



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Consumer Strategies for Building a Successful Consumer Advisory Board

August 13, 2020

Presenters



- Kasey Harding, Center for Key Populations Director
- Maria Lorenzo, Community-Based Services Manager
- Joselyn Rodriguez, Center for Key Populations Resource Navigator
- Jim Cataquet, Consumer Advisory Board Member
- Lorrie Wiggins, Consumer Advisory Board Member

Who We Are: CHC, Inc



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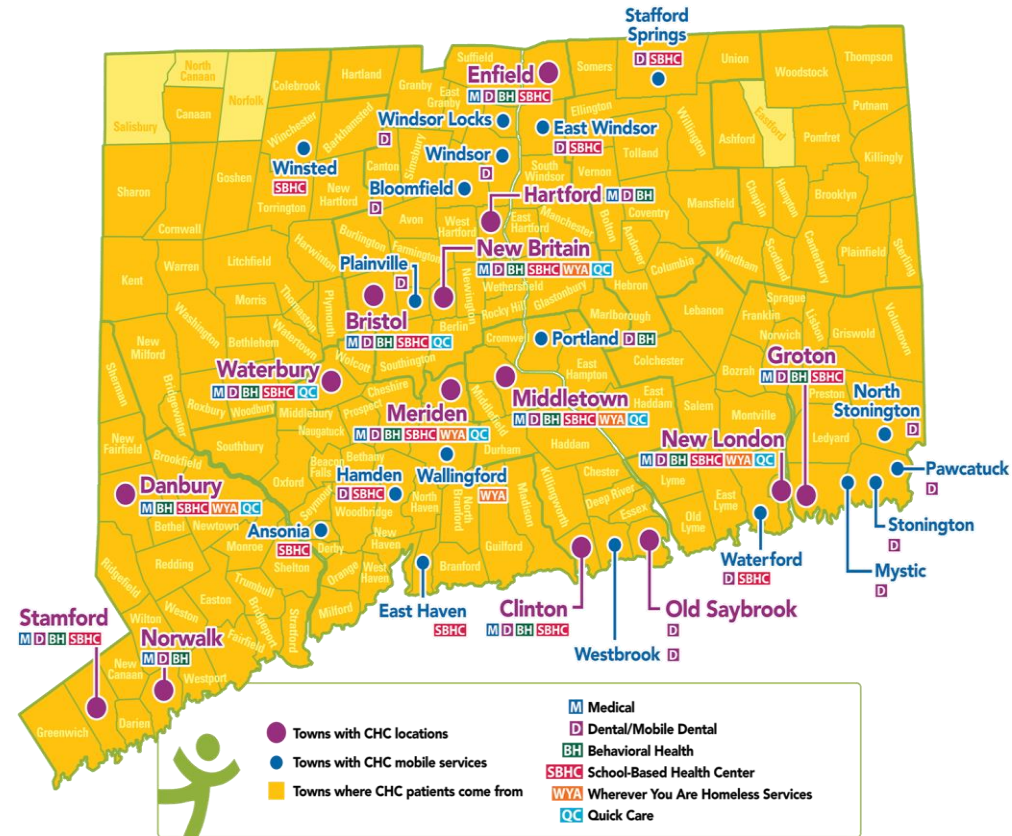


Community Health Center, Inc.

CHC Profile:

- Founding year: 1972
- Locations: 14
- Patients/year: 100,000

CHC Locations in Connecticut



THREE FOUNDATIONAL PILLARS

1 Clinical Excellence	2 Research and Development	3 Training the Next Generation
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Who We Are: CKP



The Center for Key Populations is the first center of its kind that focuses on key groups who experience health disparities secondary to stigma and discrimination and who belong to communities that have suffered many barriers to healthcare.

