



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

For Us, By Us:

Ending the Epidemic with Consumer-led
Quality Improvement

Disclosure



- We have no financial disclosure or conflicts of interest with the presented material in this presentation.

Objectives



- Attendees will leave with tools for increasing client engagement in quality improvement.
- Attendees will be able to strengthen their Quality Committees and Client Advisory Boards and recognize how such participation empowers clients to serve and advocate on behalf of their communities.
- Attendees will recognize the necessity of building and maintaining Client Advisory Boards and Quality Committees that represent the communities they serve in order to improve health outcomes and end the HIV epidemic.

Presenters



- Ashton Whitehead, Peer Support Specialist and former Chair of Client Advisory Board at Health Emergency Lifeline Programs/Corktown Health Center in Detroit
- Kenny Rose, Quality Improvement Coordinator at Health Emergency Lifeline Programs (HELP)/Corktown Health Center in Detroit
- Stafford Sykes, former Chair of Client Advisory Board and current member of Client Advisory Board at Health Emergency Lifeline Programs/Corktown Health Center in Detroit

Overview of Presentation



- Why the title of this presentation?
- Background of Health Emergency Lifeline Programs (HELP)/Corktown Health Center
- Client Advisory Board (CAB)
- Quality Committee (QC)
- Consumer-led quality initiatives
 - Newsletter
 - Client-satisfaction survey
 - Peer Speakers Series

Why “For Us, By Us”?



- History of PLWH at forefront of HIV advocacy and activism saying that there can be “nothing for us, without us”, so why should quality improvement be any different
- History of PLWH and particularly Black Trans and Queer people having to create innovative solutions to combat racism, transphobia, stigma and other barriers to care and survival
- Who knows better about the experience of living with HIV than PLWH



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Health Emergency Lifeline Programs (HELP) Corktown Health Center

Health Emergency Lifeline Programs: Background



- Founded in 1986 in response to HIV epidemic
- Serves approximately 1,500 people each year
- Services 6 counties, primarily Detroit residents
- Serves majority Black population over the age of 40
- Food and nutrition
- Behavioral health services
- Case Management and Early Intervention Services
- Tobacco cessation
- Health insurance navigation
- Emergency financial assistance with utilities and housing

Corktown Health Center: Background



- LGBTQIA+ primary care clinic
- Opened in 2017
- Just over 1,200 patients in first year and a half
- Serving people throughout greater Detroit Metropolitan area
- HIV care and HIV prevention/PrEP
- Aging services
- Keep it Movin' program
- Behavioral health services
- Health insurance navigation
- Transgender health services
- Breast and cervical cancer screening
- Tobacco cessation



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

Client Advisory Board

Client Advisory Board : Background



- Began in Fall of 2016
- Approximately 7-12 members maintained
- Administration support and budget
- Application process and Recruitment
 - Timeline for recruitment and application deadline
 - Distribute applications
 - Consumers involved in calling and interviewing
 - Clear expectations
 - Incentives, food and transportation
 - Representative of populations served

Client Advisory Board: Structure



- Meet at least once a month
- At least 90 minutes
- Communication and work in between meetings
- Staff and administration visit and discuss roles and programs
- Staff liaison(s) attend meetings
- Agendas and notes
- Bylaws
- Group guidelines and review frequently
- Define elected roles: Chair, Co-Chair, Recorder, & Sergeant at Arms

Client Advisory Board : Mission & Vision



- Mission and vision developed by CAB members
 - **Mission:** *To evaluate and advise the services provided by Health Emergency Lifeline Programs.*
 - **Vision:** *This is a brave space. A space where we recognize the difference in the room, where the difference is accepted, honored, and validated. This is a space where we take the opportunity to be aware of conflict and feelings. A brave space is a space where we can explore and challenge ourselves and each other.*

Client Advisory Board: Meeting Agenda



Meeting #36 Agenda 2/18/2020

Mission: To evaluate and advise the services provided by Health Emergency Lifeline Programs.

