

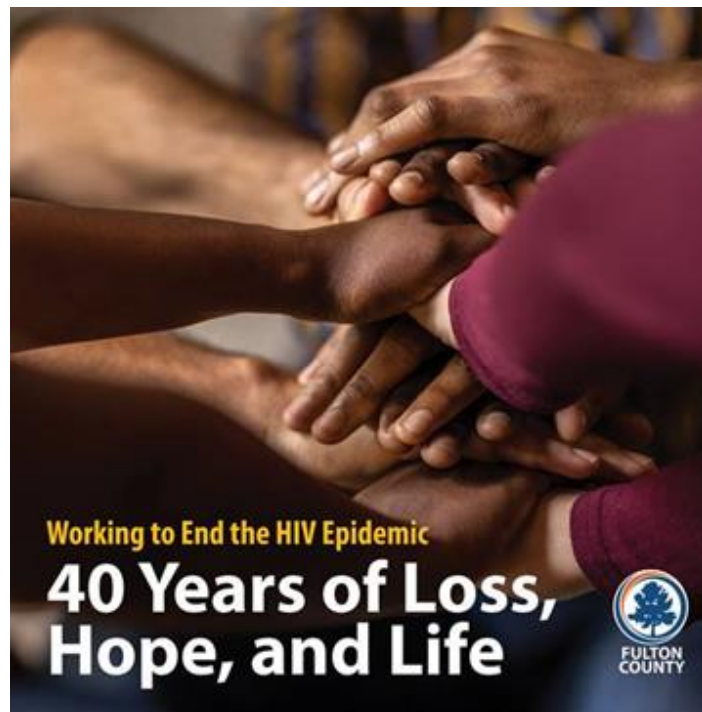


FULTON
COUNTY
HIV
ELIMINATION

Consumer
Advisory
Board
Manual

Department for HIV Elimination
March 2023

A Consumer Advisory Board Manual for Part A & EHE Subrecipients



Getting Started

The Department for HIV Elimination utilized the CAB Manual of AIDS Alliance for Children, Youth & Families of Washington, D.C. to create this manual as a tool for DHE subrecipients to guide in the development and maintenance of Consumer Advisory Boards. Subrecipients may utilize this manual in whole or in part to best suit the development of their CAB.

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Introduction

This manual provides the basic steps for creating, maintaining, and improving the Consumer Advisory Boards (CABs) that are required for Department for HIV Elimination (DHE) subrecipients.

This manual is designed to assist all persons involved with the creation or implementation of a CAB— whether a subrecipient staff person, organizational leadership, or a community member.

People and families who are living with HIV often know what they need. They know which services are most important to them, how and why they can or cannot use them, and what improvements need to be made. As consumers of services, they have experiences and perspectives that health and social service providers may lack. For this reason, participation of people living with HIV (PLWH) in a CAB is paramount.

CABs are an expectation of Ryan White Part A & EHE (see PPPN 031). Input of consumers is an integral part of a program's development, implementation, and evaluation. The main purpose of a CAB is to provide a consumer perspective and represent the community in making sure Part A & EHE activities are carried out in a way that best meets consumers' needs.

“In the 1980's, providers began to recognize the importance of better understanding the needs of consumers by getting their input into developing and providing services. There was a commitment to changing services in ways that were found to be better for consumers, even if the changes turned out to be inconvenient to providers. CABs became a way for consumers and providers to talk to each other so that consumers could make a difference in the delivery of services.”

Therefore, DHE requires that subrecipients get input from consumers as they plan, carry out, and evaluate their work. As a result, there are people who have years of experience with CABS and know the basic steps for creating them and ensuring their effectiveness. This manual benefits from their experience.

Be aware from the start that this information will need to be adapted for your own agency and clients, but there are issues that are common to most CABs, so we offer general guidelines to help get you started on this important work.

Purpose

The Ryan White HIV/AIDS Program Part A & EHE fund grants to Eligible Metropolitan Areas (EMAs) that are most affected by the HIV epidemic.

Part A & EHE programs must provide the following activities:

- Access to comprehensive, culturally, and linguistically competent, coordinated services focused on consumers and their families.
- Consumer involvement in care management and in the planning, implementation, and evaluation of Part A & EHE.
- Enrollment and retention of persons of the priority populations in care.
- Prevention of transmission of HIV.
- Outreach to and enrollment of people living with HIV who are not in care.

The CAB is one way for providers, consumers, and the community to communicate with each other. The CAB members can serve as a link between the providers and the community, giving the community information about services and bringing community concerns and ideas back to the provider.

The CAB cannot tell a provider how to run an agency. However, CAB members can provide expert assistance and guidance based on their knowledge and experience as consumers.

Laying the Groundwork

For CABs to be effective, it is recommended that CABs establish bylaws and a mission statement, as well as define the responsibilities and expectations of voting members. These elements, when carefully considered and written, lay the foundation for an effective working group.

Bylaws

A CAB is a formal group with a clear purpose, a set of rules, and a structure that outlines when and how meetings are held and defines the roles and responsibilities of CAB members and agency staff. This information is written in a set of guidelines called bylaws. Bylaws prevent misunderstandings by defining exactly how the CAB will carry out its work, and it can also serve as a kind of “safety net” of rules to follow when disagreements occur. These rules also reinforce the group’s purpose if it begins to stray from its mission.

