CONSUMER ENGAGEMENT IN THE NEW YORK EMA:

COMMUNITY ADVISORY BOARDS (CABs)

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Power of Quality Improvement Conference

Kimmel Center, New York University

November 19, 2018

TODAY'S WORKSHOP

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- **WELCOME & INTRODUCTIONS**
  - Lisa Best & Billy Fields, Co-Chairs, Consumers Committee of the NY HIV Planning Council
- **WORKSHOP PRESENTERS**
  - Justin LiGreci, HIV Training Institute, Cicatelli Associates, NY
  - Darryl Wong, NY HIV Planning Council, NYC DOHMH, NY
- **CAB PANELISTS**
  - Callen- Lorde – Rob Walker
  - Hetrick Martin Institute – Jackson Katz
  - William F. Ryan Center – Leonardo Ruiz
  - Hudson Valley Community Services – Lisa Beal

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WORKSHOP OBJECTIVES

- Define **CONSUMER INVOLVEMENT**
- Become familiar with other systems of **CLIENT INPUT**
- Revisit *purpose and the role* of the **COMMUNITY ADVISORY BOARD**
- Identify *characteristics* of **HIGHLY EFFECTIVE** CABs
- What does an **INCLUSIVE** CAB look like?
- Obtain real-time **FEEDBACK** on best practices & recommendations from CAB panel

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INTRODUCTIONS OF WORKSHOP PARTICIPANTS

- Please state your **NAME**
- What are your **PREFERRED GENDER PRONOUNS**?

- Using the index cards distributed, please record your thoughts about:
  - Something **positive** you've heard or experienced about CABs *and*
  - Something **negative** you've heard or experienced about CABS
  - How prepared/ready are you in establishing, leading and/or participating in the CAB where you receive services?

    Please circle – **NOT VERY, SOMEWHAT** or **VERY PREPARED**

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WHY DO WE NEED CONSUMER INVOLVEMENT FROM PEOPLE LIVING WITH HIV IN THE NEW YORK EMA?

- To improve the **QUALITY OF SERVICES** at Ryan White-funded agencies in order to meet the needs of PLWH
- To provide **CRITICAL PERSPECTIVES from PLWH' LIVED EXPERIENCES** as consumers of Ryan White services
- To comply with Federal & Local **REQUIREMENTS** to demonstrate **CONSUMER ENGAGEMENT** in policy & program design, implementation, evaluation and quality improvement (PCN 1502)

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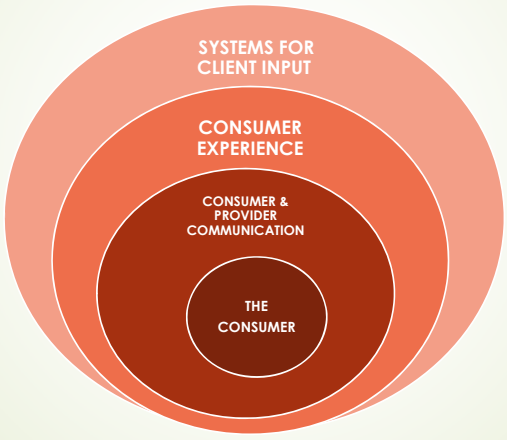
THE CONSUMER SOLAR SYSTEM



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"Once social change begins, it cannot be reversed.

You cannot un-educate the person who has learned to read.

You cannot humiliate the person who feels pride.

You cannot oppress the people who are notafraid anymore."

- Cesar Chavez

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THE DENVER PRINCIPLES

- We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."
- Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

NOTHING ABOUT US, WITHOUT US

This statement, written in June 1983 by the advisory committee of the People with AIDS Coalition, launched the PWA self-empowerment movement. The document is a valuable reminder of AIDS history in this 35th year of the epidemic.

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NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS (NASTAD)

- PLWH play a **UNIQUE ROLE** in identifying emerging **trends** in the epidemic, assessing **unmet needs** and identifying **effective services**
- PLWH are able to evaluate the feasibility of proposed programs and policies through a **personal lens**
- PLWH navigation of the HIV service delivery system can inform policy making as they identify and address the **gaps in services or barriers to care.**

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"People cannot achieve their fullest health potential unless they are able to **take control of those things which determine their health.**"

–World Health Organization, 1986

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The Consumers Committee of the New York HIV Planning Council brings together those with lived experiences of HIV and AIDS, as well as the parents and/or guardians of minors living with HIV/AIDS within our funding area. The Consumers Committee makes up one-third of the HIV Planning Council membership.