The Center brings together healthcare, training, research, and advocacy for: **People who use drugs, the LGB and Transgender populations, the homeless and those experiencing housing instability, the recently incarcerated, and sex workers.**



HIV Primary Care & Testing

Hepatitis C Screening and Treatment

Medication Assisted Treatment for Substance Use Disorders

Health Care for the Homeless

LGBTQ-focused Health Care

Community Drop-In Center

HIV PrEP (Pre-Exposure Prophylaxis and PEP Post-Exposure Prophylaxis)

Sexually Transmitted Infections

Meet Jimmy and Lorrie



Jimmy Cataquette
CAB Member
since 2008

Lorrie Wiggins
CAB Member
since 2017



Meet Maria and Josie



Josie Rodriguez
CKP Health
Resource
Navigator



Maria Lorenzo
Community Based Services
Operations Manager

Learning Objectives



- **The participant will learn how to assess their CAB structure and model through consumer input and look for weaknesses to be improved.**
- **The Participant will learn from consumers about the most successful recruitment and retention strategies for CABs and the impact that participation can have on their lives.**
- **The participant will identify cost neutral enhancements that can be made to transform a CAB into a key element of QI and a tool for the empowerment of consumers.**



Eligibility to participate in CHCI CAB

- Member must be living with HIV
- Member must be enrolled in RW services

Community Advisory Boards (CABs) provide clinics with input and guidance from patients regarding the design and delivery of care. To be effective, CABs follow operating procedures to guide them to carry out tasks like selecting members, convening meetings, gathering feedback, and working with clinics to improve their operations.

www.targethiv.org

About the CAB



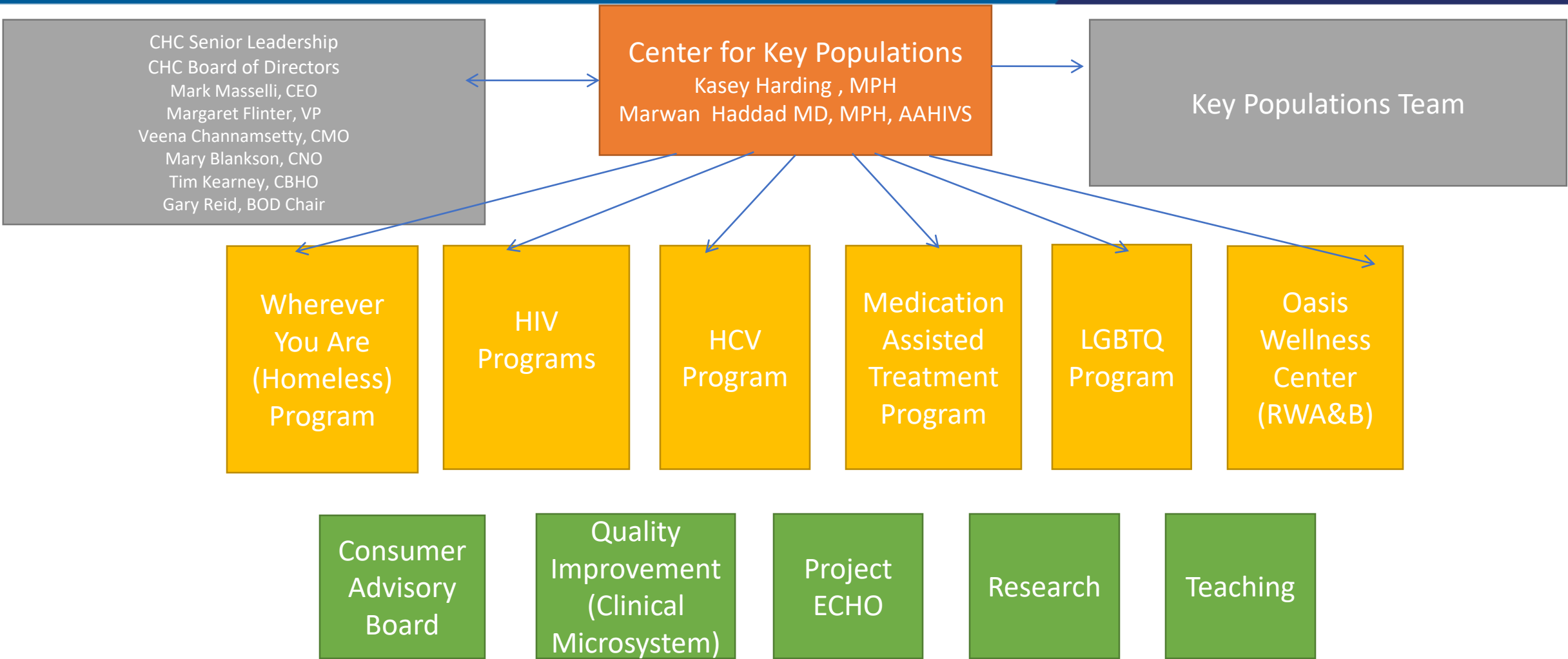
- The Center for Key Populations Consumer Advisory Board (CKP-CAB) consists of a group of consumers living with HIV who receive some form of healthcare or services at CHCI.
- The mission of the Center for Key Populations Consumer Advisory Board is to create an open environment for the exchange of ideas regarding services at CHCI. The CAB aims to use education, advocacy, quality improvement and storytelling to promote and provide equitable prevention, education and treatment services that are consumer driven and patient centered.