Bylaws should include much of the information that is presented in this manual and answer the following questions:

- What is the purpose or mission of the CAB?
- What are the responsibilities of the CAB?
- How many members will there be?
- Who is eligible to be a member?
- What are the roles and responsibilities of the members?
- How long do members serve, and can they serve more than one term?
- What kind of orientation will be provided for new CAB members?
- How are new members recruited, selected, and dismissed?
- Will CAB members have expenses reimbursed?
- When, where, and how many times a year will the CAB meetings be held?
- How are the CAB meetings structured?
- What are the notification requirements regarding meetings?
- What is the quorum for a CAB meeting?
- How will decisions be made (for example, by vote or consensus)?
- Will the CAB have officers and, if so, which officers with what roles and responsibilities?
- How will the officers be selected and how long will they serve?
- Will the CAB have committees and, if so, how will they function?
- How will the CAB communicate with Part A or EHE agency and vice versa?
- What are the roles and responsibilities of agency staff?
- How can the bylaws be amended?
- How will the CAB be evaluated?

The bylaws can be as simple or elaborate as the CAB wants them to be. The sample in appendix B shows how bylaws are written, although it does not cover all the issues that need to be addressed. It might be helpful as an example, but don't simply adopt a set of rules written by someone else. Bylaws should be tailored to meet the needs of the Part A or EHE agency and the CAB. Remember that bylaws are not set in stone – they can, and should, be changed as the CAB grows and its roles, responsibilities, and expectations change.

(See Appendix A)

Mission Statement

Before a CAB can do its job, its members must first decide what they expect to accomplish. The CAB's purpose should be expressed clearly in a short description called a mission statement that tells people what the CAB is, what it does, and why. A good mission statement is no longer than three or four sentences and can tell your CAB's story in less than 60 seconds.

Mission statements are not necessarily quick and easy to write. They describe what the CAB will do, so it's important for the group to take time, look at some examples, and put effort into writing a good one. In addition, the exercise of writing the mission statement will help bring everyone into agreement about why they are working together. Therefore, both CAB members and agency staff need to be involved. They will be more committed to the CAB, and the CAB will be more effective, if everyone believes in the mission statement because they participated in developing it.

(See Appendix B)

The CAB Is Not a Support Group

CABs tend to become informal support groups when the real purpose of the meetings is forgotten, and instead, time is spent on personal concerns or issues. While all of us need support from time to time, that is not the reason for a CAB. To keep members on track, a CAB can begin each meeting with someone reading the mission statement. This can help remind new and old CAB members about the organization's purpose and why they are there.

Responsibilities of CAB Members

A mission statement gives CAB members a general idea of their purpose, but members must also know and understand their specific responsibilities. Consumers should be involved in all phases of program development – from design through implementation and evaluation. The specific responsibilities of each CAB will differ, depending on the Part A or EHE agency and the services they provide. A good way to start is to look at the agency’s work plan, which will list the goals, objectives, activities, evaluation methods, and timeline for the Part A & EHE program. For example, if the work plan says the agency is to conduct an annual survey of consumer needs, CAB members may be responsible for helping develop the survey to make sure the questions make sense to consumers.

Other general responsibilities of CABs may include:

- Reviewing Agency’s program policies and procedures to see if they are focused on the needs of consumers and their families.
- Looking at ways to recruit and retain hard-to-reach populations (such as injection drug users) or populations with special needs (such as youth or women who are pregnant) in programs providing services.
- Reviewing Agency’s data collection and evaluation surveys to see if they ask clear, understandable, and relevant questions about consumer needs.
- Holding quarterly meetings with the community gate keepers about Part A or EHE services to get community feedback.
- Give input on clinical trial procedures, help interpret these procedures for consumers, and provide a link between the researchers and the community.
- Ensuring that agency publications are easy to understand and are appropriate for the population served.

Expectations of CAB Members

In addition to knowing their responsibilities, CAB members must have a realistic idea about what will be expected of them and how much time it will take, keeping in mind that they are volunteers who usually have other job and family commitments. No matter how much they would like to participate, they may lack the time to do so.

What is expected of CAB members varies, but some general examples are:

- Attending regularly scheduled meetings.
- Taking part in virtual and/or in person meetings.
- Reviewing materials (such as program policies and procedures, literature, marketing materials and surveys) outside of the meeting.
- Participation in meeting discussions.

It is important for potential CAB members to be aware of these expectations before they join.

Developing a job description for a CAB member can help potential members decide if the “job” is right for them and remind current CAB members what they signed up for. CAB officers might have separate job descriptions

CAB members commit to:

- Attend meetings as scheduled, arrive on time, and stay until the meeting ends.
- Participate in meeting discussions.
- Respect the opinions and ideas of other CAB members and following the ground rules.
- Review and comment on written materials.
- Attend community meetings.
- Complete and turn in reimbursement forms in a timely manner.
- Perform other duties as assigned by the CAB Chair or Agency Designee.

CAB Part A & EHE Program Requirements

CAB members can be consumers of Part A or EHE services or an affected family member, who has knowledge about HIV, or stakeholders and be willing to work with others.

In the next section, we will provide ideas about how to recruit and select members of a CAB. In doing this, membership terms will be discussed, the selection of officers and their roles, and the formation of subcommittees.

Recruitment

If you want consumers to participate in a CAB, they first need to know about it. Depending on the Part A or EHE agency, its resources, and the community, there are several ways to advertise:

Agency staff can tell consumers about the CAB during appointments or by giving out easy-to-read flyers, website, or social media platforms.

Information can be provided to staff (such as case managers and peer educators) at other agencies that work with the same populations.

Announcements can be made at meetings, social media platforms, or on a website. Flyers can be posted at the agency and on community bulletin boards.