Committee meetings are generally held once a month at different locations throughout New York City. The council encourages and supports consumer participation by providing round trip Metro cards, a meal, language interpretation and child care services (with two weeks' advanced notice).

All meetings are held in spaces accessible to people with mobility and hearing impairments. For questions about accessibility, please contact the Office of the NY HIV Planning Council at 347-396-7441 or nyhiv@health.nyc.gov.

For Consumers Committee meeting calendars, schedules and announcements, visit the New York HIV Planning Council's website at nyhiv.org or call 347-396-7441.

New York HIV Planning Council

The New York HIV Planning Council is part of the federal Ryan White HIV Program, which began as the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The program helps cities, states and local community-based organizations provide primary care and support services to uninsured and under-insured people living with HIV/AIDS (PLWHAs). The New York HIV Planning Council is a 50-member community planning body whose mission is to ensure PLWHAs receive quality care. Members are chosen by the mayor and include PLWHAs, primary care and social service providers, governmental representatives and community-based partners.

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Division of Disease Control
New York City Department of Health and Mental Hygiene
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Your Voice Matters:

Join the Consumers Committee

A Committee of the New York HIV Planning Council

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https://hab.hrsa.gov/livinghistory/voices/media/m4v/living-high-res.m4v

THE HISTORY

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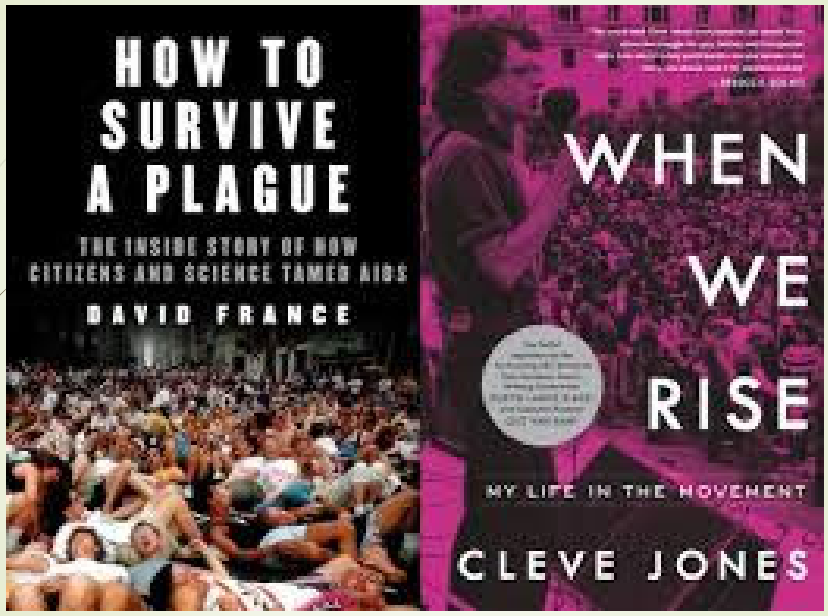
HOW TO SURVIVE A PLAGUE
THE INSIDE STORY OF HOW CITIZENS AND SCIENCE TAMED AIDS
DAVID FRANCE
WHEN WE RISE
MY LIFE IN THE MOVEMENT
CLEVE JONES

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WHY CONSUMER FEEDBACK?

- **Why** would a consumer want an agency to obtain feedback on services and programs?
- **How** have agencies where you've received services made changes to programs and services in the past? How effective have those changes been in improving services?
- **What** are some ways a consumer could provide feedback to an agency?

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WHY CONSUMER FEEDBACK?

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RYAN WHITE PART A CABS BACKGROUND & HISTORY

- The NY EMA, or Eligible Metropolitan Area, has been committed to ensuring that a **structure for consumer involvement & feedback** be developed and implemented at the contractor level since the inception of Ryan White funding.
- HRSA has provided guidance on consumer involvement in the Part A planning process, although **CABS are not mandated by HRSA**
- **In the NY EMA, CABS are mandated, but not funded**
- Public Health Solutions (PHS) has worked with the Planning Council to **implement the requirement for advisory board development and consumer participation.**
- In the past, the Planning Council distributed CAB surveys to all contractors. However, community members questioned if the **surveys were faithfully implemented and if the responses were a representative and meaningful sample of membership.**

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HOW ARE CONSUMERS INVOLVED?