CAB Participation

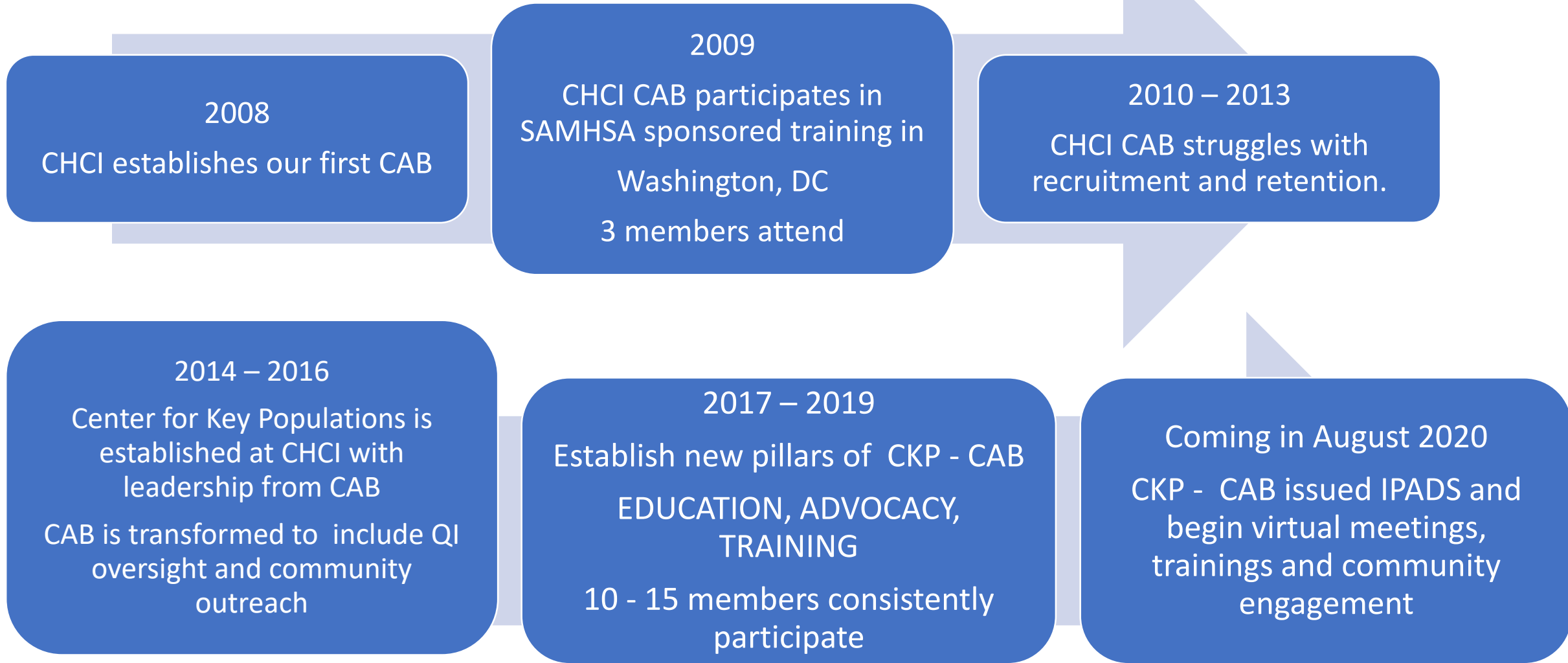


Let's hear from the CAB members!