Recruiting members is something that happens all the time – not just when a CAB is being put together. The CAB will lose members along the way and will need to be replaced. Besides, it is always good to add new people with energy and fresh ideas. For this reason, it is useful for a CAB to have a standing Membership Committee so that recruitment can be an ongoing process.

Membership in CABs

CABs are small groups that represent the larger population of people who use the services of the agency. In general, the membership should be inclusive, and representative of clients served.

How many members should you have? In general, the smaller the group, the easier it is for everyone to agree, but this must be balanced with the need to represent different populations. A good number to start with is five to seven people, since the group will be learning as they go about how to operate as a CAB. The group can grow and become more diverse, if necessary, as the CAB gains experience. Another way to determine the size of your CAB can be by the size of your agency. Smaller agencies may consider fewer members, on the other hand, larger agencies may have a larger group of members.

Of the persons on the CAB, one will become the Chair. Since the Chair rarely votes, the remaining members become the voting members. When these voting members cannot agree, the Chair votes to break a tie.

Agency Staff

Each Part A & EHE agency is responsible for assigning a staff member to work with the CAB. This staff member, usually called a CAB Coordinator or Staff Liaison, is the direct line of communication between the two groups, bringing topics from the agency to the CAB for discussion, and taking recommendations from the CAB back to the agency.

When the CAB is first set up, the agency liaison should help members understand the role and purpose of the group, as well as the priorities and activities of the Part A & EHE agency. Once the CABs role and function are established, the CAB can lead its activities with the staff liaison available for support if needed.

The staff liaison might help the group by:

- Maintaining CAB records.
- Coordinating reimbursement of expenses.
- Ordering refreshments.
- Updating CAB contact lists and other materials.
- Serving as a liaison with invited guests.
- Communicating with the Chair and other officers.
- Preparing and distributing meeting minutes (if the CAB's Secretary doesn't do it).

It is important that the CAB members feel comfortable communicating and working with the staff member. Without a certain level of mutual trust and respect, it will be difficult for the CAB to function effectively as an advisory body to the agency. Good lines of communication and feedback from the CAB to the agency and back again are essential for assuring that the relationship between the two entities works smoothly and effectively.

Selection of CAB Members

When first starting a CAB, form a small committee to help select voting members. The group might include two to four people. One or two who are staff as the Agency Liaison/CAB Coordinator and consumers who are not interested in becoming CAB members. When agency staff members are assigned to start a CAB, they should recruit a community leader to help them.

Once the CAB is formed, the selection process should be taken over by the voting members, with administrative support from the Agency Liaison/CAB Coordinator. To help figure out who should be selected for a CAB, an application may be developed which can be used to identify people who best represent consumers and the community. The selection committee can meet to review each person who applies and rate him or her based on the established criteria. The applicants

with the highest ratings would be asked to become the first CAB voting members. The committee should choose two or three others as alternate members in case some of those selected are not able to participate. Also, don't forget to inform the applicants that were not chosen as a voting member they have been selected as a non-voting member who can add value to the CAB.

For more help ensuring your CAB members are diverse and reflect the Part A or EHE consumer population the sample chart in appendix D identifies the characteristics desired of CAB members listed on the left, and potential CAB members listed at the top. No single person will fulfill all the CAB's requirements, but with the proper mix of members, the CAB can get closer to the representation it wants. You can also add characteristics that your CAB decides are important for your agency. **(See Appendix C)**

Membership Terms

CABs usually limit the length of time their voting members can serve because it keeps the members from burning out – and brings new ideas and energy to the CAB. It is best if members serve for more than a year, because it takes a while to figure out how the CAB works, and you don't want members leaving just as they are getting the hang of it. A two or three-year term is more desirable.

Some CAB members have varying terms to maintain continuity. For example, one CAB member may serve for two years, and another may serve for three. This helps ensure that there is always a consumer on the CAB who knows its history. You might also allow CAB members to serve more than one term, especially if few consumers in the community are able to participate.

Be specific about the dates when a CAB member's term begins and ends, as well as when, why, and how members can be dismissed before their time is up (which will be discussed later).

CAB Officers

Someone needs to run the CAB meetings and make sure they are held according to the rules. These members are called officers, and they have more responsibilities than other CAB members. There are usually three officers:

- **Chair** facilitates meetings, makes sure the agenda is followed, keeps track of time, and keeps the discussion on topic. The Chair also communicates with agency staff about CAB business. Some CABs have two members who serve as Co-Chairs. This way, one person doesn't have to take on all the responsibilities of being Chair but can work with a Co-Chair to get things done.
- **Co-Chair** steps in when the Chair is unable to participate. In this case, they temporarily assume all the Chair's responsibilities and keeps the Chair informed about what happens. If the CAB has a Co-Chair, a Vice Chair is unnecessary.
- **Secretary** keeps track of attendance, takes minutes, and works with agency staff to distribute the minutes from previous meetings. Sometimes the agency staff provides administrative support to the Secretary or assumes the role of Secretary entirely.

Some CABs let any member serve as an officer, while others limit eligibility to those who have served a certain amount of time on the CAB. Usually, a member is nominated (or nominates themselves), ballots are distributed for a secret vote, and most voters selects the Chair.

Sometimes the very first Chair of the CAB is elected, but when their term is up, the member who is the Co-Chair automatically becomes the new Chair and an election is held for the Co-Chair and Secretary.

CAB Subcommittees

CABs sometimes have a lot of work and not enough time at regular meetings to get everything done. If this is the case, the Chair or CAB may ask for volunteers to join an ad hoc subcommittee to work on an unfinished issue. The subcommittee meets separately to get the work done and then reports back to the full CAB. The CAB decides if the subcommittee has the power to make a final decision or if it must submit a recommendation to the full CAB for a vote.