- Satisfaction/Experience Surveys (87%)
- CABS (68%)
- Focus group participants (36%)
- Other strategies (27%)

HOWEVER, 75% OF SURVEYED AGENCIES DO NOT SYSTEMATICALLY OBTAIN INPUT

* NYSDOH, AIDS INSTITUTE 2006

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SYSTEMS OF CLIENT INPUT IN THE NEW YORK EMA

- **Medical Monitoring Project (MMP)** – National/Local
- **Community Health Access Information Network (CHAIN)** – Local
- Client Experience Surveys (NYCDOHMH) – Local
- **PLWH Focus Groups – 2017 Consumer Solar System Project –** Local
- **Consumers Committee of the NY HIV Planning Council** – Local
- **Community Advisory Boards (CABs)** – Local

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WHAT IS A CAB?

- For this workshop, CAB stands for **"Community Advisory Board"**
- CABS are defined as " a body that provides it's organization with guidance on questions relevant to consumers"
- A CAB is one type of an Advisory Board which can include members from the **community, consumers, clients or patients.**
- Usually the Advisory Board determines who qualifies for membership
- Clients are ***stakeholders*** in the community and therefore have experience, expertise or value as a member
- Can be closed or open groups
- Normally have an application and nomination process

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MISCONCEPTIONS OF CABS IN THE NY EMA

- CABs **do not authorize programs or services**
  - Effective CABs are knowledgeable about agency programs and **provide and obtain feedback** about programs from clients
- CAB members **do not write agency policy**
  - They provide and obtain **feedback** about programs from clients
- CAB members **do not advocate** on behalf of special interest groups
  - Pharmacies, medical equipment, etc
- While informed by personal experience, CABS are **not a support group**
- CABS are **not a THEM vs US** dynamic

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https://www.youtube.com/watch?v=7K53xqsBMIQ

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WHY CABS?
BENEFITS OF CONSUMER INVOLVEMENT FOR CONSUMERS & PROVIDERS

- Recognizes consumer **SELF-DETERMINATION & INDEPENDENCE**
- Supports the development of **LEADERSHIP SKILLS & EMPOWERMENT**
- Increases **CONSUMER KNOWLEDGE** & **PROVIDER SENSITIVITY** to the client experience
- Improves **SERVICE QUALITY**, informing program evaluation & provider policies

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HEALTH BENEFITS OF EFFECTIVE CONSUMER ENGAGEMENT

- Increased ability to **self-manage** one's health & HIV
- More likely to become & remain **adherent**
- More **effective communication** with provider & staff
- Decrease in **stigma** => positive health effects
- Creation of networking opportunities/support systems that increase **consumer knowledge**
- Increased **consumer empowerment** through active involvement in informing and educating peers

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WHY THE CAB SURVEY PROJECT?

- To inform the NY HIV Planning Council on best practices to support optimal CAB functioning by identifying best practices for CABs
  - **RECRUITMENT, ENGAGEMENT & RETENTION**
  - **LEADERSHIP & COORDINATION**
  - **COMMUNICATION, CLIENT INPUT & FEEDBACK**
  - **POLICIES/PROCEDURES/BYLAWS & CONFLICT MANAGEMENT/RESOLUTION**

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2014 RYAN WHITE PART A COMMUNITY ADVISORY BOARDS BEST PRACTICES & RECOMMENDATIONS

- In 2012/13, staff and clients of Part A funded agencies with CABs rated the overall effectiveness of their CABS with a **48 question survey.** The survey was based on a formative literature search and other compendia of best practices.
- Of the 88 CABs contacted for participation, 40 CABs completed surveys (45% RR) and 31 CABs completed Members surveys (35% RR).
- **83% of survey responses indicated that these CAB best practices were being implemented**
- In 2014, these best practices were synthesized into recommendations for consideration by the Planning Council to support optimal CAB functioning.

