

# Getting Started

A CONSUMER ADVISORY BOARD MANUAL FOR TITLE IV PROGRAMS



AIDS Alliance advances the partnership between consumers and providers – we are the voice of women, children, youth and families living with HIV and AIDS.

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FOR TITLE IV PROGRAMS

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Cooperative Agreement, Grant No. U69HA00051  
AIDS Alliance for Children, Youth & Families

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# Introduction

This manual provides the basic steps for setting up and improving the Community Advisory Boards (CABs) that are required by Title IV programs. It is designed to assist anyone – whether you are a Title IV agency staff person or a community member – who has been charged with this responsibility.

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 lack. 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.

This is why HRSA's Division of Community-based Programs requires that agencies with Title IV programs get input from consumers as agencies 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 community and situation, but there are issues that are common to most CABs, and so we offer you general guidelines to help you get started on this important work.

# A CAB's Purpose

Title IV of the Ryan White CARE Act funds programs designed for women, infants, children, and youth living with HIV, as well as their families. From its inception as the Pediatric AIDS program, Title IV has included the input of consumers as an integral part of its development, implementation, and evaluation. Consumer Evaluation Boards, or CABS, are thus an expectation of Title IV programs.

The main purpose of a CAB is to provide a consumer perspective and represent the community in making sure Title IV activities are carried out in a way that best meets consumers' needs. Title IV programs must provide the following activities:

- Access to comprehensive, culturally and linguistically competent, coordinated services focused on consumers and their families.
- Consumer education about and access to clinical research.
- Consumer involvement in care management and in the planning, implementation, and evaluation of Title IV programs.
- Enrollment and retention of women in care.
- Prevention of transmission of HIV from mother to child.
- Outreach to and enrollment of people living with HIV who are not in care.

The CAB is one more 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 is an advisory board that 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*

The first and most fundamental tasks for CABs include creating bylaws and a mission statement, as well as defining the responsibilities and expectations of the members. These elements, when carefully considered and written, lay the foundation for an effective working group. If your CAB is not functioning as well as you wish, or if it is straying from its mission, perhaps you need to revisit these elements and find out if they have been well defined from the start. If so, the CAB members may need to remind themselves about – or even revise – what they have charged themselves to do.

# CAB 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 groups’ purpose if it begins to stray from its mission.

One of the first tasks of a CAB is to write its bylaws, which should include much of the information that will be presented in this manual. Bylaws should 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 the Title IV 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 that follows shows how bylaws are written, although it doesn't cover all of 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 your Title IV agency and 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.

## **Sample Bylaws of a Title IV Consumer Advisory Board**

### Article I. Name and Definition

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

### Article II. Mission

The mission of the CAB is to help the Title IV agency improve access to services by creating a client-friendly environment where people living with HIV and their families can provide input and suggestions for having their needs properly met.

### Article III. Membership

Section 1. The minimum number of members will be seven.

Section 2. Eligibility for membership on the CAB is limited to people who are receiving, or have received, primary care or support services under the Title IV program.

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 Title IV program.

### Article IV. Membership Terms

Section 1. Half of the members will serve one-year terms, and half will serve two-year terms.

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 and Vice Chair.

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. Vice 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.

# My Ideas

The sample bylaws answer only a few of the questions they should. What else should be included in your bylaws?

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# The CAB 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. This is why 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 actually believes in the mission statement because they participated in developing it.

## 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 Interest, 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

**The CAB Is Not a Support Group**

CABs have a tendency 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.

*My Ideas*

Take a minute to write down some ideas about what your CAB’s mission might be:

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# 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 Title IV 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 time line for the Title IV 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 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 data collection and evaluation surveys to see if they ask clear, understandable, and relevant questions about consumer needs.
- Holding quarterly meetings for the community about Title IV services to get community feedback.
- Giving input on clinical trial procedures, helping interpret these procedures for consumers, and providing a link between the researchers and the community.
- Ensuring that agency publications are easy to understand and address real community needs.