As previously stated, CABs may need a Membership Committee to make sure that new members are recruited and chosen when needed. For this reason, some CABs may have the need for a permanent Membership Committee in their Bylaws.

Taking the Next Steps

Once CAB members have been selected and have begun defining their roles, they will need to decide how meetings will be run and decisions made. In the process, they need to consider the special topics of avoiding conflicts of interest and maintaining confidentiality. When these issues are resolved, the group is ready to tackle a work plan.

CAB Meetings

The CAB decides on the regularity of meetings- how often they should meet and where meetings will be held. They might meet once a month, every other month, or even every three months. Determining the regularity of meetings can be guided by the types of projects/tasks on hand, as well as deadlines to complete tasks. Unless there are special circumstances (in an isolated rural area, for example), CABs should not meet less than every three months.

Meeting times should be scheduled in advance so that everyone can mark their calendars. Choose meeting times that are convenient for most members. This can be done by surveying the group by a poll. Agency staff can update the meeting schedule as needed and make sure that all CAB members have it.

Depending on the time of the meeting and how long it will take, the Part A or EHE agency should consider providing a meal or refreshments. Some CABs have dinner or breakfast meetings or meet in the late afternoon with coffee and snacks. Keep in mind that people living with HIV sometimes have special dietary requirements. The Part A or EHE agency is also encouraged to consider providing transportation and childcare, as needed. Virtual/hybrid meeting schedules should also be considered.

CABs also must think about meeting locations. Most CABs meet at the Part A or EHE agency because it's usually a convenient and easy-to-remember place. But this is not always true, and some consumers may feel uncomfortable talking about the agency while in its offices. Pick a location that works best for most people. Sometimes a CAB rotates between two or more locations (for example, between the main agency office and a local park or library) or changes locations to accommodate more people (as when the larger community will participate). You can also change the place or focus of a meeting to help keep CAB members from getting bored. Many CABs, for example, substitute an outdoor picnic for a regular summer meeting or have a dinner of appreciation near the winter holidays.

Although CABs may want to hold closed meetings to discuss confidential issues, their meetings should be open to the public on a regular basis. The information sharing that happens at open meetings can benefit the CAB, the Part A and EHE programs, and the community. Open your meetings to the public at least on a quarterly basis.

Agendas

Groups of people may have trouble staying on topic during a meeting. To avoid this, each CAB meeting should have an agenda. An agenda simply lists all the issues that should be addressed at a meeting, sometimes according to a time schedule. The Chair, with help from other CAB members, often sets the agenda for the next meeting at the end of each meeting. Most agendas include:

- A welcome and call to order.
- Introductions or a roll call of voting members present.
- The review and approval of the minutes of the last meeting.
- Member or committee reports.
- Unfinished business that needs to be discussed.
- New business.
- Announcements.
- Agenda items for next meeting.
- Adjournment.

What are Minutes?

Minutes are written notes that provide a summary of what happened at a meeting. They usually list members who were present, non-members who attended, and briefly describe group discussions, any decisions that were made, and issues that still need attention. The meeting agenda and any materials distributed or discussed at the meeting should be attached. Minutes from the previous meeting are usually reviewed as part of the agenda and should be made available to CAB members before each meeting. Each CAB should decide when (for example, one week before the meeting) and how (by email, or regular mail) that happens.

Quorum

CABs only make decisions during an official meeting of the group. A meeting is official when a minimum number of members – called a quorum — is in attendance. A quorum requirement, which needs to be in the bylaws, helps to ensure that actions are taken by a representative number of CAB members, rather than by just a few people. If a quorum is not present, the proceeding of that meeting is invalid.

Each CAB must decide what its quorum is, although it should be at least 51% of members present at the meeting. It is best to start with a low quorum requirement because otherwise, official meetings might never take place. The CAB can always increase the quorum later, as appropriate. You can also decide whether to allow members to be counted as part of a quorum if they participate virtually or by phone.

Making Decisions

Each CAB must figure out how it is going to make decisions and write this in its bylaws. There are two basic ways to make decisions – by vote or by consensus.

When a CAB votes to make decisions, each member is asked if they are for or against a decision. A simple example is voting to approve the questions on a client satisfaction survey. CAB members either vote “yes” or “no,” and the votes are counted to make the final decision.

There are different ways to conduct the voting process, but Robert’s Rules of Order are often used. The basic process is a member presents an idea (a motion), a second member expresses support for discussing the idea (seconding the motion), a discussion is held, and a vote is taken about whether to adopt the motion. The Chair is responsible for enforcing Robert’s Rules of Order, which you can read about online at www.robertsrules.com.

Some CABs find Robert’s Rules of Order too rigid or difficult to follow. You can decide not to use them, or you can also adapt them so that they are simpler to use.

Plurality vs. Majority

There are two different ways of counting votes to make a decision.

- A **majority** means that more than half of the CAB members voted for the issue. For example, in a CAB of 10 members, 6 voted to accept the client satisfaction survey.
- A **plurality** means that less than half voted for the issue, but that vote got more than any other vote. For example, in a CAB of 10 members, 4 voted to accept the survey, 3 voted not to accept, and 3 voted to decide later.

Consensus

Consensus involves group discussion where CAB members work through differences and come up with a decision that is acceptable to everyone. Consensus does not mean that all the CAB members think the decision is the best one possible. It means that in making a decision, no one felt that their ideas or concerns were misunderstood or ignored, and each member agrees to abide by the group decision.