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CAB RECRUITMENT, ENGAGEMENT & RETENTION

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CAB PANEL CHECK IN # 1

PANEL:

- Please describe your successes and or/challenges in **RECRUITING & RETAINING** your members in your agency's CAB?
- How has your CAB overcome or addressed these issues?

AUDIENCE:

- As a CAB member, what have been your challenges to fully participating in the CAB process?

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BEST PRACTICES FOR RECRUITMENT & RETENTION OF CAB MEMBERS

- Host a CAB-specific special event, town hall, etc.
- Post notices of CAB meetings in waiting areas
- Have a defined application period vs. rolling applications
- Recruit consumers with qualities, skills and shared experiences related to the mission and goal of the CAB through contact with agency staff
- Identify a "champion" of your agency's CAB (social workers, client service staff, navigators and outreach workers) to promote the CAB to potential members
- Have a defined, structured process for the CAB member appointment process
- Offer ongoing trainings including"
  - Reading, analyzing and interpreting data
  - Working with policy makers
  - Working effectively in groups
  - Cultural competency training
- Be able to respond to basic questions about your role as a CAB member (what a CAB member does and how the input will be used)

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SETTING YOUR MEETING CALENDAR

- Plan a year's calendar of meetings, if possible
- Frequency, time & data should be set by CAB members with input from the agency and should be consistent
- A minimum number of meetings per year should be written into the CAB ByLaws
- Be aware of sensory, physical and developmental disabilities affecting members' participation and find workable solutions

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CAB
LEADERSHIP & COORDINATION

CAB PANEL & MEMBER CHECK IN #2

CAB PANEL:

- With respect to **CAB LEADERSHIP & COORDINATION**, please describe some of the challenges your CAB has faced.
- How has your CAB overcome or addressed these issues?

MEMBERS:

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- How has the CAB where you receive services overcome challenges in leadership and coordination? What positive changes have you seen?

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CAB LEADERSHIP

- CAB leadership should possess **strong leadership skills** and assist in establishing a **culture of engagement and respect** which allows individuals to state their opinions and where **group participation is the norm and expectation**;
- CAB leadership should possess **strong facilitation and active listening skills which foster communication and validates member input.** CAB chairs should seek input and viewpoints (verbal or written) from all, **allowing everyone a chance to express their thoughts**;
- CAB leadership should **not prioritize personal agendas and not dominate the conversation**, but should **encourage those who are hesitant** to participate;
- CAB leadership should demonstrate **appropriate behavior, set the tone for the meeting** and be **pro-active** in diffusing negative comments and **preventing escalation** of a conflict or an issue;
- The CAB's policies and procedures should clearly **identify the role and responsibilities of the facilitator**;

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CAB LEADERSHIP

- The CAB should utilize **Rules of Respectful Engagement and a Code of Conduct** to assure a fair environment, while focusing on **solutions** rather than blaming or accusing. Follow the Rules of Respectful Engagement and a Code of Conduct and be committed to implementing them;
- CAB leadership should establish/develop a **climate of trust and safety**, where **confidentiality** is assured and enforced**;**
- The CAB should assure that members have a **shared understanding of their roles and responsibilities**, with a **designated facilitator** recognized for each meeting. The agenda should clearly state who **responsible parties** are for presentations, actions & follow up;
- The CAB should ensure that 1) **meeting minutes record highlights of relevant discussions & the actions taken/to be taken and 2) parking lot issues/report backs** to CAB are part of the next meeting's agenda; and
- CAB leadership should also **identify CAB members who agree to take lead roles in addressing follow up actions** (as agreed to by the CAB).

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CABS REQUIRE WORKING TOGETHER

- Clear and consistent groups goals
- Consistent, active participation
- Clear communication
- Active listening skills
- Sharing of ideas
- Safety & Trust
- Excellent leadership!