CKP Org Chart



CKP's Timeline



Jimmy and Lorrie

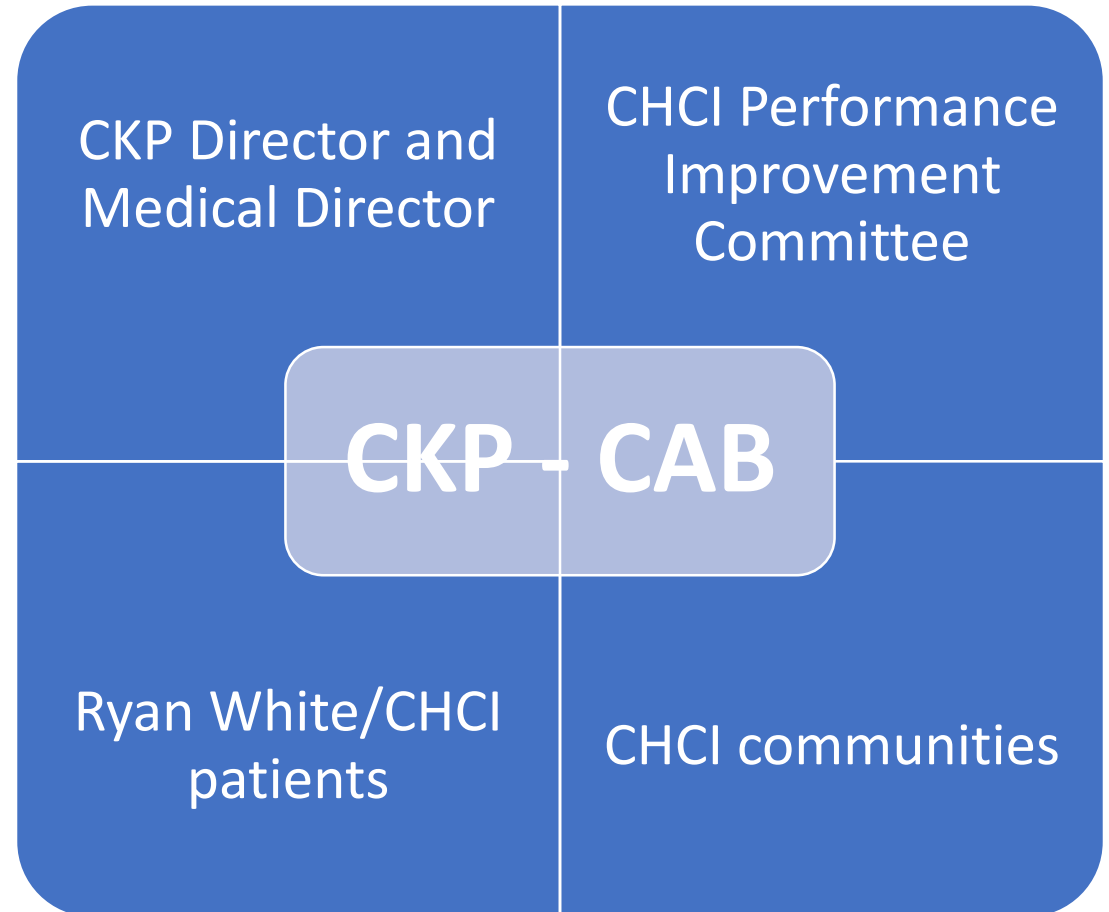


Let's hear from the CAB members!

CKP Consumer Advisory Board Structure 2015



- Monthly Meetings for planning
- Timed agenda
- Role Assignment for Members
- Facilitation by Bi-lingual RW staff
- Attendance by CKP Director every quarter.
- QI data presented quarterly
- Attendance by RW Providers and staff as requested



Jimmy and Lorrie



Let's hear from the CAB members!

CAB - Setting Priorities



- Getting more involved in advocacy
- Getting more involved in HIV Prevention efforts
- Working in the communities we serve to make a difference
- Learning more about CHCI and our services
- Learning about funding and services
- Creating an environment of learning for Consumers
- Creating an environment of learning for staff/community
- Creating opportunities for networking and sharing
- Develop activities that build professional skills for CAB members

Jimmy and Lorrie



Let's hear from the CAB members!

AIDS Life Campaign



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- The AIDS LIFE (Legislative Initiative and Funding Effort) Campaign - a program of AIDS Connecticut - is Connecticut's only statewide group that focuses solely on all of the policy-related issues impacting people living with and at high risk for HIV/AIDS - from prevention and education, including needle exchange; to supportive services; to health care, such as Medicaid and CADAP; to housing.



