Standard Package Includes:
Curriculum access for up to 60 students +
3 Facilitators

- Canvas course customer support
- Community project & health monitoring support
- Certificate of completion for each student
- 3 passes to TOT training (held 3 times per year, virtually)



Young Adult Mental Health Worker Curriculum - Standard

The Standard Package Includes:
Curriculum access for up to 60 students +
3 Facilitators

- Canvas course customer support
- Community project & health monitoring support
- Certificate of completion for each student
- 3 passes to TOT training

Lessons Learned

- To stay on track with the plan for the program curriculum, the order of the program had to change- the new order worked out better
- Some of the You Tube video links with Project CAATCH did not work or no longer existed
- Attrition is to be expected with the age group of our youth 16-24 years
- Perinatal infected participants were more engaged and completed the program
- Postnatal acquired HIV participants verbalized a perceived stigma from the perinatal infected participants
- Roadblocks to Externships due to age of our participants, school schedules, delays in onboarding at various sites
- While working through the roadblocks, we added another 6 week program “A Better U!”
- Externships turned into mentorships with community agencies
- We created a youth cohort that is empowered to find their voice with lived experience and a possible career path
- Collaboration with our Community Partners continues to create sustainability: facilitate the CHW programs, increase the number of participants and improve health outcomes.

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