The decision is acceptable enough that no CAB member is totally against it. Usually, when it seems like the CAB members agree on a decision, the Chair will ask if there are any more objections or reservations. If there are none, the Chair will call for consensus and, after a moment of silence, if there are still no objections, the decision is final. Some CABs think that making decisions by consensus can take too long, or they like the “officialness” of a vote. Again, it depends on how each CAB works best.

It’s not important whether CABs agree to make decisions by voting or by coming to a consensus. What’s important is to choose one process to follow at each meeting. Regardless of the process chosen, the Chair should take a minute after each decision to repeat it to the group. This helps make sure that everyone understands what they have agreed to do and that the decision is correctly recorded in the minutes.

Conflict of Interest

One challenge for CAB members is putting aside their personal goals and needs to make decisions that will benefit the community of HIV positive people and their families who are using Part A or EHE services. Making decisions for your own benefit – or the benefit of family, friends, or a business – creates a conflict of interest and can have a very negative impact on the CAB’s effectiveness and acceptance by the community or Part A or EHE agency. Even the appearance of a conflict of interest can cause problems and should be avoided.

In general, CABs can help prevent potential conflicts of interest by recruiting members with different interests and allowing open discussions to provide a balanced viewpoint. You could also:

- Require CAB members to submit a Conflict-of-Interest Disclosure Form that lists any family, friend, or business relationships that might hinder them – or appear to hinder them – from making an impartial decision.
- Ask CAB members if anyone has a potential conflict of interest before starting a discussion. CAB members can be given a Conflict-of-Interest Card to hold up if needed.
- Have CAB members disqualify themselves from voting on certain issues when there is a potential conflict of interest.

- Establish a Conflict-of-Interest Review Panel that can review any potential conflicts to determine if there really was a conflict and come up with a fair solution.

All potential conflicts of interest should be recorded in meeting minutes so that they are openly acknowledged.

Confidentiality

Confidentiality is the assurance that private or sensitive information is properly treated inside and outside of CAB meetings. There are two main reasons to think about confidentiality:

- The first reason is that CAB members (or other participants in CAB activities) may or may not want to disclose their HIV status or the HIV status of family members. CAB members must respect these feelings and come to an agreement about how to handle issues of disclosure.
- The second reason is that during discussions about HIV programs, CAB members may talk about other sensitive issues. Since members may give input based on their experiences, discussions can get personal, and people might discuss issues related to sexuality, drug use, mental health, domestic violence, or anything else people might want to keep private. Warn the members not to discuss personal issues that they wish to keep private when the public is present at meetings. When the public is not present, make a rule that whatever is said at the meeting stays at the meeting and will not be discussed in public settings where others may hear what is said. Keep in mind that discussions, in or out of CAB meetings, should not include discussions about individual clients or family members.

CAB members also must be aware of what happens when confidentiality is broken. Disciplinary action should be taken to demonstrate the CAB's commitment to confidentiality and to build trust among the members and the community. The consequences, which should be spelled out in the bylaws, could include suspension of membership on the CAB.

There are a few simple ways that CABs can protect the privacy of their members:

- Refer to CAB members as community representatives or community advisors, instead of people living with HIV or consumers.
- Provide training to CAB members and staff about the importance of protecting confidentiality.
- Hold private "executive sessions" that are not open to the public when sensitive matters are discussed.
- Have CAB members sign a Statement of Confidentiality on a yearly basis.

(See Appendix D)

Developing a CAB Work Plan

When a CAB has identified goals that it wants to accomplish, it needs to be written out in detail explaining what needs to be done, when, and by whom; this is then called a Work Plan. Work plans help you sketch out your activities ahead of time.

Before the CAB writes out its own work plan, it usually examines the Part A or EHE agency work plan to see what the agency is committed to doing. The CAB then chooses which agency activities it will be involved with, after consulting with agency staff and hearing their comments and recommendations.

For example, a CAB might decide to help a Part A or EHE agency find out how consumers feel about the agency's services. To meet this need, the CAB could develop a client survey. But how will it get done? It could develop a work plan. **(See Appendix E)**

Making CABs More Effective

This section discusses several ways to improve the functioning of a CAB. For example, the way CAB members are oriented to their jobs and trained along the way can make a big difference in how they feel and interact as a group. It is also important to support members by addressing challenges such as the financial cost of participating, emotions such as frustration and stress, and other special needs. There are also times when a member might be asked to resign, which can be a difficult situation that should be discussed well before the group must face it.

Finally, an evaluation plan helps the group to know how well they are functioning and meeting their goals – and the reasons why or why not.

Balanced CAB Participation

Many times, CAB members have different levels of knowledge, understanding, and skills. All members should have access to the same information and the same opportunities for learning and improving their skills. This will help give each CAB member an equal voice in making decisions.

Orientation

Each new member should receive a complete orientation before they start on the CAB, which should be stated in the bylaws. In some instances, a group orientation program is appropriate (as when all members are new), and in others, a one-on-one orientation may work better (as when a new member joins an existing CAB).

- When a CAB is newly formed, all members will need information about the CAB and what is expected of it. They need to know that some of their first duties will be to develop the bylaws and work on a mission statement and job description. They will need to examine issues such as membership terms, which officers will be needed and how they will be elected, how decisions will be made (by voting or consensus), how to handle possible conflicts of interest and protect confidentiality, and how often the group will meet. To help with this process, the person organizing the CAB can provide the group with sample documents such as the ones provided within this manual.
- A new CAB will also need to understand about the Part A and EHE agency's priorities and activities and what level of input they are looking for from the CAB.
- Part A and EHE personnel need to explain what kind of support the agency can offer to the CAB, such as administrative costs and support, food, transportation, and childcare.
- Could the CAB have access to the agency computer and copy machines if needed? Is an agency person available to take notes during CAB meetings?
- New CAB members also need to understand that working on boards or committees such as this one can be a time-consuming process that includes discussion, disagreement, and rules. They can be encouraged not to become too discouraged with the process itself, which should become more familiar and comfortable with time.
- Each new member of an existing CAB should be given the job description, bylaws, work plans, and any forms they need to complete.