I. Introductions & Ice Breaker (4:00pm -4:10pm)

- A. Moment of silence
- B. Name, pronoun, what's your favorite romantic movie
- C. Review guidelines

II. Review Notes from January Meeting (4:10pm – 4:15pm)

III. Liaison Report (4:15pm – 4:25pm)

- A. Food Bank open during lunch hours
- B. Dietitian got new job at another clinic
- C. New staff and changes of positions
- D. Hiring Peer Support Specialist, Care Managers and Dietitian
- E. Admin response to suggestion box

IV. Review and Ratify Proposed Changes to Bylaws (4:25pm – 4:40pm)

V. Review Suggestion Box (4:45pm – 5:00pm)

VI. 5 Minute BREAK

VII. Newsletter (5:00pm – 5:20pm)

- A. Bi/monthly
- B. Review the newsletter
- C. Topics/themes/articles for newsletter in April

VIII. Peer Speakers Series (5:20pm – 5:40pm)

- A. Who will lead?
- B. Topics
- C. Speakers
- D. Participant cap and budget
- E. Deadlines

IX. Survey Questions (5:40pm – 5:50pm)

X. Vote on New Member (5:50pm – 5:55pm)

XI. Close Meeting (5:55pm – 6:00pm)

- A. Announcements
 - a. Thursday Keep it Movin Health and Wellness
 - b. May 8th Cheers to HELP
 - c. Other announcements
- C. Meeting adjourned

Client Advisory Board: Successes & Challenges



Successes

- Increase in applications and desire for consumers to get involved
- Relationships built among members, staff and administration
- Voice at agency and in the community
- Advocacy and action

Challenges

- Adherence to guidelines and bylaws
- Engaging younger consumers
- Communication
- Sustaining engagement with other life priorities
- Logistics, budget and support

Client Advisory Board: Recommendations



- Importance of having a CAB that represents the populations served
- Empowering everyone to have a voice
- Following guidelines and bylaws
- Defined mission, vision, and roles
- Structure and organization
- Support from staff, administration, and community partners
- A budget that compensates the work of CAB members
- CAB leadership and decision-making



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

Quality Committee

Quality Committee : Background



- Two consumers on committee, one a liaison between CAB and QC
- Consumer quality training
- Value of consumers' knowledge, experiences, and access to community
 - Root cause analyses
 - Developing Quality Improvement Projects
 - Plan-Do-Study-Acts (PDSAs)

Quality Committee: Successes & Challenges



Successes

- Consumer quality training
- Building relationships between consumers, staff and community partners
- Collaboration between CAB and QC
- Consumers' voices in quality improvement efforts

Challenges

- Limited consumer engagement
- Consumers are not staff and lack of access to critical information
- Consumers are not financially compensated
- Limited leadership opportunities for consumers

Quality Committee: Recommendations



- Compensate consumers for their time and work
- Do not tokenize consumers
- Provide critical information and include in the work
- Remove other barriers for participation
 - Additional training
 - Transportation
 - Consider time of meetings
- Mentor and support consumer leadership



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Consumer-Led Quality Improvement Initiatives: Newsletter

Newsletter: Background



- CAB started a newsletter in December 2019
- A way for the CAB to keep peers informed about events, self-care and current events that impact the community
- Provide encouragement and uplift community to support consumers with staying in care and taking care of their health
- To let consumers know about the CAB and the work they are doing at HELP/Corktown Health Center
- Improve physical and mental health outcomes for consumers

The Inclusion: Corktown and HELP Community Reader



THE INCLUSION: Corktown and HELP Community Reader By the Client Advisory Board

Mental Wellness Written By James Helberg

Good news, spring has sprung! Say goodbye to snow, freezing cold & heavy coats! Say hello to green grass, mild temps & light jackets! Longer daylight will eliminate Seasonal Affective Disorder (that is a real thing). To me spring brings hopefulness (& Cadbury Crème Eggs). I want the light to be visible to you. Something you can do is called 'Self-Care.' It's more than just showering, eating food, & drinking plenty of water. In these times we can stress about the events of our lives, especially if you are a parent. Take a step back and care for yourself & your wellbeing. Spring is a great time to do that! Take time to do things YOU enjoy. If you enjoy bike riding, do it. If you enjoy outdoor activities, do it. Doing things that center on you is one way to care for yourself & your mental wellness. You could already be doing that which is good but if it's a new concept to you, spring is a great time to begin.