Jimmy and Lorrie



Let's hear from the CAB members!

Community Partnerships/Collaborations



- Collaboration with case managers from other AIDS Service Organizations.
- Collaborations with Advocacy campaigns that are statewide and national
- Collaborations with other healthcare organizations
- Partnerships with community organizations that conduct trainings – CT Harm Reduction Coalition, CT Coalition to End Homelessness.
- Partnerships with statewide planning bodies. (CT HIV Planning Consortium, RW Planning Council)
- National Networks and Councils



Jimmy and Lorrie



Let's hear from the CAB members!

Quality Improvement



Ryan White and HIV data presented quarterly
DCKP attends data meeting quarterly

Training conducted on
Data analysis
Understanding data
Patient centered care
Program Implementation
Funding/potential funding
Evaluation/Impact

Feedback from consumers on projects and outcomes
Participation in CHCI QI teams as needed
Participation in CHCI committees like PCMH+
Communications materials approved by CAB

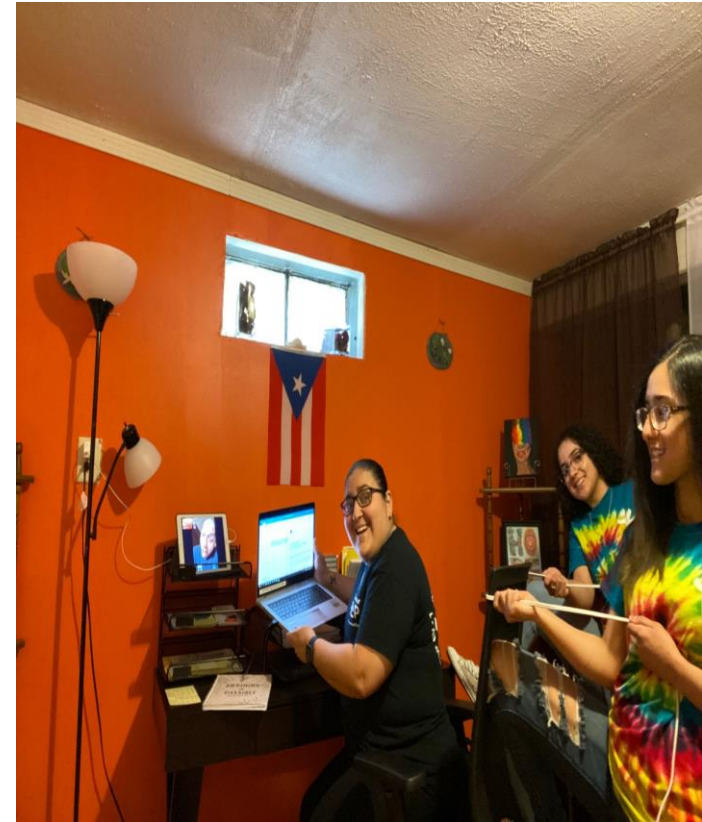
CAB Staff Facilitation

The right facilitator for the CAB makes all the difference in it's success!

The CAB must have some authority and the ability to recognize their impact.

Appreciation for culture and beliefs of each individual are important to create an environment for sharing. Creating this relies heavily on the facilitator.

Consistency and Communication are the keys to effective facilitation for the CAB.



Jimmy and Lorrie



Let's hear from the CAB members!

CAB Member Benefits



- Consumers learned- public speaking, learned to care for others, respect and the importance of privacy towards others, validate opinions, humble to others.
- Learning about HIV and the importance of how to better care for health with a healthy lifestyle and following up closely with medical care.
- Learn to appreciate other cultures, belief systems and lifestyles.
- Stress Management
- Organizational Skills
- Responsibility and Accountability
- Experience in healthcare infrastructure and structure
- Created environments for learning, growing and transforming
- Learn to have a positive social network.
- Learn to create positive impact on their existing social networks and families

Lessons Learned



- **Educational Trainings- HIV, Disease Management, Leadership, Organization, Roberts Rules of Order, Effective Meeting Skills, Quality Improvement**
- **It is important to the CAB to work on quality improvement projects with the care team and to use them to learn about patients needs before you start projects.**
- **CAB Members have become more dedicated and enthusiastic about CHC goals and purpose of CAB once they understood the importance.**
- **Creating Peer Support group amongst CAB Members is a really important element.**
- **Bi-Lingual staff with training in motivational interviewing and facilitation can lead to more success.**