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CAB COORDINATION

- CAB leadership should consider an **orientation** at the beginning of the cycle to assure that members have a shared understanding of their **roles & responsibilities;**
- CABs should begin each cycle/year with **team-building and/or ice breaker exercises;**
- CAB meetings should be scheduled on a **recurring basis** (same day of week, time, location, etc);
- M**ember lists, phone & email** trees should be used to keep members informed of meetings;
- CABs should consider the use of a **paired buddy system** to keep communication flowing;
- CAB leadership should explore more **formalized mentoring** for seasoned CAB members who can guide & inform newer members;

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CAB COORDINATION

- CABs should provide **printed calendars of meetings**, a **timeline** of goals and activities & **Rules of Respectful Engagement (RRE)** to govern participant behavior & communication;
- CABs should be facilitated by an identified chair and/or staff liaison who are the **primary contacts for the CAB;**
- CABs should provide a **detailed agenda** identifying items to be discussed, as well as **timeframes** for discussions in order to help guide the discussion;
- The CAB agenda should be developed by CAB staff, leadership and members to assure that **all perspectives are included in discussions & presentations**; and
- All CAB members should have a good understanding of the CAB's goals by providing an orientation with a focus on **roles & responsibilities, policies & procedures for client concerns, grievance procedures** and a **clearly delineated process for client engagement, input, discussion and feedback.**

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CAB COMMUNICATION, CLIENT INPUT &FEEDBACK

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CAB PANEL CHECK-IN # 3

CAB PANEL:

- With respect to **CAB COMMUNICATION, CLIENT INPUT & FEEDBACK** what kinds of challenges has your CAB experienced? … and….
- How has your CAB overcome or addressed these issues?
- How do you obtain feedback from your CAB members?

CAB MEMBERS:

- As a CAB member, do you feel your feedback is valued/valuable?
- How has the CAB where you receive services overcome challenges in communication and consumer feedback? What positive changes have you seen?

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TEAM COMMUNICATION

- Rules and policies for member participation in meetings should be **reviewed at each meeting;**
- CAB leadership should develop and **offer opportunities for CAB members to express themselves** (verbally or in writing) and to contribute their feedback, thoughts or concerns;
- Meeting agendas should be developed which allow for **individuals who are reluctant to speak to use the public comment time period** (with 2-3 minute time limits) or other systems for written comments/input;
- CAB leadership should **encourage those individuals who tend not to actively participate** to contribute their thoughts and/or opinions;

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TEAM COMMUNICATION

- Meeting procedures should **establish time restraints in order to diffuse or de-escalate heightened interaction** between members and/or members and agency staff;
- Agendas should be developed with CAB leadership & membership **allowing for flexibility to discuss issues not previously identified;** and
- **There should be designated times for discussion/action items.** The CAB facilitator has the responsibility to keep to the agenda, but also to be **flexible when group consensus supports additional discussion.**

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OBTAINING CLIENT INPUT & FEEDBACK

- CAB membership should be **inclusive of diverse expertise and experiences** and include a wide cross section of agency/program clients, representing all age groups;
- While the **CAB's mission, goals and policies should be focused on meeting client needs**, CAB members should understand the **role of the CAB** in prioritizing and meeting needs, as well as understanding when that is not possible;
- CABs should ensure that there is a mechanism in place or agency CAB staff person on board to **advocate in support of clients' needs;**
- CAB should establish and enforce **RRE** for all CAB members and meeting attendees and insure that all those participating agree to this conduct. **Personal agendas are secondary** to issues which may have a material impact on the services the agency's clients are receiving;

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OBTAINING CLIENT FEEDBACK

- **Client input and feedback policies should be developed** in order to efficiently and expeditiously address specific client needs;
- CABs should establish methods and/or **tools to reach agency consumers/clients (**other than CAB members) to get **broad perspectives;** and
- CABs should develop an **awareness of client needs** through client feedback, surveys and other means and develop a method to **prioritize expressed needs** and to **follow up** and propose solutions to address/resolve client needs. Written records, which respect **client confidentiality,** should be maintained.

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WHAT CAN GO WRONG?

- Postponing meetings
- Member absenteeism
- Membership turnover
- Inability to gather quorum (Majority vote)
- Members feeling a lack of purpose or lack of enthusiasm
- Not sticking to policies/ByLaws
- Lack or insufficient agency oversight, buy in or support ($ or admin)
- Tokensim

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BARRIERS TO CAB PARTICIPATION

- Consumers' lack of interest (48%)
- Lack of incentives/compensation (45%)
- Lack of funding for CABs (42%)
- Family & health issues (38%)
- Transportation to and from meetings (36%)
- Confidentiality & disclosure issues (25%)

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CAB POLICIES/PROCEDURES/BYLAWS & CONFLICT MANAGEMENT &RESOLUTION

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CAB PANEL CHECK-IN # 4

CAB PANEL:

- With respect to **CAB POLICIES, PROCEDURES/BYLAWS & CONFLICT MANAGEMENT & RESOLUTION** what kinds of challenges has your CAB faced? … and…
- How has your CAB overcome or addressed these issues?