All new members of a new or existing CAB should also receive information about the Part A or EHE agency (such as brochures that explain the services), data about the local HIV epidemic, information about service needs (such as needs assessment reports), and information about the general system of care (such as a resource directory). Some CABs put this information together in a folder packet, but others are more formal and create a CAB member handbook.

Make sure that each CAB member is comfortable with the information presented at the orientation. There is a lot of information to digest, including terminology and acronyms that are unfamiliar to most people. Also don't forget to include something fun in the orientation. Being a CAB member is hard work, and a little bit of fun can make it easier.

Mentoring new CAB members

Mentors are experienced CAB members who have volunteered to "show the ropes" to new members. They can answer questions, make suggestions, and offer better ways of approaching opportunities or challenges. Mentors can choose to make themselves available via email, on the phone, or at a regularly scheduled meeting. The relationship should have boundaries (for

example, only CAB business is discussed) and could be for a specific length of time (perhaps for the first six months of membership).

If your CAB does not have a formal mentoring program, encourage new members to obtain some of the same benefits by listening and watching the more experienced people around them. This is how many people learn how to participate in an unfamiliar setting.

Skill building

Education and training opportunities help CAB members learn new skills so they can participate more effectively. Most CAB members welcome the chance to learn, and there are different ways to offer this opportunity. For example:

- Include regular education sessions as a part of your CAB's meetings.
- Schedule a guest speaker every other month to talk about specific topics.
- Hold special workshops.
- Offer an in-service training as needed about any changes in Ryan White funded programs, including budgets, rules, and priorities.

Many Part A or EHE agencies provide resources for CAB members to attend local, regional, or national conferences and seminars. Topics that may help consumers participate more effectively include:

- Living with HIV.
- Working in groups.
- Cultural competence.
- Family-centered care.
- Communication skills.

If CAB members have written their interests and needs on their application form to become a CAB member, you can look at these forms to figure out some good topics for training sessions. But don't forget to ask the CAB members what they would like or need!

Working in Groups

Participating in a CAB requires people to listen to one another's ideas and opinions and talk things out before making decisions. This interaction helps people learn, think, and come up with new ideas. Since it is not always easy for people to work together in this way, consider the following ideas:

- People usually work better together if they know each other's names and a little about one another, especially about experiences that relate to CAB activities. These may include experience living with HIV, caring for a family member, or working in an HIV program. Therefore, CABs should make time for members to introduce themselves to each other and get to know one another. This may be done by taking a few extra minutes at the beginning or end of every meeting for socializing or having regular summer picnics and holiday parties.
- Everyone should be encouraged to participate in discussions. The Chair can make it easier by making sure that everyone has a chance to speak, either by going around the room and asking if people would like to share, or by making sure that there is time for everyone to talk.
- Sometimes it is better to get all ideas out in the open before talking about them. A group brainstorming session (see the following page) is a good way to do this. One CAB member should write down all the ideas mentioned on a large sheet of paper so that everyone can see. The Chair can make sure that all comments are noted.
- Setting ground rules for behavior before meetings is a good way to create a positive atmosphere that supports open and honest discussion, is respectful of different viewpoints, and helps make sure all voices are heard. Members should identify and agree to the ground rules at the first meeting. The Chair should enforce the ground rules, when necessary, by calling the attention of a member who may need a reminder. Some examples of typical ground rules are:
 - All meetings will start and end on time as scheduled.
 - One person speaks at a time.
 - Speak for yourself without claiming to speak for others.
 - Respectful disagreements are acceptable but insults and accusations are not.
 - Always preserve confidentiality
 - Allow everyone a chance to speak and listen.
 - There will be no sidebar conversations.

- Time limits may be placed on discussions.
- Cell phones should be turned off or set to silent instead of ring.

How Do You Brainstorm?

The purpose of brainstorming is to generate as many ideas as possible in a short period of time. The general rules are to:

- Decide on a topic, make sure everyone understands what it is, and then write it down where everyone can see it.
- Set a time limit for discussing the topic. How much time will depend on the topic and the size of the group, but 20 minutes is a good starting point.
- Invite everyone to call out ideas, which are then written down. No one is allowed to comment about, disagree with, or criticize anyone else's ideas.

Once the time is up, the CAB can look at all the ideas and decide which ones should be discussed in more detail.

Keeping CAB Members

Participating in a CAB can be challenging for several reasons. Below are a few suggestions for supporting members so they can more easily participate.

Finances

One of the biggest barriers to participation in CABs is cost. Many consumers have limited incomes and can't afford to go to meetings if, for example, they must pay for travel or childcare. There also may be costs such as faxing, copying, or postage that go along with doing CAB business. If reimbursement of these costs is not possible, agencies may be able to provide no-cost services through volunteers or other providers. For example, a volunteer could be available at CAB meetings so consumers can bring their children and not have to pay for a babysitter. You may also need to schedule meetings at times that are convenient to bus or school schedules.