What is the top priority of your life? Think about taking a self-care assessment.

- 1) The first thing I do in the morning is...
- 2) When I'm taking care of myself, I feel...
- 3) My favorite self-care activity is...
- 4) My least favorite self-care activity is...
- 5) I know I need to stop and take care of myself when I feel...
- 6) After I engage in a self-care activity, I feel...

Being aware of what holds you back is the first step in conquering it! Do a spring cleaning of your mind and let the brightness in! Make self-care a part of your daily routine. And take the time to stop and smell the spring flowers!



Spiritually Speaking Written By Vicki Couch

"No matter how dim my light is I will Rise and Shine so others will see I'm proud to be me."

Spring is a time where we plant our seeds and wait for them to blossom. The same technique can be applied to our own growth as well. We must plant our seeds of healing, doing and overcoming. Speaking with confidence as we bring our garden into full bloom. Let's spring forward and grow closer to our destiny while embracing our self-worth.

Diabetes and HIV Written By Richard Campbell

According to the US Department of Health and Human Services if you are an older adult living with HIV, you are more likely to have type 2 Diabetes. Type 2 Diabetes develops when blood sugar levels (glucose) are too high. Other factors for diabetes include having a family history of diabetes, being overweight, and over the age of 45. Over a period of time, diabetes can cause serious health problems like heart disease, stroke, kidney disease, eye problems, and neuropathy (nerve damage).

Even though this doesn't sound good, there are things you can do to prevent, delay, or manage Type 2 Diabetes. Maintaining a healthy weight can help you control your blood sugar, but for some this can be hard. Bad habits are hard to break, but new good habits are easier to develop. Eating healthy is an easy habit to develop over time. Limiting your intake of fat, sugar, and salt is the simplest way to do it. When you enter a supermarket look for foods in their whole form like vegetables, meats, and dairy. Stay away from the high sugar processed items you find in the aisles.

Exercise can help you to look and feel better, and also help you manage HIV and Diabetes better. We all know that going to a gym daily would be the best thing to do, but for some that could be unrealistic and that is okay. There are things you can do in your day to day life to increase the amount of exercise you get. Increase your exercise gradually over time and make it your new normal. It's best to get at least 30 minutes a day 5 days a week.

HIV and COVID-19 Information from CDC website

Please note, this is an emerging, rapidly evolving situation and up to date information can be found at the CDC website as it becomes available.

Are People Living with HIV at higher risk for COVID-19 ?

At the present time, we have no specific information about the risk of COVID-19 in people with HIV. Older adults and people of any age who have a serious underlying medical condition might be at higher risk for severe illness, including people who are immunocompromised. The risk for people with HIV getting very sick is greatest in:

- People with a low CD4 cell count, and
- People not on HIV treatment (antiretroviral therapy or ART).

People with HIV can also be at increased risk of getting very sick with COVID-19 based on their age and other medical conditions.

What can people living with HIV do to protect themselves from COVID-19?

There is currently no vaccine to prevent COVID-19. The best way to prevent getting sick is to avoid exposure to the virus. People living with HIV should take everyday preventive actions to help prevent the spread of COVID-19.

Preventive Actions:

- Eating right
- Getting at least 8 hours of sleep
- Reducing stress as much as possible
- If you have to go out in public to get needed items such as groceries or medication, keep six feet distance from others
- Avoid crowds as much as possible
- Avoid cruise and air travel
- Remain at home unless you must leave to go to grocery stores pharmacies, or health care
- Limit close contact and wash your hands often

STAY HOME AS MUCH AS POSSIBLE

Staying healthy helps your immune system fight off infection should it occur. If you have HIV and are taking your HIV medicine, it is important to continue your treatment and follow the advice of your health care provider. This is the best way to keep your immune system healthy.