CAB MEMBERS:

- How has the CAB where you receive services overcome challenges in policies & procedures and conflict management? What kinds of changes have you seen?

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BY LAWS : WHAT'S IN A RULE?

- Bylaw definition: A rule that an organization, agency, board or group makes and that it's s members must follow
- Common elements:
  - Organization goal/mission statement5
  - Guiding principles
  - Membership composition
  - Officers/leadership
  - Committees (if any)
  - Meetings and proxy rules
  - Membership terms, appointments, resignation & removal
  - Conflict of interest policy
  - How to amend

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ESTABLISHING BY LAWS, POLICIES & PROCEDURES GUIDES

- **Every CAB must create, vote to accept and implement their own Bylaws**
- It may take **more than one meeting**
- It's Ok for an agency to develop them first and then have CAB members review them and make desired changes
- It's up to CAB members to ratify and adheres to ByLaws and the CAB leadership **must** enforce them
- **ByLaws must be respected** but may have rules added, removed or modified over time by the accepted procedure as indicated in the ByLaws

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CONFLICT RESOLUTION & MANAGEMENT

- CABs should use **Robert's Rules of Order (RRO)** to assure that meetings are run according to **Parliamentary rules**, with an emphasis on giving **all members an opportunity to voice their opinions and/or viewpoints;**
- Establish **conflict/dispute resolution guidelines & procedures** to resolve issues and/or disagreements among members. Members should **commit to following procedures** in order to arrive at resolutions;
- Encourage **individual member participation & discussion** when dealing with conflicts/issues affecting the CAB's work, mission & goals;

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CONFLICT MANAGEMENT & RESOLUTION

- Everyone has a **right to respectfully state their opinion/point of view using the RRE** to govern discussions and behavior;
- **Identify problem(s) and/or issue(s) and develop realistic outcomes and/or goals,** while following guidelines for discussion as established by the CAB; and
- When an issue or conflict arises that affects the CAB's functioning, the **CAB leader should become actively involved in the facilitation of the conflict resolution process** with members, in order to prevent disrupted meetings.

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CHARACTERISTICS OF EFFECTIVE CABS

- **Recruits** PLWH (93%)
- **Responds** to issues from clients receiving HIV services (93%)
- **Provides input** in developing/refining HIV program mission (90%)
- **Actively participates** or links to agency's internal Quality Improvement/Management committee within the HIV program (79%)
- **Appoints individuals** to facilitate and/or chair the meetings (76%)
- **Develops** their **own agenda** (69%)
- **Develops policies & procedures** to conduct meetings (69%)
- **Develops and sets work plan** goals and objectives (59%)

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CLOSING PANEL & MEMBER HIGHLIGHTS

PANEL

- What successes and or milestones has your CAB achieved, such that your CAB is "highly effective"?
- Which strategies have made your CAB particularly effective? What have been the most significant changes that have resulted in a better functioning CAB?

MEMBER

- Is the CAB of which you are a member effective in helping the agency meet/better meet your HIV service needs?

ALL

- After this workshop, do you feel more confident or prepared in leading or participating in your agency's CAB?
- Please indicate by a show of hands:

  Not Very or **Somewhat** or **Very Prepared**

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CONTACT INFORMATION

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- **Billy Fields**, Co-Chair, Consumers Committee, NY HIV Planning Council
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THANK YOU!!

- Part A 2014 survey respondents and their CAB members for their interest, time and INSIGHTS
- The NYC & Tri County Consumers of the NY HIV Planning Council for their participation in the 2017 Consumer Solar System Project
- NYCDOHMH staff for their support:
  - Epidemiology & Field Services, Cristina Rodriguez-Hart, Ph.D.
  - Research & Evaluation Unit, HRTP interns, CAB Best Practices project
  - Quality Management Program, Kristina Rodriguez

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OTHER SYSTEMS OF CLIENT INPUT IN THE NY EMA

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QUANTITATIVE VS. QUALITATIVE METHODS

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CLIENT SATISFACTION/EXPERIENCE SURVEYS

