

The AIDS Support Group of Cape Cod

Client Advisory Board

Representing

Cape Cod ~ Martha's Vineyard ~ Nantucket

Handbook

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DRAFT

Acknowledgments

In 2014, this handbook was created for guidance for the combined CABs representing persons living with HIV/AIDS accessing services at the AIDS Support Group of Cape Cod, ACCESS Nantucket, Infectious Disease Clinical Services of Cape Cod Healthcare, and Outer Cape Health Services.

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Client Advisory Board Handbook

Purpose

This handbook was developed through a collaborative effort between the Client Advisory Board and Client Service Program of the AIDS Support Group of Cape Cod (ASGCC), Consumer Office of the Massachusetts Department of Public Health (MDPH) Office of HIV/AIDS (OHA) order to integrate and strengthen the Client Advisory Board (CAB) system on Cape Cod, Martha's Vineyard, and Nantucket and to support the involvement of people living with HIV in the planning, delivery and assessment of HIV-related services in the region.

The Client Service Office

The Client Services Office of the AIDS Support Group of Cape Cod (ASGCC) works to ensure that people living with HIV/AIDS have input into the creation, development, and implementation of ASGCC services and policies. The Client Service Office is available to support consumers in accessing services and to work with consumers and regional agencies on grievances that have not been resolved at the agency level, and provide other support as needed to people living with HIV. The Client Service Office is currently staffed by Krystin M. St.Onge, MSW, LCSW Director Client Services. Contact information is as follows:

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Introduction

In June 1983, the Second National AIDS Forum was convened in Denver, Colorado. At the meeting, an advisory committee of people with AIDS drafted the “Denver Principles” affirming the right of people with AIDS (PWA) to actively participate in their own health care and to be involved at every level of decision making. Five of the 17 principles played a particularly important role in shaping AIDS policies and programs in the United States. They stated that PWA:

- Have a right to quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status and race;
- Have a right to full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives;
- Have a right to confidentiality of medical records, to human respect, and to choose who their significant others are;
- Should be involved at every level of decision making and specifically serve on the boards of directors of provider organizations; and
- Should be included in all AIDS forums, with equal credibility as other participants, to share their own experiences and knowledge.

The formation of local PWA (People with AIDS) coalitions and the National Association of People with AIDS (NAPWA) helped keep consumers involved at the forefront of America’s response to the AIDS epidemic. HIV service demonstration projects funded by private foundations in the 1980’s strongly encouraged consumer participation in assessing service needs and planning for delivery of coordinated health and support services. In addition, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act mandated PWA representation on HIV/AIDS Consortia through what came to be known as the Consumer Advisory Board (CAB) system.¹

¹ HRSA Care Action, Positive Partners: Consumer Involvement in HIV Care

The Client Advisory Board for Cape Cod, Martha's Vineyard, and Nantucket

The combined Client Advisory Board (CAB) for Cape Cod, Martha's Vineyard, and Nantucket was created in 2002 in the belief that the opinions, experiences and perspectives of individuals living with or affected by HIV/AIDS (hereafter referred to as clients) are essential to the development of strategies to effectively address issues raised by the HIV/AIDS epidemic. As agencies funded by the MDPH OHA for Client Health services are required to create, support, and maintain a CAB. If an agency is unable to support a CAB, they must identify another mechanism for consumer input into services, which must be approved by their OHA Contract Manager. The CAB System refers to the Statewide Consumer Advisory Board and agency CABs.

It is the mission of the Client Advisory Board (CAB) to maintain client involvement and thereby work collaboratively, in an advisory role, with the AIDS Support Group of Cape Cod, Access Nantucket, Outer Cape Health Services and the Infectious Disease Clinical Services of Cape Cod Healthcare on a range of strategies, policies and programmatic issues affecting the lives of people living with HIV/AIDS and those at risk.

The SWCAB System

The CAB system is committed to providing a mechanism for clients to have meaningful input into the development of policies and programs that address their needs. CABs seek to support the creation of comprehensive, community-based HIV/AIDS prevention, care and support services that are accessible, inclusive, responsive and of high quality.

As service users, clients are well positioned to assess the quality, appropriateness, and effectiveness of funded services. In the pursuit of this mission, the CAB system has set the following goals:

- To provide client input to the development and implementation of Massachusetts Department of Public Health (MDPH) HIV/AIDS programs and policies and community- based providers.
- To ensure significant client input to community programs providing HIV/AIDS-related services through the development of local CABs and the inclusion of clients on agency Boards of Directors.
- To act as liaison between clients, the MDPH Office of HIV/AIDS and service providers.
- To educate and bring together clients through a variety of activities that support health promotion and encourage client involvement.

The SWCAB achieves these goals through their direct relationship with the OHA; agency CABs achieve these goals through representation on the SWCAB, or through contact and work with the Consumer Office.