## What is HIV-related Clinical Research?

Clinical research (or a clinical trial) is a scientific study with human volunteers that tries to answer a specific health-related question. For example, it might ask: How effective is a new medication in fighting HIV? How does the medication affect the central nervous system? What happens when people skip doses?

Clinical research is carefully controlled, and there are guidelines about who can participate. Usually the research is conducted by a team of health care professionals who check the health of participants, give instructions about what to do, and monitor progress. Many people believe clinical research is important for finding the best way to treat people living with HIV. Because there are benefits and risks to participation, people must learn all the facts before deciding whether to become involved.

## *My Ideas*

What do you think some of your CAB's responsibilities might be?

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# 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 conference calls.
- Reviewing materials (such as program policies and procedures, literature, and surveys) outside of the meeting.
- Participating 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.

## **Sample Position Description for a Consumer Advisory Board Member**

RESPONSIBILITIES: CAB members commit to:

- Attending one 2-hour meeting each month, arriving on time and staying until the meeting is finished.
- Participating in meeting discussions.
- Respecting the opinions and ideas of other CAB members and following the ground rules.
- Reviewing and commenting on written materials.
- Attending community meetings.
- Completing and turning in reimbursement forms in a timely manner.
- Performing other duties as assigned by the CAB Chair.



**REQUIREMENTS:** CAB members must be consumers of Title IV services or an affected family member, have knowledge about HIV, and be willing to work with others.

Some consumers who want to participate will find it difficult to do so. Because each person's input is valuable, different levels of participation can be offered. For example, members who can't attend all of the required meetings may be welcome to come to the meetings that they can attend, but they are not permitted to vote. There may also be subcommittees in which non-CAB members can participate. Even a consumer who cannot participate in a CAB at all may be able to help with activities such as completing surveys and participating in focus groups. The point is to make sure everyone who wants to participate can do so in a meaningful way.

## *My Ideas*

What do you think should be expected of your CAB members?

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# Members, Officers, and Committees

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

# Membership on CABs

CABs are small groups that represent the larger population of people who use the services of a Title IV agency – which generally means women, infants, children, youth, and families living with HIV. However, a Title IV agency may target specific populations such as African American women or youth, meaning that the CAB would reflect that targeted population. In general, the membership should be a mix of ages, genders, races and ethnicities, geographic areas, people who are living with HIV, affected family members, and care givers.

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 seven to nine 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.

Of the seven or nine people who first form the CAB, one will become the Chair. Since the Chair rarely votes, the remaining members (an even number of six or eight) become the voting members. When these voting members cannot agree, the Chair votes to break a tie. This is why an even number of voting members is recommended.

## Recruitment

If you want consumers to participate in a CAB, they first need to know about it. Depending on the Title IV agency, its resources, and the community, there are a number of ways to advertise:

- Agency staff can tell consumers about the CAB during appointments or by giving out easy-to-read flyers.
- 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, in newsletters, or on a website.
- Flyers can be posted on agency and community bulletin boards.
- An advertisement can be put in the community section of a local newspaper or announced on a local radio station.

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 you'll need to replace them. 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 and for recruitment to be an ongoing process.

## *My Ideas*

How do you think you might get the word out about your CAB?

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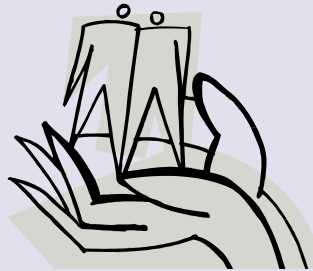
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## Sample Recruiting Flyer

**ATTENTION**  
**Title IV Consumers and Recipients**  
**We Want You!!!**  
**We Need You!!!**

We need you to be a part of our Title IV Consumer Advisory Board. If you are interested in issues concerning HIV and women, children, youth, or families and want to give your input or be part of community involvement, we want you.



Our next meeting will be:  
at 11:00 AM on Wednesday  
January 18, 2006  
at The Agency Conference Room  
123 Main Street, Suite 100

Refreshments will be served.  
Transportation and childcare are available.

Please call Lesley at 123-456-7891 for more information.