ADVANTAGES

- Easier to plan
- Inexpensive
- Can provide a wide range of information, depending on questions
- Can be done "anonymously" (ACASI)
- Allows for quantifiable, measurable "trends" over time
- Data relatively straight-forward

DISADVANTAGES

- Low response rate
- Response bias – only those who use the service are surveyed
- Too many surveys – burnout
- Literacy level – too high or too low?
- Misinterpretation of question can lead to "wrong" answers
- May be impersonal

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PLWH FOCUS GROUPS

ADVANTAGES

- Useful to obtain detailed information about group feelings, perceptions and opinions
- More cost effective
- Can provide a broader range of information
- Offers the opportunity to seek clarification
- May encourage self-reflection
- Encourages greater ownership/stakeholder buy in vs other methods

DISADVANTAGES

- Disagreements and irrelevant discussions can distract from focus
- May be hard to control and manage
- May be tricky to analyze
- Consumer-centric Community Based Participatory Research
- Participants may find sharing highly personal information intimidating or off-putting and may feel pressure to agree with the dominant group

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CONSUMER SOLAR SYSTEM BACKGROUND

- While great progress in viral suppression has been achieved in NYC, quality improvement initiatives have long focused on providers' experiences with the clients they serve
- Less frequently are such initiatives directly informed by the clients' lived experiences as people living with HIV/AIDS (PLWHA) and as consumers of services
- Consumers' views and experiences are integral to efforts in quality improvement. Their experience is driven by the level of positive interpersonal interaction at every point during their encounter
- Poor consumer/provider relationships and communication accounts for 62% of dissatisfied consumers in NYC and 53% of consumers in the Tri County region (CHAIN Report, 2007-2a)

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ANALYSIS/PROJECT METHODOLOGY

- **Goal**:
  - To evaluate how to establish positive client-provider relationships from the perspectives of PLWHA
- **Objectives were to assess**:
  - Barriers and enablers to receiving HIV care among PLWHA at their HIV health provider
  - How the client-provider relationship either supports or hinders adherence to HIV medications and maintenance of viral suppression

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CONSUMER SOLAR SYSTEM FOCUS GROUP PARTICIPANT CHARACTERISTICS

	Total		NYC		Tri-County	
Participant Characteristics	**N**	**%**	**N**	**%**	**N**	**%**
Total	27	100.0	14	100.0	13	100.0
Age Mean (Range)	59 (37-69)		56 (37-68)		62 (50-69)	
Gender						
Male	17	63.0	11	78.6	6	46.2
Female	10	37.0	3	21.4	7	53.9
Race/Ethnicity						
Black	17	63.0	7	50.0	10	76.9
Latino	6	22.2	3	21.4	3	23.1
White	4	14.8	4	28.6	0	0.0
Other	0	0.0	0	0.0	0	0.0
Sexual Orientation						
Heterosexual	13	48.2	4	28.6	9	69.2
Gay/Homosexual	10	37.0	8	57.1	2	15.4
Bisexual	2	7.4	2	14.3	0	
Other/Unknown	2	7.4	0	0.0	2	15.4
Area of Residence						
New York City	12	44.4	12	85.7	0	0.0
Tri-County Region	15	55.6	2	14.3	13	100.0

CONSUMER SOLAR SYSTEM FOCUS GROUP PARTICIPANT CHARACTERISTICS

	Total		NYC		Tri-County	
Participant Characteristics	**N**	**%**	**N**	**%**	**N**	**%**
Total	27	100.0	14	100.0	13	100.0
Year of Diagnoses Median (Range)	1995 (1986-2012)		1997 (1987-2012)		1992 (1986-1998)	
Area Where HIV Services Are Obtained						
New York City	15	55.6	14	100.0	1	7.7
Tri-County Region	12	44.4	0	0.0	12	92.3
Year Initiated Taking HIV Medications Median (Range)	1997 (1987-2014)		2000 (1987-2014)		1994 (1989-1999)	
Currently Taking HIV Medication						
No	0	0.0	0	0.0	0	0.0
Yes	27	100.0	14	100.0	13	100.0
Has Stopped Taking HIV Medications						
No	13	48.2	6	42.9	7	53.9
Yes, but for less than 6 months	8	29.6	4	28.6	4	30.8
Yes and it was at least for 6 months	6	22.2	4	28.6	2	15.4