Benefits to Clients and Providers

The relationship between clients and service providers creates an environment that fosters the following benefits to both consumers and the agencies or other community groups they advise:

- The development of client self-determination and independence through increased knowledge, the fellowship and support of other clients (peer support), and an environment of decreased stigma and isolation.
- The development of leadership skills and a sense of empowerment among clients that aids them in their roles as advisors to agency CABs and Board of Directors.
- The maintenance of a partnership in wellness with clients aiding providers in improving service quality, informing type of service, informing program evaluation, and focusing provider programmatic policies on clients needs and concerns.
- The creation of networking opportunities that increase client knowledge and provider sensitivity to client needs.

Client Involvement

Agency CABs

Agency CABs are composed of current or past HIV+ clients who advise the agency on policy and programmatic issues. All OHA Client Health Services funded agencies are required to support and maintain a CAB. If an agency is unable to fulfill this requirement, they must identify alternative mechanisms for soliciting client input, which must be approved by their Contract Manager. In addition to CAB requirements, all AIDS Service Organizations (ASOs) are required to have 25% representation from clients on their board of directors.

As advisory bodies to agencies, agency CABs require active engagement and support of agency staff. Agencies bear the responsibility for their CAB's actions and for the needs and safety of its members. The agency CAB is responsible to the agency itself as it represents an aspect of the agency's work and reflects the agency's goals and mission. Through this collaboration agency CABs represent an essential link to the agency and to the services the agency provides.

Agency CAB Requirements

Relationship Between Agencies and CABs

CABs and agencies work in partnership to achieve their goals. While CABs should be involved in all aspects of CAB operations, agencies have ultimate responsibility for the functioning of the CAB, and final decision making authority. A CAB is not a decision making board but acts in an advisory capacity to the agency. Agencies have the responsibility to bring issues and/or projects to the CAB. Agencies are responsible for

providing support to the CAB, including securing a location, providing staffing, and providing food and other incentives. CABs should have significant input into all documents of operations, such as by-laws and annual plans, with agencies having the final approval. The same applies to CAB membership and agenda setting. CABs are not independent bodies, they are partners with the agency, and both the CAB and the agency they advise must work together to develop the partnership.

CAB Membership

CABs should be composed of current or past HIV+ agency clients. On rare occasions, CABs may decide on a case-by-case basis to allow non-HIV+ clients to participate on their CAB. If CABs allow non HIV+ clients to participate, their role should be clearly articulated, they should not hold leadership positions, and their voting rights should be discussed by the CAB prior to their seating. Non-HIV+ CAB members should never represent a majority of the CAB. CABs and agencies should work together to decide on member recruitment and the process for selecting and seating members, with final decision making authority resting with the agency.

Meetings and Minutes

Every agency CAB is required to meet at least four times per year. At each meeting, minutes must be recorded and then forwarded to the Consumer Office. Some CABs assign a CAB member to take minutes, however it is ultimately the responsibility of the agency to ensure that minutes are taken and distributed.

By-Laws and other Articles of Organization

By-laws, guidelines, and other documents that describe how a CAB functions are not a strict requirement, but are strongly encouraged. By-laws describe the purpose of the CAB, how it operates, who can participate, and what is expected of members and leaders. While some CABs create their own articles of organization, it is the responsibility of agencies to ensure that these articles exist and are up- to-date, to provide any support to the CAB for the creation of appropriate documents, and to ensure that the documents are in line with agency policies.

All by-laws should include the following sections:

- The CAB's mission
- The CAB's definition of a client (client, parent/guardian, partner, caretaker, etc.)
- When and how leaders are elected (chair, vice-chair, secretary, etc.)
- The roles and responsibilities of the leaders
- How someone becomes a member
- Rules about attendance and voting procedures, including quorum
- Code of conduct

- Stipend eligibility
- How grievances are handled

Other CAB Activities

There are other activities that all CABs are encouraged to engage in with collaboration with Peer Support Staff and approval by the Client Services Office, such as:

- Reaching out to HIV-positive individuals who may or may not know their HIV status but are not receiving medical care and social support;
- Supporting newly diagnosed individuals;
- Educating the larger community about issues and challenges raised by the epidemic through speaking engagements, HIV/AIDS literature, radio spots, community access cable channels, etc.;
- Volunteering at provider agencies to assist staff who may be operating with less capacity due to funding losses;
- Participating in community events and
- Any other activity that advances the OHA's goals of 1) getting individuals to learn their HIV status, 2) reducing the number of new infections, and 3) improving the health and quality of life of people living with, and those at risk of, HIV.

Fundraising

Strict compliance with all applicable federal, state and local laws associated with fundraising is critical. That said, CABs are encouraged to conduct fundraising to help enhance services in their regions or to support consumer educational and networking events. In order to conduct fundraising activities, the CAB should consult with the Events Coordinator at the AIDS Support Group of Cape Cod at (508) 487-9445.

Participation in Community Events

CAB visibility contributes to the reduction of HIV-related stigma by putting a face to the epidemic and dispelling myths and misconceptions about HIV and those who are living with it. It is therefore important for the CAB to have visibility within the community that it represents. World AIDS Day, AIDS Walks, fundraising events, ethnic festivals, political events, etc., represent opportunities for the CAB to make its role and purpose known within the community. It also provides opportunities to recruit new members for the CAB or to encourage others to learn their HIV status and get into care.