## *Selection of CAB Members*

When first starting a CAB, you may want to form a small committee to help select the members. The group might include two to four people who are agency staff and consumers who are not interested in becoming CAB members (to avoid conflict of interest). 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 members, with administrative support from agency staff if needed.

To help you figure out who should be selected for a CAB, you may want to develop an application form that 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 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 so they know their interest was appreciated. These applicants may want to participate another way or reapply for the CAB in the future.

For more help in selecting members and making sure that CAB members reflect the Title IV consumer population and have the necessary skills, knowledge, and experience, outline what the ideal CAB would look like. In the sample chart below, the characteristics desired of CAB members are listed on the left, and the names of potential CAB members are listed at the top. No single person will fulfill all of the CAB's requirements, but with the proper mix of members, the CAB can get closer to the representation it wants.

## 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				
Woman with infant		X	X		
African American		X	X	X	
Hispanic					X
Experience with advocacy				X	X
Experience with CABs				X	
Knowledgeable about HIV	X	X		X	X
Facilitation skills				X	
Knowledgeable about service providers		X	X		X



## Sample Consumer Advisory Board Application

Name:			
Mailing address:			
Home phone: (     ) Alternate phone: (     )			
E-mail address:			
Best time(s) to reach you by phone:			
May we leave a confidential detailed message?			
If yes, at which phone numbers?			
Areas of interest:	Recruitment?	Planning?	Surveys?
Other areas of interest and skills:			
Why do you want to participate on the CAB?			
Are you currently serving on other community committees?			
If yes, which one(s)?			
Have you served on a Consumer Advisory Board before?			
In case of an emergency, who should we contact?			
Is this person aware of your diagnosis?			
Relationship to you:			
Home phone: (     ) Alternate phone: (     )			
Signature:		Date:	



## Membership Terms

CABs usually limit the length of time their 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). After all, not everyone is cut out to be a volunteer.

## My Ideas

What kind of term limits might your CABs' members have?

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# CAB Officers

Someone needs to run the CAB meetings and make sure that 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:

- **The Chair**, who 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.
- **The Vice Chair**, who is the second in command and steps in when the Chair is unable to participate. In this case, he or she temporarily assumes all of the Chair's responsibilities and keeps the Chair informed about what happens. If the CAB has a Co-Chair, a Vice Chair is unnecessary.
- **The Secretary**, who 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 himself or herself), ballots are distributed for a secret vote, and the majority of voters selects the Chair. Sometimes the very first Chair of the CAB is elected, but when his or her term is up, the member who is the Vice Chair automatically becomes the new Chair and an election is held for the Vice Chair and Secretary.

## What are Minutes?

Minutes are written notes that provide a brief 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 fax, email, or regular mail) that happens.

## *My Ideas*

What skills do you think that the officers of your CAB need? What should be their responsibilities?

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# 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 has been said, CABs will probably always need a Membership Committee to make sure that new members are recruited and chosen when needed. For this reason, some CABs state the need for a permanent Membership Committee in their Bylaws. Depending on the responsibilities and circumstances of particular CABs, there may be other permanent committees. For example, a CAB that takes on the responsibility for reviewing grievances against a clinic or its personnel may form a standing Grievance Committee. This, too, could be stated in the 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, and we will give you an example of what a work plan can look like.

# CAB Meetings

The CAB decides how often and when they should have regular meetings. They might meet once a month, every other month, or even every three months. Unless there are special circumstances (in an isolated rural area, for example), CABs probably should not meet less than every three months. Infrequent meetings can send the wrong impression. CAB members, agency staff, and the rest of the community need to know that the CAB's contribution is real, and they are not meeting just because it's a requirement. Meeting times should be scheduled in advance so that everyone can mark their calendars. Choose meeting times that are convenient for the most members. 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 Title IV agency should provide 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 Title IV agency is also encouraged to provide for transportation and childcare, as needed.

CABs also have to think about meeting locations. Most CABs meet at the Title IV 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 the best for the most people. Sometimes a CAB rotates between two or more locations (for example, between the main agency office and a local clinic) 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 Title IV program, and the community. Open your meetings to the public at least on a quarterly basis.