from: <https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/hiv.html>

Newsletter: Successes & Challenges



Successes

- Bi-monthly newsletter published by CAB members
- Topics that peers can relate to
- Provides information from consumers' perspectives
- Allows CAB members and other consumers to feel like they have a voice

Challenges

- To have all of the CAB members involved
- Barriers to distribution, before the pandemic it was only available in print
- Adhering to timelines, both CAB members and administration
- Difficulty developing way to measure effectiveness when distribution has been limited

Newsletter: Recommendations



- Consider capacity of CAB members' time and skills
- Start small and simple
- Build on strengths of CAB members
- Engage staff and administration
- Consider audience and their abilities and needs
- Papers copies, email, and social media



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Consumer-led Quality Initiatives: Client-Satisfaction Survey

Client-Satisfaction Survey: Background



- CAB members wanted to assess clients' experiences after Corktown Health Center opened in summer of 2017
 - Wait time
 - Overall experience
 - How could experience be improved

Client-Satisfaction Survey: Process



- Researched different client-satisfaction surveys
- Assessed for ease to read, understanding, and timeliness for completion
- Provided to Quality Committee for feedback
- Finalized and implemented survey

Client-Satisfaction Survey: Example



1. What department(s) did you meet with today? (Check all that apply)	
Department Name	(X)
Corktown Health Center	
Triage Specialist	
Food/Nutrition	
Behavioral Health (Therapy)	
Emergency Financial (housing/utilities)	
Case Manager	
Early Intervention Specialist (EIS)	
Support Group	

2. How long was your wait time today?					
Department Name	Did not use this service	0-5 min	6-10 min	11-15 min	More than 15 min
Corktown Health Center					
Triage Specialist					
Food/Nutrition					
Behavioral Health (Therapy)					
Emergency Financial (housing/utilities)					
Case Manager					
Early Intervention Specialist (EIS)					
Support Group					

Client-Satisfaction Survey: Example



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

4. Please rate your overall experience.

Department Name	Did not use this service	Excellent	Good	Fair	Poor
Corktown Health Center					
Triage Specialist					
Food/Nutrition					
Behavioral Health (Therapy)					
Emergency Financial (housing/utilities)					
Case Manager					
Early Intervention Specialist (EIS)					
Support Group					

5. How can we improve your experience?

A large blue rectangular area intended for handwritten or typed feedback responses to the question "How can we improve your experience?".

Client-Satisfaction Survey: Results



- Feedback

- Mostly positive feedback
- “My appts. are usually @1pm and I usually have to wait out in the Doorway area. That’s my only real complaint, otherwise I love this place.”
- “Everything is already great”
- “Offer snacks”
- “More food/ beverages, more help w/ transportation”

- Outcomes

- Lobby open during lunch hour
- Volunteer opportunities (Suggestion Box)
- Lyft rides

Client-Satisfaction Survey: Successes & Challenges



Successes

- Learned a lot from process
- Acquired some feedback from consumers
- Some action steps taken to respond to some consumers' needs

Challenges

- Only 26 surveys completed in a two-month timeframe
- Added burden to staff to remind consumers to complete
- Possible language and literacy barriers

Client-Satisfaction Survey: Recommendations



- Get more staff buy-in
- Shorter timeframe for collecting surveys
- CAB member could encourage consumers to complete
- Surveys could be completed at exit
- Translate into Spanish
- May have to read surveys to clients
- One-sided page and simplify format
- Focus groups instead
- Incentives
- Take feedback seriously & take action and share progress



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

Consumer-led Quality Improvement Initiatives: Peer Speakers Series

Peer Speakers Series: Background



- Developed in 2018 out of wanting to provide peer support to consumers
- Submitted a proposal to administration
 - *Project Description: The Client Advisory Board will host a monthly Peer Speakers Series, providing guidance and an experienced voice to people who are living with HIV. The series will focus on people who are out of care or who are not virally suppressed. Speakers will tell their stories of how and what it took to become undetectable and how they have sustained their health.*
 - *Project Justification: This series will directly impact people who are having trouble staying in care, assist individuals with tools to lower their viral loads, and ultimately reduce HIV transmission in the community.*