There are CAB members who do not feel comfortable disclosing their HIV status to the community. While some clients believe that public disclosure is essential, others may be more

comfortable with limited disclosure in which they may be willing to make their status known within the CAB or other forum with the understanding that their status will not be revealed to the general public. These individuals can still participate in public events if they wish to and identify as client advocates, community health advisors, or community representatives. Progressive disclosure may occur with these individuals as their experience of living with HIV/AIDS evolves over time. Each CAB must respect and support an individual's decision about how widely s/he wishes to disclose.

Code of Conduct

The ASGCC is committed to maintaining a safe environment free from violence, threats of violence, harassment, intimidation, and other disruptive behavior. In order to promote and maintain civility and effectiveness in the CAB system, it is essential that not only the policies and procedures be fair and clear but that the members are held accountable to a fair and clear code of conduct. Infractions of the CABs Code of Conduct may result in a request to immediately vacate the CAB meeting, subject to disciplinary action, terminated from attendance at future CAB meetings, or both. :

- CAB members will demonstrate respect for fellow members during CAB meetings
- CAB members will respect the opinions of others, even if they disagree, and engage in open and productive discussions
- The confidentiality of all CAB members will be protected
- CAB members will arrive on time for meetings and stay until the conclusion of meetings, except for reasons discussed with a CAB officer or staff person prior to the meeting
- CAB members will take on and complete their fair share of the CAB work, as necessary
- CAB members will conduct themselves in full accordance with local and statewide guidance relating to CAB membership and participation
- CAB members will attend meetings fully prepared to participate in CAB business
- CAB members will not attend meetings under the influence of drugs or alcohol. If the CAB member does, s/he may be asked to leave the meeting
- CAB members will focus on issues and not individuals, will not make derogatory remarks about another member or staff person, use rude language, or disrupt the course of the meeting. Comments which reflect homophobia, racism, sexism, or are of a personal, non-CAB related nature are unacceptable in the context of CAB interactions and discussions
- Additionally, ASGCC has a “Zero Tolerance to Violent Behavior Policy”. ASGCC defines violent behavior to include, but not limited to the following: any act of physical violence such as punching, kicking, biting, etc.; oral or written statement-direct, implied or veiled threats; gestures; abusive language or harassment;

intimidation; and expressions that communicate a direct or indirect threat of physical harm.

Recruiting Clients as CAB Members

CABs should try to recruit a diverse membership that is reflective of the local epidemic in terms of race/ethnicity, gender, sexual orientation, age and mode of transmission. This is usually accomplished through carefully planned outreach into many different communities with the help of a variety of individuals, providers and other community groups. For CAB recruitment, ultimate responsibility rests with the Client Services Office in collaboration with the Peer Support Program Coordinator's.

Conflict of Interest

CAB members are expected to openly identify any potential areas of conflict of interest in fulfilling their responsibilities. Identification of conflict of interest should be made verbally during any meeting in which a conflict arises and in writing to the chairperson in advance if possible. Conflict of interest is defined as participation in any decision that might result in actual or perceived, direct or indirect financial benefit to the CAB member or a member of their family.²

Grievances

If a client has a problem with a particular service or provider at a particular agency, that individual must utilize that agency's grievance procedure. This section is specifically about grievances between the CAB and agency or within the CAB between members. A grievance is an expression of dissatisfaction with a decision that has been made by the agency or the CAB, with the way some activity has been carried out, or with the behavior of a particular CAB member. The best way to handle a grievance or potential grievance is to prevent it in the first place. Grievances may be prevented if the CAB engages in consistent, open, and fair practices that allow for a wide array of input. Whether or not a CAB works to prevent grievances, a CAB member may still feel that a particular decision or action was unfair. If this were the case, it would be preferable for the CAB to handle the situation informally by talking openly about it and trying to reach some kind of resolution. If this informal method does not work the CAB should consult their grievance procedure identified in their by-laws. If neither method is successful then the Director of Client Services is to work with the CAB and the Executive Director should be consulted for further assistance. The DPH OHA Consumer Office should only be consulted after all of these steps have been taken and the issue is still unresolved.

² Statewide Consumer Advisory Board By-laws

Appendices

Appendix A: Meeting Structure, How to Run and Participate in a Meeting

There are multiple options for CAB structures. Most CABs follow a simplified version of *Robert's Rules of Order* (also known as *parliamentary procedure*), which is a set of rules for conducting meetings that allows everyone to be heard and to make decisions without confusion. For CABs that use this structure, the following guidelines may be helpful.

Electing a Chairperson

Each CAB should have a chair. The chair of the group generally serves as the meeting leader. In the absence of a chair, the co-chair or vice chair will generally be the meeting leader.