## Agendas

Groups of people sometimes have trouble sticking to the topics they are supposed to cover at a meeting. To keep people on track, each CAB meeting should have an agenda. An agenda simply lists all of the issues that should be covered 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 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.

## Quorums

CABs only make decisions during an official meeting of the group. A meeting is official if 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 topic is saved until the next meeting.

Each CAB must decide what its quorum is, although it should be at least 51%. 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 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.

- **By voting.** 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 or not to adopt the motion. The Chair is responsible for enforcing Robert’s Rules, which you can read about online at [www.robertsrules.com](http://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 at a later date.

- **By consensus.** Consensus involves group discussion where CAB members work through differences and come up with a decision that is acceptable to everyone. Consensus doesn’t 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 his or her 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 particular 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 will be correctly recorded in the minutes.

## *My Ideas*

Do you think your CAB should make decisions by voting or by consensus? Why?

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# Conflict of Interest

One challenge for CAB members is to put aside their personal goals and needs and make decisions that will benefit the community of HIV positive people and their families who are using Title IV 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 Title IV 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.

## Sample Conflict of Interest Disclosure Form

Each member of the CAB must disclose any affiliations with any organization during the past year that might present a conflict of interest in making decisions on behalf of the community. CAB members have a conflict of interest when they or an immediate family member might benefit from a CAB decision because they:

1. Are affiliated with an organization as a employee, board member, volunteer, contractor, officer, trustee, partner, investor, or owner.
2. Are negotiating with or have an arrangement with a person or organization to become involved with them in the capacities listed above.

These are my possible conflicts of interest:

Organization (please use back of page if necessary)	My affiliation with this organization

I, \_\_\_\_\_, certify that I have listed any possible conflicts of interest. If I have listed nothing, then neither I nor a member of my immediate family has a conflict of interest with respect to my participation on the CAB.

Signature:	Date:
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# 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 are supposed to 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. Some kind of disciplinary action should be taken in order 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.



## Sample Consumer Advisory Board 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 very confidential 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

## *My Ideas*

How do you think your CAB should deal with confidentiality issues?

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# Developing a CAB Work Plan

When a CAB has identified something that it wants to accomplish, it needs to write out a work plan that shows what has to be done, when, and by whom. Work plans help you sketch out your activities ahead of time.

Before the CAB writes out its own work plan, it usually examines the Title IV 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 Title IV agency to 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 this done? It could develop a work plan such as the following:

## Sample CAB Work Plan

**NEED STATEMENT:** Our Title IV Agency doesn't have a way to collect information from consumers about its programs.

**GOAL:** To administer a client survey to find out what clients think about the services they are using and what services are missing.

Objective	Key Action Steps	Completion Date	People Responsible
To create a standard survey for gathering client information.	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 doesn't include as many goals, objectives, or activities as your CAB might have, but it gives you a basic format to adapt if you like.

## What are Goals and Objectives?

Goals are general statements that tell us what we want to get done. In the example above, the CAB's goal is to get information from consumers.

The objectives, on the other hand, explain how the CAB will accomplish the goal. In the example above, the objective is to create a client survey. This objective is specific and will let you know when you have accomplished your task. Make sure that your objectives are achievable, realistic, and based on the experience, skills, and resources of your CAB.

## *My Ideas*

What do you think your CAB might try to accomplish? What are the goals, objectives, and activities that might be included in your work plan to complete this task?

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# Making CABs More Effective

This section discusses a number of 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 it 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 book.

A new CAB will also need to understand about the Title IV agency's priorities and activities and what level of input they are looking for from the CAB. Title IV personnel need to explain what kind of support the agency can offer to the CAB, such as administrative costs and support, food, transport, and childcare. Could the CAB have access to the agency fax and xerox 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 Title IV 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. And 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.

## *My Ideas*

Do you have any ideas about what to include in your CAB's orientation?

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## *Mentoring a new CAB member*

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 doesn't 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.

## *Skills building*

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

- 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 budgeting, rules, and priorities.

Many Title IV 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!