Lessons Learned



- **An open and welcoming environment is essential to recruitment, retention and productivity at all times.**
- **Conflict management is a necessary component of CAB meetings. It can be uncomfortable but this skill is more necessary than most.**
- **Confidentiality and Privacy are worth mentioning every single time you meet.**
- **Well run meetings with agendas and business model are integral to success.**
- **Being responsive to the equity question for patients is essential – not everyone comes from the same place or is comfortable sharing their personal beliefs.**
- **Politics has no place in the CAB.**

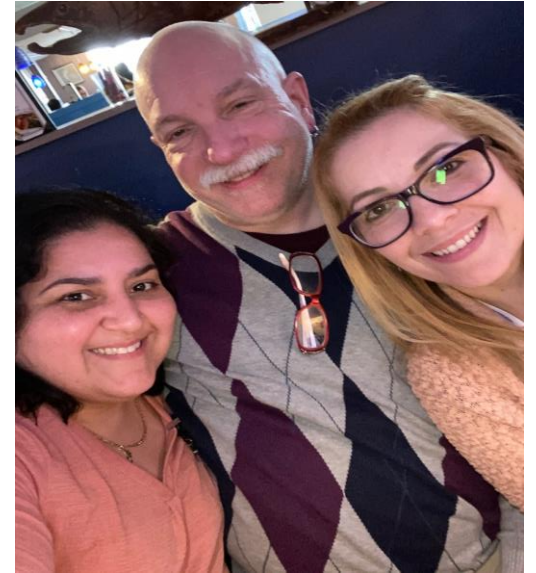
Jimmy and Lorrie



Let's hear from the CAB members!

Predictors of Success

- Consistent scheduling every week – day and time
- Don't cancel unless absolutely necessary
- Bi-lingual staff facilitation
- Provision of transportation
- Provision of food/shared meal
- Create a support system as a secondary benefit to participation
- Organize group trips as incentives
- Small monetary are always appreciated for hard work.



Covid-19 Impact



- CAB feedback was integral to providing the appropriate support to Ryan White patients at the start of the pandemic.
- Innovative models of CAB participation have been explored from across the country
- Ryan White Project Officer was happy to hear that part of our Covid funding would be spent on technology and incentives for CAB participation remotely.
- IPADS will be distributed to CAB along with a one year wireless network plan to enable participation regularly in meetings.
- CAB members will keep IPADS for personal use so it will aid in telehealth capabilities and outreach to members.
- CAB input during crisis is even more vital than in normal times.

Provider/Staff Feedback



“Through participation in CHC’s Ryan White Community Advisory Board (CAB), my patients develop greater HIV health literacy, gain the confidence to advocate for themselves and communicate their needs in medical visits, and get to connect with other individuals living with HIV/AIDS in their communities, often resulting in lifelong friendships. In turn, I notice an increase in health-seeking behavior and overall wellbeing in many of my patients who are members of CAB.”

Jeannie McIntosh, APRN

Ryan White Provider

Provider/Staff Feedback



“Input from the CAB is critical in ensuring that our program’s services and direction remain focused on what is most important to our patients. It is essential that we listen to our patients and that we keep them central to all that we do. The CAB keeps us grounded and in touch with what our patients’ needs are, as a program, as providers, as case managers.”

“Over the years, Jimmy has been our constant, the driving force behind the success and perseverance of the CAB with his dedication, his advocacy, and his honesty.”

Marwan Haddad, MD

Ryan White Provider

Medical Director of the Center for Key Populations

Provider/Staff Feedback



“Lorrie is an important part of our CAB and has been since she began attending. Lorrie is all about education – whether it is youth or community members she really believes that she can be a driving force in helping to teach safety and health to everyone. She has been a positive influence on everyone she meets and always expresses the importance of making changes to be more healthy. She is a joy to work with.”

Maria Lorenzo

CBS Operations Manager

Next Steps



- Distribute IPADS to CAB members
- Train Members on remote participation in CAB
- Develop schedule of meetings/trainings
- Provide effective remote participation and facilitation on-going
- Evaluate success of remote CAB participation
- Provide replicable model of remote CAB participation

Thank You!



Contact Information

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