The chair (of any CAB) is responsible for several things:

- **Facilitate the meeting.** Facilitation includes many different responsibilities, including all of the following:
- **Call the meeting to order.** The chair is the person who will decide when to begin the meeting.
- **Move through the agenda.** It is up to the chair to ensure that the meeting moves smoothly and does not get stuck for too long on any one topic.
- **Recognize people who want to speak.** The chair should decide who should speak when so that everyone does not speak at the same time.
- **Acknowledge motions.** Once a member has made a motion, the chair must acknowledge it and ask for a second. The chair must then be sure that the group follows established voting procedure when acting on the motion.
- **Keep track of time.** Most people don't have all day to sit at a meeting. It is the chair's job to ensure that the meeting runs at a fluid pace and does not run over time.
- **Close the meeting.** In some cases, the chair will request a motion to adjourn. In other cases, the chair will simply end the meeting if no one has anything else to say.³

Preparing an Agenda

The CAB chair is responsible for preparing the meeting agenda with input from CAB members. A comprehensive meeting agenda will include the following core components:

- **Welcome.** This is where the chair will call the meeting to order and welcome members and guests.

³ Leadership Training 2000, Meeting Mechanics

- **Introductions.** This is always an important step, especially where group members and guests may change from meeting to meeting.
- **Review/Approval of minutes from last meeting.** This is the group's opportunity to confirm or not confirm the report of what happened at the last meeting.
- **Reports** (e.g. SWCAB, agency, budget, etc)
- **Old Business.** This item gives the group the opportunity to revisit any issues from previous meetings that have not yet been resolved.
- **New Business.** This is where the group has the opportunity to bring up new items that have not yet been discussed.
- **Presentation (if any).** This is the time during which any members or invited guests would have the opportunity to give a presentation about a particular topic of interest to the group.
- **Announcements/Information Sharing.** This is when group members may announce upcoming events, items of interest, the time and date of the next meeting, etc.
- **Adjourn.** The chair may or may not ask for a motion to adjourn and then, after a vote if the group requires one, end the meeting.

Taking Minutes

The minutes serve as the official written record of a meeting. Here are some tips for ensuring that the happenings at your meeting are preserved on paper and that all group members are kept up to date:

- **Have a recorder.** Without someone to take notes, you can't have minutes. This person can be the group's secretary, coordinator, or any other person who volunteers to listen and record what's happening.
- **Record everything.** This does not mean that every word spoken at the meeting should show up in the minutes, but it does mean that every topic discussed should at least be mentioned and all decisions documented. Some topics will require longer explanations than others.
- **Include attendance.** It is helpful to note who was at the meeting, and who was not. This will also help the person responsible for maintaining attendance records. (See confidentiality section below).
- **Be brief.** Use as few words as possible to explain what happened. Members are more likely to read the minutes carefully if they're not too long.
- **Distribute.** In order for everyone to be kept up to date, everyone must receive the minutes. This includes all group members, not just those who were at the

meeting. It is also important to distribute the minutes quickly so that there is time to make necessary changes.

- **Maintain confidentiality.** Some groups use only first names in their minutes some use only initials some use full names. It is up to each group to decide. Be sure that the person taking minutes knows what the group has decided. Also, be sure not to identify people as being HIV+ unless they explicitly request that they be identified as such.⁴

Operating Procedure/Respecting the Process

Here are some helpful hints for becoming a more effective member of the CAB:

- **Arrive on time.** The meeting process is often disrupted when people walk in after the meeting has begun.
- **Stay for the entire meeting.** The meeting process is often disrupted when people get up and leave before the meeting has ended.
- **Listen.** An effective participant in community planning listens to what others have to say.
- **Wait to be recognized before speaking.** A meeting runs smoothly when people who want to speak wait until they are recognized by the chair instead of calling out.
- **Be informed about the issues.** If you want to be a voting member of a group, it is very important that you understand the issues that are being discussed.
- **Ask questions.** If you do not understand the issues that are being discussed, be sure to ask someone in the group to explain them to you.
- **Focus on issues, not on personalities.** It is unlikely that you will like every person at the meeting. It is important to keep your focus on the issues at hand, and not on your dislike for someone in the group.
- **Refrain from side conversations.** While the meeting is being conducted, it is disruptive for people to be having other conversations at the table.
- **Be familiar with the group's by-laws.** Understanding the group's operating structure will help you understand what's happening at meetings.

Consensus and Voting

Every attempt should be made to reach consensus on decisions. Consensus means that while each member may not think a particular decision is the best one, it is a decision each member understands and is willing to support in public. Where consensus is not possible, a vote will be taken and a simple majority of a quorum will suffice. Here are a few tips for making sure that voting goes smoothly at your CAB:

⁴ Leadership Training 2000, Meeting Mechanics

- **Be consistent.** Use the same voting procedures for every vote at every meeting.
- **Use ballot votes for sensitive issues.** This allows for input without potentially embarrassing self-disclosure.
- **Ensure a quorum.** The group's by-laws should set out how many people make a quorum (that is, how many people are enough in order to take a vote. Generally, it's 50% of the entire membership plus one).