## *My Ideas*

Take a minute to write down ideas about what issues your CAB might need information or training on:

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# 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 disagreement is acceptable, but insults and accusations are not.
  - Preserve confidentiality at all times.

- Allow everyone a chance to speak and listen.
- There will be no sidebar conversations.
- Time limits may be placed on discussions.
- Cell phones and pagers should be turned off or set to buzz 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 of the ideas and decide which ones should be discussed in more detail.

## *My Ideas*

What ground rules do you think your CAB should follow?

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# Keeping CAB Members

Participating in a CAB can be challenging for a number of 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 have to 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 a number of 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:

- Title IV programs serve youth, so it's important to include their perspective. Yet 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 Title IV services and need to have their voices heard, but you need to adopt rules that prohibit CAB members from participating in meetings while under the influence of alcohol or other drugs.

## *My Ideas*

How should CAB members be supported?

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# 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 Title IV 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 swearing, fighting, or excessive absences. It may not be appropriate if the issue at hand is more serious.

## *My Ideas*

Do you think there are reasons why a CAB member should be dismissed?  
Which are these?

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# Working with the Title IV Agency

Each Title IV 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 Title IV agency. Once the CAB's 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.

## *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 Title IV 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 Title IV program, 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.

## *My Ideas*

How do you think your CAB and the Title IV agency can work together?

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# Evaluating the CAB

CAB members and the Title IV agency need to know if the CAB is working well and if members are able to do all the activities in their work plan. Therefore, you should 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 time line 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 time line 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 other?
- 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, Personal Experiences, and the Ryan White CARE Act*

We wrap up this manual with descriptions of two effective CABs, one woman's story about her journey to becoming a courageous CAB member and advocate, and a summary of the Ryan White CARE Act.

# Best Practices at Work

There are many CABs working with Title IV programs across the country. Each one is different in its structure and activities. Your own CAB will reflect the needs and resources of your agency and community, but we thought it might be helpful for you to get a glimpse at two successful CABs.

## Metropolitan Community Health Services: A Rural CAB at Work Washington, North Carolina

**Mission statement:** *to serve both the infected and affected HIV/AIDS communities, through outreach and networking, and to assist Metropolitan Community Health Services with the services provided by the Ryan White CARE Act.*

The Agape Community Health Center is the primary care clinic of Metropolitan Community Health Services (MCHS), Inc. in Washington, North Carolina. The clinic serves eleven counties in rural Eastern North Carolina. The clinic provides primary medical care to children, youth, and adults and offers a wide range of support services that include outreach, HIV counseling and testing, case management, support groups, transportation assistance, and emergency financial assistance. Funded in large part by Ryan White CARE Act grants, MCHS offers specialized services to people living with HIV/AIDS within the context of its overall community and faith-based family-centered primary health care.

The CAB is represented on the MCHS Board of Directors, is in constant contact with the staff liaison, and participates in many activities in addition to the monthly CAB meeting. The CAB membership includes the program's Peer Advocate, and several members are state certified for counseling and testing, which supports the clinic's outreach program. Members also participate in national trainings, enhancing their skill to benefit the CAB.

The MCHS CAB has been directly responsible for several changes in service delivery. As an example, the CAB decided to address the reluctance of at-risk adolescent African American males in the region to test for HIV and to come into care if they tested positive. Two years ago, the CAB developed a regional health fair in collaboration with a network of community-based organizations and area businesses that sponsored and participated in the

event. The summer health fair, which is now annual, offered games, writing and art competitions, food, health-related literature, and the opportunity to enroll in health care. The primary goal was to offer testing for cholesterol, diabetes, high blood pressure, and HIV. Over 150 people attended the first fair, and more than 25 African American male adolescents and several multi-generational families tested for HIV. Attendance at the clinic by African American male adolescents has since increased by 50%.