Peer Speakers Series: Process



- Collaborated with Quality Committee to run reports and collect data to identify people who were not virally suppressed
- Developed survey to assess interest, convenient times to meet, resources needed to attend, and barriers to medication adherence
- Staff with more familiarity with the consumers called them and completed surveys over the phone
- CAB members used results to identify topics and a budget to meet the needs of consumers

Peer Speakers Series: Logistics



- Developed 6-week Peer Speakers Series
 - Two-hour meetings
 - Light refreshments provided
 - Bus tickets
 - \$10 dollar store gift card for participants
 - \$20 gift card for support-person and \$25 gift card for presenter
- Training for CAB members
 - How to facilitate group
 - How to tell your story
 - Empathizing with peers

HELP'S CLIENT ADVISORY BOARD PRESENTS:

PEER SPEAKERS SERIES

- LIGHT REFRESHMENTS, GIFT CARD, AND BUS TICKETS WILL BE PROVIDED
- SESSIONS WILL BE PRESENTED BY PEERS WHO RECEIVE SERVICES AT HELP
- SESSIONS WILL INCLUDE TOPICS SUCH AS PHYSICAL AND MENTAL HEALTH, SUBSTANCE USE, AND STIGMA.

YOU'RE INVITED!

TUESDAYS	July 24 TO August 28
3:00 TO 5:00 PM	PLEASE JUST BRING YOURSELF AND AN OPEN MIND! EVERYTHING ELSE WILL BE PROVIDED.

The flyer is a vertical rectangle with a light blue background. At the top, it says 'HELP'S CLIENT ADVISORY BOARD PRESENTS:' in a small, spaced-out font. Below that is the title 'PEER SPEAKERS SERIES' in large, bold, black letters. A list of three bullet points follows, detailing the benefits and topics. A bright yellow horizontal band contains the text 'YOU'RE INVITED!' in large, bold, black letters. The bottom section is a dark red/orange color and contains a table with the schedule and a note. The table has two columns: the first lists 'TUESDAYS' and '3:00 TO 5:00 PM', while the second lists the dates 'July 24 TO August 28' and the note 'PLEASE JUST BRING YOURSELF AND AN OPEN MIND! EVERYTHING ELSE WILL BE PROVIDED.' There are small white icons in the top corners of the flyer.

Peer Speakers Series: Format



- Each session facilitated by a CAB member (some exception for guest speaker)
- Facilitator presented their own experiences related to topics
- A support-person (another CAB member) and CAB liaison from staff or intern was there to assist
- Time for discussion and for participants to share their stories related to topics
- Some activity or resource take-away provided
- Break included
- Time at end for participants to meet with Case Manager if needs identified
- Evaluations

Peer Speakers Series: Sessions



July 24th	Health and Medication
July 31st	Basic Need
August 7th	Mental Health
August 14th	Substance Use
August 21st	HIV Stigma
August 28th	Aging and Other Health Issues

3-5pm every Thursday

Peer Speakers Series: What happened?



- 7 participants attended throughout 6-week series
- 4 out of 7 participants attended 50% or more of the sessions
- Participants generally eager to talk and engaged
- 1 participant had significant barriers to basic needs met, including need for mental health treatment and was referred to support services
- 1 participant decided to go into substance usage treatment mid-way and continued to work with Case Manager to address barriers to care; maintained an undetectable viral load for the first time in 4 years and unfortunately received an advanced stage cancer diagnosis and died this past December.
- Certificates provided

Peer Speakers Series Evaluation: Participants' Feedback



- What did participants find helpful?
 - “The fact that we were able to talk and relate”
 - “The *Unhelpful Thinking* activity”
 - “The topic on aging on medication with HIV”
 - “The topic today and the speaker was great”

1. Would you tell a friend to come?



2. Did you like the topic choice?



3. Was the speech useful for you?



4. Was the conversation useful for you?



5. Was there something specific you liked?

6. What we can do better? →

Peer Speakers Series Evaluation: Participants' Feedback



- “Better food selection, real food”
- “Explain/ talk more in detail about the topic of choice”
- “If we had female (women) participants in our meetings”

1. Would you tell a friend to come?



2. Did you like the topic choice?



3. Was the speech useful for you?



4. Was the conversation useful for you?



5. Was there something specific you liked?

6. What we can do better? →

Peer Speakers Series Evaluation: Presenters' Feedback



“Participants had a lot of questions.”