If you want your group's votes to be fair, follow the steps below and you won't go wrong:

- **Someone makes a motion.** A voting member of the group must "move" that an issue be voted on.
- **Someone seconds the motion.** At least two people must agree that a vote should be taken.
- **Issue opened for discussion.** At this point, the chair should ask if any further discussion about the issue is necessary before a vote is taken.
- **A vote is taken.** The chair will ask who is in favor of the proposed motion, who is opposed to it, and who chooses to abstain from the vote. A person may abstain (that is, not take part in the vote) any time the person feels that voting is not appropriate.
- **The votes are recorded.** The secretary, or whoever is taking the meeting minutes, should record how many people voted for or against the motion, and how many people abstained.
- **Motion carries or doesn't carry.** If enough people vote in favor of the motion, it carries. If there are not enough votes to carry the motion, it fails.

Cape and Islands Regionally Funded Programs

Client Health Services

The Client Health Services Unit oversees the provision of health-related support services for people living with HIV/AIDS including Medical Case Management, Peer Support, Housing Search and Advocacy, Rental Assistance, Food Services, Medical Transportation, Legal Services, Acupuncture, Dental Services, Non-Traditional Mental Health, Corrections-to-Community reintegration services, and HIV case management, prevention, and counseling and testing in Massachusetts County Jails. The Client Health Services Unit also provides funding that supports technical assistance and an HIV health resource library. All services for clients are intended to support engagement in medical care, health promotion, and disease self-management.

- **Clinic-based, community-based and home-based medical case management** is intended to facilitate access to medical care and to support continued retention in care. These services include medical care coordination, social services coordination, adherence support, sexual health promotion, substance use risk reduction, benefits counseling, and housing search and advocacy.
- **Peer Support** is provided by individuals living with HIV/AIDS in one-on-one and group settings and provides opportunities for education, skill-building, and emotional support.
- **Housing Search and Advocacy** helps clients access and stay in housing by identifying housing resources, assisting with application processes, and supporting stable tenancies.
- **Rental Assistance** is a statewide short-term and/or emergency service which provides rental start-up and homelessness prevention services in addition to utilities assistance.
- **Food Services** provide clients with access to nutritionally balanced food by means of home-delivered meals, congregate meals, and food bank packages.
- **Medical Transportation** services help clients access medical and health-related support services appointments.
- **Acupuncture** is a therapeutic treatment used for the management of HIV disease symptoms, medication side effects, substance abuse detoxification and treatment, and smoking cessation.
- **Dental Services** provide access to routine and emergency dental care for persons living with HIV/AIDS who have no dental coverage or limited third party coverage.
- **Corrections-to-Community Reintegration Services** help incarcerated clients successfully transition to the community through the provision of intensive short-term case management support that includes linkage to medical care and more long-term service provision.

- **Technical Assistance** services support the capacity-building needs of individual agencies and service systems.
- The **HIV Health Library** provides providers, HIV+ individuals, and other community members with access to fact sheets, articles, and reports about HIV and related issues.

Prevention & Screening

The Prevention and Screening Unit, one of two service areas in the Office of HIV/AIDS (OHA), is tasked with developing and sustaining contractual relationships with a network of clinic-and-community-based organizations delivering a range of prevention and screening services for HIV, viral hepatitis, and sexually transmitted diseases (STDs) prevention, as well as treatment services for STDs. Through contract awards with organizations throughout the state, providers offer integrated, low-threshold, effective, and evidenced-based interventions and screening services delivered to client population groups and individuals at risk of HIV, STD, and viral hepatitis infections and acquisition.

Prevention and screening services funded through the Unit are delivered using an integrated prevention and screening service model. Emphasis is placed on more comprehensive and targeted approaches to preventing new infections. Screening, counseling, and STD treatment services are paired with evidence-based practices and interventions to ensure individual and populations recognize their personal risk and implement plans for mitigating them. Through this integrated approach, the HIV/AIDS Prevention and Screening Unit aims to achieve the following goals: to reduce the levels of HIV risk behavior among prioritized client population groups; to reduce the incidence of new HIV infections; to increase access to, and frequency of, HIV and STI screening services; to address the complex factors that contribute to risk; and assist HIV-positive individuals with the full array of preventative and care options to maximize their health status.

Primary activity of the Unit includes the procurement, management, and support of awarded organizations with clinic and community based organizations through program development, training, and specialized capacity building assistance. The statewide network of awarded organizations is highly specialized and varied services are strategically placed in a variety of clinical and non-clinical settings throughout the Commonwealth. This positioning is based on relevant epidemiologic data, as well as assessment of the prevention needs of the communities within these regions. Particular emphasis is placed on ensuring access to a wide scope of services, including mental health, gay men's and women's health, substance use treatments, and prevention programs, and organizations devoted to serving particular ethnic and cultural communities. The Unit continues to actively respond to national and local trends through specialized initiatives to curb HIV risk in communities disproportionately represented in

HIV/AIDS incidence data. Unit services are guided by the Massachusetts Comprehensive HIV Prevention Plan developed by the (MPCC) and recommendations from the Statewide Consumer Advisory Board (SWCAB).