For the Tri-County sample, there were missing answers for: 2 for sexual orientation, 2 for year of diagnosis, 2 for year initiated

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RECOMMENDATIONS

9 recommendations have resulted from the QI Project:

- 3 in the provider domain: diagnosis visits, holistic provider communication, comorbidities and continuity of care
- 2 in the mental health and substance use domain: mental health illness and substance use addiction, expanded mental health support for all consumers
- 2 in the family and peers domain: family and peer support, stigma and disclosure
- 2 in the consumer empowerment and engagement domain: HIV education and advocacy, consumer involvement in QI

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RECOMMENDATIONS IN THE PROVIDER DOMAIN

- **Diagnosis visits**
  - During these visits provide emotional support and begin educating the consumer on HIV as this visit impacts future engagement in care
- **Holistic provider communication**
  - During medical visits, take the time to talk to consumers about a comprehensive set of concerns as this fosters trust, a will to survive, and positive outlook towards health care
- **Comorbidities and continuity of care**
  - Comorbidities are common requiring better integration of care. Plans need to be in place for when consumers switch providers to provide continuity of care

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RECOMMENDATIONS IN THE MENTAL HEALTH and SUBSTANCE USE DOMAIN

- **Mental health illness and substance use addiction**: Consumers with mental health illness or substance use addictions need more intensive and integrated services to remain engaged
  - Example: Mental health professionals need to understand consumers' HIV care issues
- **Expanded mental health support for all consumers**: Expanded mental health support is needed for all consumers and should be explicitly addressed at diagnosis and care visits
  - Example: Create a holistic approach to mental health, mental health "universal precautions"

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RECOMMENDATIONS IN FAMILY & PEER DOMAIN

- **Family and peer support**: Facilitate access to the support of family and peers as they are key for consumers' emotional health and their outlook on the importance of treatment and adherence
- **Stigma and disclosure**: Disclosure may not happen if consumers fear stigma. Although whether to disclose is the consumer's decision, providers can start the conversation on disclosure in order to facilitate consumer's access to more support from family and peers

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RECOMMENDATIONS IN THE CONSUMER EMPOWERMENT & ENGAGEMENT DOMAINS

- **HIV education and self-advocacy**
  - Connecting consumers to support groups and self-advocacy activities contributes to consumer empowerment and a greater desire to take care of oneself and other consumers
- **Consumer involvement in QI**
  - Provider-centric perspectives or client satisfaction surveys as QI initiatives may be inadequate without involving consumers in these QI activities in a client-centered and meaningful way

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MEDICAL MONITORING PROJECT (MMP)

- CDC- funded surveillance system to understand the experiences and needs of PLWH
- Collects data each year from June to May
- Produces nationally & locally representative data
- Combines behavioral and medical data
- NY HIV Planning Council's Consumers' Committee Co-Chairs

  Billy Fields & Lisa Best are the local Community Advisory Board members
- The NYC MMP CAB has input into the local questionl

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COMMUNITY HEALTH ADVISORY & INFORMATION NETWORK PROJECT (CHAIN)

- Provides a **profile of PLWH** in New York City and the Tri-County Region
- Assesses the system of HIV care –both health and social services –from the **perspective of PLWH**
- Reports on **unmet needs, service utilization trends, and outcomes** to the Planning Council and its Committees for service & program planning
- Makes research results available to the wider provider, consumer, and other stakeholder communities
- CHAIN is committed to including **voices of those often not included or under represented in research -**
  - In and out of medical care
  - Homeless/ transient living arrangements
  - Multiple competing life challenges
  - Mental health and/or substance use challenges
  - Distrust medical providers/ government agencies/ academic researchers
  - No easy phone contact

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EXAMPLES OF CHAIN REPORTS

- Adherence Support Services Report
- Predictors of Long-Term Survival for PLWH
- Trauma Exposure and HIV in NYC
- Dropping Out of HIV Medical Care
- HIV and Aging: People Aged 50 and Over
- Delayed Entry Into HIV Care
- Community Briefing on Housing Need
- Hepatitis C Lifetime Prevalence and Treatment Report
- Service Location Report
- Prevalence of Non-HIV Comorbid Health Conditions

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