Emotions

Participating in a CAB can give new meaning to someone's life, but it also can be time consuming, demanding, and stressful. Many consumers still face challenging personal and health issues that can lead to them feeling overworked and make participating in the CAB complicated. In addition,

CAB members may become impatient with bureaucracy and agency rules, especially if they are not used to the way the system works. Frustration can grow as people feel unable to change things. All of this can lead to what is commonly known as “burnout.” Often, burnout presents itself with such behaviors as frequent lateness, poorly done work, irritability with others, and a negative attitude. There are several ways you can help your CAB members prevent themselves from burning out:

- Make sure the work plan is realistic and does not overload members with too much to do.
- Keep things “light” with humor, fun activities, and time to socialize.
- Provide ongoing education and training.
- Acknowledge the contributions of CAB members by distributing certificates of appreciation or achievement. If possible, have random drawings for small gifts. You may be able to get some local companies or groups to donate items.
- Have trainings that address personal issues of living with HIV so that CAB members feel more emotionally comfortable or physically able to participate.
- Let CAB members know that it’s fine for them to take a break and come back later. Everyone needs a break every once and awhile.

Unfortunately, when someone is starting to burn out, others usually notice it first. This can lead to conflict between CAB members. It might be a good idea to have a training session about how to recognize burnout and how to deal with it.

Special Needs

CABs are likely to include some members who have special needs that require extra attention. These may include:

- Part A or EHE programs serve youth, so it’s important to include their perspective. However, young people are in a different developmental stage than adults and therefore may behave differently, see things in a different way, and have different things going on in their lives. CABs with youth members may need to schedule meetings around school times, arrange transportation, or take extra steps to make sure youth are comfortable working in a room full of adults. You may also have a youth subcommittee or even a separate youth CAB.
- Some consumers may not understand spoken or written English very well, whether this is because they are not fluent in English or because their educational background is limited. If this is an issue, CABs need to make sure that written materials are easily

understood, that all members have a chance for training and skills building, and that translation and interpretation services are available if necessary. A subcommittee may be needed to work on these tasks.

- Active substance users are consumers of Part A or EHE services and need to have their voices heard, however, adopt rules that prohibit CAB members from participating in meetings while under the influence of alcohol or other drugs.

Dismissing CAB Members

Unfortunately, there may be circumstances when a CAB will have to ask one of its members to resign, which is why each CAB needs to develop a policy to deal with this issue before it arises. The Part A or EHE agency should make the CAB aware of any existing agency regulations that may apply to this situation.

The dismissal policy should describe which actions or inactions are significant enough to deserve dismissal. These may include:

- Illegal activities.
- Harassment or threats.
- Use of information discussed by the CAB for personal benefit.
- Excessive absences.
- Breach of confidentiality.
- Repeatedly attending meetings while under the influence of alcohol or other drugs.

The policy should describe how individual cases will be investigated and decided, as well as how CAB members can appeal a dismissal. For example, the Chair may form a subcommittee to look at information regarding a possible dismissal and make a recommendation to the full CAB. This subcommittee should be entrusted with making a fair decision so there is no need to discuss the whole situation again at the larger CAB meeting. An alternative is to have a neutral party look at the issue and make recommendations.

CABs can also establish a progressive system in which a member is:

- Warned on the first occasion.
- Warned again on the second occasion and told that if it happens again, the member will be dismissed.
- Automatically dismissed on the third occasion.

A progressive system can be used for lesser infractions such as using profanity, fighting, or excessive absences. It may not be appropriate if the issue at hand is more serious.

Board of Directors

Another way for the agency to show its commitment to the CAB is to have the Chair (or another member) serve on the agency's Board of Directors, which is the group that governs the agency. Including the CAB member gives the Board a greater understanding of what consumers need, shows agency staff and the community that the consumer perspective is an important part of the agency and gives the CAB a chance to learn more about the agency. The CAB members assigned to the Board can help keep the Board updated on the progress of the CAB, raise any pressing issues, and make sure the voice of the client is heard. They can also facilitate the two-way flow of information between the Board and CAB.

Evaluating the CAB

CAB members and the Part A & EHE agency need to know if the CAB is working well and if members can do all the activities in their work plan. Therefore, take the time to evaluate the CAB's progress in meeting its objectives and determine if members are satisfied with the CAB and its progress. Someone, either agency staff, the CAB Chair, or a CAB subcommittee, can review the work plan and timeline to check if things are getting done on time. If objectives are not being met, the CAB may need to revise the work plan so that the activities and timeline are more realistic. This person should also check in with each CAB member, either through anonymous CAB satisfaction surveys or interviews, to find out how the CAB is working. Some questions to ask might be:

- Are people following the ground rules?
- Do more rules need to be added or do they need revision?
- Is everyone contributing to the discussions?
- Are people listening to one another?
- Is the CAB able to accomplish the work that is expected of it? Are individual members having a hard time keeping up?
- Are there disagreements within the CAB that need to be addressed?
- What areas does the CAB need more help with?
- Is everyone enjoying the work and feeling like their contributions are meaningful?

Best Practices at Work

There are many CABs working with Part A & EHE programs across the country. Each one is different in its structure and activities. An agency's CAB will reflect the needs and resources of the agency and community, but it might be helpful to get a glimpse at two successful CABs.

Atlanta Legal Aid Society: -- Atlanta, GA.

Mission and Establishment

The Atlanta Legal Aid Society helps low-income people meet basic needs through free civil legal services. Founded in 1924 by 17 prominent attorney volunteers, we now have 75 attorneys on staff. During our 98-year history, we have helped to establish the Atlanta Volunteer Lawyers Foundation, coined the term "predatory lending," pioneered legal services for people with AIDS and Cancer, established the first medical-legal collaborative serving children in the Southeast, and won a landmark Supreme Court case on behalf of people with disabilities.