Support Units

Policy & Planning

The Policy and Planning Unit is responsible for development of programmatic policy, planning, consumer participation, training and public information. Acting in a support capacity, this unit works closely with the two program units, frequently facilitating inter-unit collaboration. The Unit is multi-focused and staff operates in the following ways:

- **Statewide Programming:** The HIV Drug Assistance Program (HDAP) is managed out of this unit as well as all sharps disposal programming.
- **Policy:** Unit staff focuses on state and federal legislative and policy initiatives, confidentiality, HIV testing, routine HIV screening, correctional health policy, regulatory changes and access to sterile syringes.
- **Consumer Office:** The Consumer Office oversees the Statewide Consumer Advisory Board (SWCAB), which provides input to OHA planning and programs and provides technical assistance to agency consumer advisory boards. The Consumer Office is available to support consumers who need help accessing agency based services and provides other support as needed to people living with HIV.
- **Training/Public Information:** Training staff oversee all training initiatives for funded providers as well as manage any public information and development of written educational materials.

By-Laws

Consumer Advisory Board

By-Laws

Mission, Goals, Roles and Procedures

Mission

The mission The mission of the Client Advisory Board (C.A.B.) is to maintain client involvement and thereby work collaboratively, in an advisory role, with the AIDS Support Group of Cape Cod, Access Nantucket, Outer Cape Health Services and the Infectious Disease Clinical Services of Cape Cod Healthcare on a range of strategies, policies and programmatic issues affecting the lives of people living with HIV/AIDS and those at risk.

Vision and Values

The vision and values of HIV/AIDS consumers in Massachusetts created the consumer advisory board (CAB) system, and has long held the value of maintaining consumer involvement in service creation, delivery, and assessment. The CAB system was established in the belief that the opinions, experiences, and expertise of individuals directly affected by HIV are essential for developing effective strategies to address issues presented by the HIV epidemic.

The mission, goals and procedures of the CAB are designed to provide clarity regarding the roles and functions of the CAB and to support the collaboration of all parties.

Goals

Although the objectives of the CAB may change from time to time, there are three fundamental goals that support its mission:

Goal 1

Provide client input to the AIDS Support Group of Cape Cod, Access Nantucket, Outer Cape Health Services and the Infectious Disease Clinical Services of Cape Cod Healthcare on the development, implementation and assessment of statewide HIV/AIDS policies.

Goal 2

Promote significant input to HIV/AIDS service providers through the support and education of consumer advisory boards and promote the inclusion of people living with HIV/AIDS on agency CABs, and other community based groups.

Goal 3

Act as a liaison between clients and the agencies or other community based groups, in the identification and resolution of problems.

Membership

The CAB membership is drawn from clients from Cape Cod, Martha's Vineyard, and Nantucket area. In addition, the CAB seeks to have as diverse a membership as possible so that the perspectives of people of all ages, races, ethnic groups, sexual orientation, etc., are represented.

Composition

The CAB will have at least 6 members living with HIV/AIDS.

How Members are Selected

- Any individual infected with HIV/AIDS may become a member of the CAB.
- Recruitment events will occur as needed and the CAB will circulate a description of the selection process, the roles and responsibilities of CAB members, why it's important to be involved, how one benefits from being involved, etc.
- CAB members are elected for 1 year July 1- June 30.

Responsibilities of Members

- Members are responsible for opening ongoing dialogues with other consumers in their areas.
- Members are encouraged to present the activities of the CAB to the agency or other community based group.
- Members are responsible for maintaining appropriate levels of confidentiality, and for declaring any potential conflict of interest regarding their role in CAB deliberations.
- Members are responsible for attending monthly/bi-monthly/quarterly CAB meetings.
- Members are responsible for notifying the Chair or his/her designee when s/he is unable to attend a particular meeting.

Leadership Roles

1. The leadership of the CAB will be chosen by its full membership.
2. There will be 2 Co-Chair representatives (1) from the Mid/Upper Cape, and (1) from the Outer Cape, and a Secretary elected by the membership annually.

Responsibilities of the Co-Chairs

The Chair will be responsible for:

- collaboratively planning the agenda of CAB meetings with the appropriate agency or other community based group.
- serving as the primary link between the CAB and the agency or other community based group.
- chairing the meetings of the full membership of the CAB.
- other duties that s/he agrees to assume at the request of or with the permission of the membership.

Responsibilities of the Secretary

The Secretary will take notes at every meeting and distribute them to the members as quickly as possible.

Making Decisions

Consensus

Because the CAB has a commitment to collaborative process, every attempt will be made to reach consensus on decisions. Consensus means that while each member may not think a particular decision is the best one, it is a decision each member understands and is willing to support in public. Where consensus is not possible, a vote will be taken and a simple majority of a quorum will suffice.

Quorum and Voting

A quorum for voting is fifty percent (50%) plus one of the full CAB voting membership.

Proxy representation or voting means that a substitute could represent and/or vote in place of a member. Proxy voting or representation is not allowed.