“Certificates really made a difference for people.”



“You go in with *‘I’m gonna tell, I’m gonna teach,’* but you end up learning.”



“We learned as much from them as they did from us.”

Peer Speakers Series Evaluation: Presenters' Feedback



*On facilitating a session about stigma:
“I faced things that I had been dealing
with myself.”*



“People liked the S-T-I-G-M-A
acronym I created to learn about
HIV stigma.”



“Being heard. It felt good when a
participant acknowledged I had been
through hell.”

Peer Speakers Series: Successes & Challenges



Successes

- Participants and CAB members learned from one another
- Participants shared their experiences and identified with others
- Participants received tools and strategies for improving health outcomes
- Participants referred to other resources

Challenges

- Limited budget
- Lack of attendance
- Transportation
- Some participants had barriers to fully participating, such as lack of food, substance usage, and untreated mental illness
- Did not have group guidelines set from beginning
- One presenter was unexpectedly absent

Peer Speakers Series: Recommendations



- Full meals instead of light refreshments
- Transportation
 - Using Lyft or Uber may be a better option than bus
 - Coordinating transportation with case managers was helpful
- Have a back-up speaker and support-person in cases of absences
- Having CAB member training closer to the date of the actual events
- Continue to stay in touch with participants
 - May need additional support
 - May be interested in leading a session in future Speakers Series

Peer Speakers Series: Recommendations



- Be intentional about reaching underrepresented demographics
 - Consider reasons why some groups may have been underrepresented
 - Reduce barriers for increasing participation
- Using group guidelines from the start
- Have a set budget from the start
- A stipend for the CAB members hosting each event

Peer Speakers Series II (2019)



- What happened?
 - Had budget from beginning (and was able to get increased based on more participation)
 - Opened up to both people not virally suppressed and those maintaining viral suppression
 - Accepted referrals from staff and other local clinics and HIV agencies
 - Full meals provided
 - Had back-up support in case presenter or support-person was absent
 - Reviewed group guidelines at each session
 - 13 participants attended
 - No participants used a Case Manager for transportation, mostly used bus passes provided
 - Majority of participants attended 75% or more of the 6-week sessions

Peer Speakers Series II: Successes & Challenges



Successes

- Doubled participation and budget from first Peer Speakers Series
- Participants engaged and returned each week
- Participants built supportive relationships
- Participants referred to resources and services

Challenges

- Some participants may not be ready for group
- One participant had limited verbal communication
- Having comfortable space
- Staff and CAB capacity limited to implementing series more often
- Budget limited to implementing series more often

Peer Speakers Series II: Recommendations



- Collect data and use it to support efforts to continue or pivot the quality improvement project
- Continue to engage in quality improvement efforts by analyzing and evaluating data in order to improve upon intervention
- Maintain relationships with participants and other stakeholders
- Share data with all partners (CAB, Quality Committee, staff, consumers, board members, and other community partners)
- Continue to be challenged and evolve in order to include people with all abilities
- Patience and appreciation of the process

Ending the Epidemic with Consumer-led Quality Improvement



- PLWH must have a voice at all levels in order to improve overall health outcomes and end the HIV epidemic
- Consumers have knowledge and experience that is underutilized, which should be valued, encouraged, and financially compensated
- Mentor, train, and hire PLWH, particularly those most impacted by the epidemic



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

Contact Information

Ashton Whitehead, Peer Support Specialist
awhitehead@helpoffice.org

Kenny Rose, Quality Improvement Coordinator
krose@helpoffice.org

Stafford Sykes, Client Advisory Board Member
dwayne.ss@gmail.com



VIRTUAL
**2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT**

Questions/Comments