Our mission is "to deliver legal services and legal education designed to improve the social, political, and economic conditions of low-income persons; to serve as a catalyst for social change to benefit low-income persons; to prepare and furnish information to low-income persons about their rights so as to provide full benefit, enjoyment, and protection of their legal, economic, and social rights."

Appendices

Appendix A: Sample Bylaws

Article I. Name and Definition

The name of the advisory board bound by these bylaws is (Agency Name) Consumer Advisory Board (CAB).

Article II. Mission

The mission of the CAB is to help the Part A or EHE agency improve access to services by creating an inclusive environment where people living with HIV and their families are welcome to provide input and suggestions for having their needs properly met.

Article III. Membership

Section 1. The minimum number of members can be five depending on the size of the agency.

Section 2. Eligibility for membership on the CAB should be people who are receiving, or have received primary care, core, or support services, community members or stake holders ms.

Section 3. Members must attend a CAB orientation and sign, and update as needed, a Statement of Confidentiality and Conflict of Interest Disclosure Form.

Section 4. Any member may resign at any time from active membership on the CAB without any negative affect on the receipt of services under the Part A & EHE programs.

Article IV. Membership Terms

Section 1. For history of continuity, A portion of members shall serve a one-year term, while the other portion of members will serve a two-year term. The bylaws can determine who.

Section 2. CAB members may not serve more than three consecutive terms of any length.

Article V. Officers

Section 1. The CAB officers shall be Chair, Co-Chair and Secretary.

Section 2. Officers shall be elected annually by a simple majority vote at the December meeting, with officers taking their positions at the next meeting.

Section 3. The officers shall have responsibility for the performance of the following duties:

A. The Chair:

- i. Presides over all meetings and facilitates discussion among CAB members.
- ii. Communicates with the staff liaison regarding the logistics of CAB business.
- iii. Serves as liaison for the CAB to the larger community.
- iv. Communicates CAB recommendations to the Title IV agency.

B. Co-Chair:

- i. Presides over CAB meetings in the absence of the Chair.
- ii. Assumes the position of Chair upon expiration of the current Chair's term.

C. Secretary:

- i. Take notes during each meeting
- ii. Distribute typed meeting notes to participants
- iii. Set-up and distribute agenda
- iv. Provide all members with the schedule of meetings

Appendix B: Sample Mission Statements

Sample Mission Statements

“To serve both the infected and affected community through outreach and networking and to assist Metropolitan Community Health Services (MCHS) with the services provided by the Ryan White CARE Act.”

–From the Metropolitan Community Health Services CAB, Washington, NC.

“The mission of Positive Impact and, the Consumer Advisory Board, is to take a leadership role in providing guidance and assistance to Positive Impact in a committed effort to provide culturally appropriate mental health services to people from racial and ethnic minority communities who are living with HIV.”

–From Positive Impact’s CAB, Atlanta, GA

“The Patient Advisory Council will promote education and self-advocacy for patients of Johns Hopkins AIDS Services, and to offer guidance to staff and care providers regarding our health, care, and services.”

–From Johns Hopkins ’Moore Clinic CAB, Baltimore, MD

Appendix C: Sample Chart of CAB Representation

Needed Characteristics and skills	CAB Member 1	CAB Member 2	CAB Member 3	CAB Member 4	CAB Member 5
Consumer	X	X	X	X	X
Family Member			X	X	
Youth	X				
AA Cis Gender Woman		X	X		
AA MSM		X	X	X	
Hispanic MSM					X
Transgender	X			X	
Experience with Advocacy				X	X
Experience with CABs				X	
Knowledge of HIV	X	X		X	X
Facilitation Skills				X	
Service Provider Knowledge		X	X		X

Appendix D: Sample CAB Confidentiality Statement

Statement of Confidentiality

I understand that certain information about individuals or agencies that may be discussed at meetings of the CAB, or its subcommittees is and must not be discussed in any way with people who are not a part of the CAB. Any confidential personal information that I may learn cannot be discussed without that person’s consent, except as required by law.

I know that there may be civil and criminal penalties against anyone who discloses certain confidential information. I am aware that all CAB members are required to sign a statement of confidentiality saying they will adhere to the law.

By signing below, I agree to uphold this standard of confidentiality.

Printed Name

Signature Date

Date

Appendix E: Sample CAB Work Plan

NEED STATEMENT: Our Part A & EHE Agency does not have a way to collect information from consumers about its services.

GOAL (a general statement of what we want to get done): To administer a client survey to find out what clients think about the services they are using and what services are missing.

Objective (Objectives should be SMART: specific, measurable, attainable, realistic and time bound.)	Key Action Steps	Completion Date	Person Responsible
Create a standard survey for gathering client information by end of 2 nd quarter.	1. Gather suggested questions for the survey	July 20	Survey Subcommittee
	2. Get feedback on a draft survey from the agency staff and others	August 17	Survey Subcommittee person responsible for liaison with the agency
	3. Put together the final questions for the survey.	September 21	Survey Subcommittee
	4. Present the survey to the CAB for final approval.	October 30	Survey Subcommittee

In the example above, the CAB has figured out what steps are needed to create a survey, a deadline for completing each step, and who will be responsible for doing the work. Be sure to include the whole CAB in writing up work plans such as this, because people are more committed to the work if they are involved from the beginning and know what the bigger goals are.

This sample work plan is short and does not include as many goals, objectives, or activities as your CAB might have, but it gives you a basic format to adapt if you like.