Appendix D: Glossary

501(c) 3	A designation for a non-profit agency as exempt from state and federal taxes. Many federal funds are designated for the use of non-profits only.
ACTG	AIDS Clinical Trials Group – the federal AIDS drug testing group.
ACTG 076	A study to determine if AZT was safe for use by pregnant women and newborns to reduce the rate of transmission of HIV from mother to baby. The study showed that, for the women given AZT, transmission of HIV from mother to infant was reduced from about 25% to about 8%.
Acupuncture	A branch of traditional Chinese Medicine in which thin, solid needles are applied to set body points (called meridians) to normalize and redirect energy flow to create a healing impact.
ADAP	AIDS Drug Assistance Program: State based programs funded in part by Title II of the Ryan White CARE Act that provides therapeutics to treat HIV disease (also referred to as HDAP, or HIV Drug Assistance Program).
Adherence	Sticking to your medication schedules.
Adult Day/ Respite Care	<i>See Day and Respite Care</i>
Advocacy	The act of arguing in favor of something, such as a cause, idea, or policy.
AFDC	Aid to Families with Dependent Children
AIDS	Acquired Immune Deficiency Syndrome
AHC	AIDS Housing Corporation
Alternative Therapies	Also known as complementary therapies – therapies not traditionally associated with Western medicine. Includes such therapies as massage, acupuncture, Reiki, and chiropractic services.
Antiretroviral	A substance that stops or suppresses the activity of a retrovirus such as HIV. AZT, ddC, ddI, d4T, 3TC, saquinavir, ritonavir and indinavir nevirapine are examples of antiretroviral drugs.
ASO	AIDS Service Organization: An agency that provides services for people living with HIV/AIDS as its primary mission.

Asymptomatic	In an HIV-positive individual, there are no symptoms of HIV infection with the exception of acute retroviral syndrome and persistent generalized lymphadenopathy.
BPHC	(Boston Public Health Commission) It is responsible for administering city, Title I, and city HOPWA funds.
BSAS	Bureau of Substance Abuse Services of the Mass. Dept. of Public Health
CAB	Consumer Advisory Board
CARE Act	<i>See Ryan White CARE Act</i>
Case Management	Client-centered service that links clients with health care and psychosocial services in a manner that assures timely, coordinated access to medically appropriate levels of care and support services, and continuity of care. Key activities include assessment of the client’s needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic re-evaluation and adaptation of the plan as necessary during the life of the client.
CBDPP	Community Based Dental Partnership Program
CBO	Community based organization
CD4	T-helper lymphocytes, also referred to as white blood cells, are an immune response to infection in the body. These are the host cells for HIV replication.
CDC	(Centers for Disease Control and Prevention) Federal agency with the mission to promote health and quality of life by preventing and controlling disease. This is the primary funder for the Department of Public Health prevention programs.
Confidentiality	The protections of one’s personal and medical information. Massachusetts General Law Section 70F (M.G.L. 70F) gives legal protection of HIV-related information to people living with HIV.
Consumer	A person living with HIV/AIDS, or the parent or guardian of a person under the age of 21 living with HIV/AIDS.
Contract Manager	The HIV/AIDS Bureau staff person responsible for overseeing contracts between the HIV/AIDS Bureau and an agency.

Demographic Data	Information about individuals who use HIV-related support services. This information includes where the person lives or receives services, the person's race gender, and age, as well as how the person contracted HIV. Demographic data does not include names.
Disclosure	To make known one's HIV positive status to others.
DMA	Division of Medical Assistance. This agency administers MassHealth, also known as Medicaid.
DMH	Department of Mental Health
DPH	Department of Public Health (also referred to as MDPH, or Massachusetts Department of Public Health). It is responsible for administering state, Title II, and state HOPWA funds.
EAEDC	This is the Massachusetts general relief/financial assistance program providing Emergency Aid to Elderly, Disabled and Children.
EMA	Eligible Metropolitan Area
EMMS	Enhanced Medical Management Service
Epidemiological Data	Information about the trends of the HIV epidemic, including the number of people who have ever been diagnosed with HIV/AIDS and the number of people currently living with HIV/AIDS. Epidemiological data does not include names.
Harm Reduction	This public health approach engages individuals at their particular level of motivation for behavior change and assists individuals in considering a range of options that reduce immediate harm, but which may or may not have HIV, STD, Hepatitis or substance abuse reduction benefits.
HDAP	Massachusetts HIV Drug Assistance Program
HIV	Human Immunodeficiency Virus
Home Health Care	Therapeutic, nursing, supportive, or other health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professional. Component services are typically considered to include Para-Professional Care (homemaker, home health aide, and personal/attendant care); Professional Care (routine and skilled nursing); Specialized Care (intravenous and aerosolized medication treatments, diagnostic testing, and other high tech services); and Durable Medical Equipment

(prosthetics, devices, and equipment used by clients in a home/residential setting, e.g. wheelchairs, inhalation therapy equipment, or hospitals).

HOPWA	(Housing Opportunities for People with AIDS) A Housing and Urban Development program providing housing, housing assistance, and housing related services for people with HIV/AIDS.
HRSA	(Health Resources and Services Administration) The federal agency responsible for administering the Ryan White CARE Act.
IDU	Injection or Intravenous Drug User
Informed consent	Giving written permission to share one's personal information.
In care	Being in or receiving on-going medical care and/or treatment for HIV/AIDS.
MassCARE	A DPH program to ensure that children with HIV and their families receive family centered, community based, comprehensive and coordinated care.
MassHealth	Medicaid program in Massachusetts
MDPH	Massachusetts Department of Public Health. <i>See DPH</i>
Medicaid	Basic health care support for poor and/or disabled persons
MMP	Medical Monitoring Project
MPCC	Massachusetts Prevention CC
MSM	Men who have sex with men
NAPWA	National Association of People with AIDS
NASTAD	National Alliance of State and Territorial AIDS Directors
Needle Exchange	A prevention program that exchanges used syringe needles for clean needles, provides referrals for substance abuse treatment, HIV Counseling and Testing, Hepatitis screening and vaccination, and provides harm reduction counseling.
Needs Assessment	An assessment of consumer need for HIV-related support services.
OHA	Office of HIV /AIDS previously named HIV/AIDS Bureau

OI	Opportunistic Infection: an infection that has clinically significant consequences due to a person's weak immune system. There are 19 opportunistic infections classified by infectious agent and location of infection for a possible AIDS diagnosis.
Peer Support	Services that provide assistance to clients where the person(s) providing the service is HIV-positive or affected member of the client's self-identified community.
Perinatal Transmission	Transmission of HIV from mother to baby during pregnancy, labor and delivery, or through breastfeeding.
Planning Council	The Title I planning body. It is responsible for deciding the distribution of Title I dollars among service categories, prioritizing services, and establishing a long term, comprehensive HIV services plan for the Title I EMA.
Positive Prevention	Primary prevention for people living with HIV/AIDS.
Primary Medical Care	Provision of routine, non-emergency, non-inpatient, non-specialized medical care.
Provider	An agency or organization that provides support services for consumers.
Rehabilitation Care	Services provided by a licensed or authorized professional in accordance with an individualized plan of care that is intended to improve or maintain a client's quality of life and optimal capacity for self-care. This definition includes physical therapy, speech pathology, and low-vision training services.
Resistance	When a particular drug is no longer effective because of the ability of HIV to change over time.
RFR/RFP	(Request for Responses/Proposals) The competitive process used by the MDPH to select individuals or agencies to provide services.
Risk Assessment	A conscious on-going process to gauge one's level of risk when engaging in a particular activity.
Risk Reduction	A range of behavioral options to lower one's level of risk when engaging in a particular activity.
RWCA	Ryan White Comprehensive AIDS Resource Emergency Act of 1990. This is the federal legislation that authorizes the funding of medical and non-medical services for people living with HIV/AIDS.

SCSN	Statewide Coordinated Statement of Need
SSDI	Social Security Disability Insurance
SSI	Social Security Supplemental Income
Stigma	Something that detracts from the character or reputation of a person or group, i.e. reproach, shame, blame, disgrace
STD	Sexually transmitted disease
Substance Abuse Treatment	Provision of treatment and/or counseling to address substance abuse (including alcohol abuse)
SWCAB	Statewide Consumer Advisory Board
TA	Technical assistance
TIP	Transitional Intervention Program
Title I	These funds provide direct financial assistance to EMAs that have been the most severely affected by the HIV epidemic. The purpose of these funds is to deliver or enhance HIV-related (1) outpatient and ambulatory health and support services, including case management and comprehensive treatment services for individuals and families with HIV disease; and (2) inpatient case management services that prevent unnecessary hospitalization or that expedite discharge, when medically appropriate, from inpatient facilities.
Title II	This section of the Ryan White CARE Act provides formula grants to States and Territories to improve the quality, availability, and organization of health care and support services for individuals and families with HIV infection. One major goal is to establish community-based, coordinated, continuums of care to which everyone with HIV will have access.
Title III	This section of the Ryan White CARE Act provides formula grants to existing community-based clinics and public health providers to develop and deliver early and ongoing comprehensive HIV services to persons with HIV/AIDS, on an outpatient basis.
Title IV	This section of the Ryan White CARE Act provides funds to support HIV comprehensive services for children, youth, women, and families using family-centered and youth-centered care models. Title IV also supports coordination between comprehensive care sites and clinical research programs to ensure voluntary access to clinical drug trials and other research.

Transmission	Passing HIV from an HIV positive person to an HIV negative person.
Utilization Data	Information about what HIV-related support services are being used, how often they are being used, and where they are being used. HIV Utilization data do not include names.
Viral Load	The amount of measurable virus in the blood. Tests to measure virus are PCR and bDNA.
Work Plan	A document that describes the planning activities a CAB or other community based group will undertake.

Appendix E: CAB Reimbursement Policy

If you have any questions regarding the Reimbursement Policy contact the Client Services Director. This policy applies to members of the CAB, and other client's participating in Consumer Office activities.

Meeting Reimbursement Policy

<u>Meeting Description</u>	<u>Flat Rate</u>
CAB Meeting	\$25

Other meetings, such as trainings and proposal review, will be decided on a case by case basis.

Travel Reimbursement

Carpool is encouraged when possible

- Mileage is paid at \$0.42 per mile

When to Expect Reimbursement

Expect reimbursement by check within 30 days.