## *Johns Hopkins' Moore Clinic: An urban CAB at work Baltimore, Maryland*

Mission statement: *to promote education and self-advocacy for patients of Johns Hopkins AIDS Services and offer guidance to staff and care providers regarding our health, care, and services.*

The Johns Hopkins' Moore Clinic for people living with HIV/AIDS has a CAB that is called the Patient Advisory Council (PAC). The PAC has developed a directed approach that has resolved recruitment and retention obstacles that often hinder a CAB's success. The CAB is a dual-level board consisting of a core voting group and a monthly meeting that is open to all consumers affected or infected with HIV who receive care at the Moore Clinic. Their Site Staff Liaison, who also is a Peer Advocate, Outreach Coordinator, Co-facilitator of Education, and a person living with AIDS, leads the CAB. The PAC serves clients of the Moore Clinic, which offers full one-stop service for people with HIV/AIDS, including but not limited to primary care, OB/GYN and other specialty services, case management, support groups, counseling, and emergency financial assistance. The PAC was instrumental in the development of a patient handbook that provides information about the clinic, availability of resources, responsibilities of the clinic and consumer, and general policies about access to services.

Sustaining a successful CAB is partially dependent on members who regularly attend and contribute to the monthly meetings. The PAC has, for several years, implemented three levels of participation for its members. The first level of the PAC is a core voting group that includes the officers – a Chair, Co-Chair, and Secretary who can serve for a maximum of two years. The members are accessible for immediate votes or input by telephone when urgency requires. This group also supports a monthly “Lunch and Learn”

meeting that provides peer education and presenters on topics that are selected by the Moore Clinic consumers. This core voting group is directly responsible for primary contact with the Moore Clinic Administrative leadership and interaction with network agencies and countless collaborations in Baltimore City and surrounding counties in a service area that spans a 150 square mile area.

The second level of membership consists of officers who have reached their term limit and then become members at large. This option relieves the members of some of their old responsibilities (for example, offering optional meeting attendance), but allows them to continue to participate in ways that are meaningful to them (such as new member orientation, general support, and mentoring of the group).

The third level of membership is a quarterly “Meet and Greet” meeting that is open to all clients of the Moore Clinic without regard to their participation, or desire to participate, in the PAC. CAB members are available to answer questions about the PAC at these more relaxed events, and they distribute literature regarding consumer participation and education about clinic services. These events have been successful in gaining feedback and participation in the PAC process.



# Final Thoughts

Now that you've read this manual and have a basic idea about CABs, we thought we would leave you with some comments about what it all means to one woman. The ideas, feelings, and experiences of people and families living with HIV add real meaning to the work of CABs.

Anna Wyman is a woman living with AIDS. She is now an Adherence Educator at the University of Miami's School of Medicine's Miami Family Care Program in Miami, Florida.

"I got involved with the Consumer Advisory Board at the University of Miami Title IV Program around 1992. Being one of maybe five to six members, I did learn a lot about the Title IV program, ACTG/ACTG, and Ryan White services in general. I learned a lot and met a lot of other women and men who were dealing every day with similar issues regarding our children who were also HIV infected and children who were going through the screening process.

"In this CAB, I learned to be an advocate and how to advocate in effective ways. I know that I was already an advocate for my children, but the CAB prepared and educated me to attend national conferences and to speak to my community and other communities about living and surviving HIV. Caring for my twin sons who had AIDS opened the door for me to have courage and strength do what I do today at the University of Miami – Miami Family Care Program. The CAB sponsored me to attend conferences, trainings, and forums regarding HIV/AIDS. The period when my children and I were diagnosed was a desperate time and the women in my community were silent.

"I was so worried about my children's health that I didn't access health care for myself until 1994, years after my diagnosis. And every woman I knew was really ill during the 1990's and wasn't speaking out like me and attending the national conferences and trainings like I was. I was very interested in learning more about the disease and how it affects children and women. But there was limited information. So I had to voice my feelings as an HIV infected woman caring for two children who were diagnosed with AIDS at the age of two years old. I wanted the government to know about me and my children and other women and children from Miami. My case manager at this time was instrumental in getting me involved with speaking and attending as many conferences she could find for me to attend. She knew that I had the strength and courage to be an advocate. She never gave up on me even when I was in denial. I truly believe that I wouldn't have been

as strong and educated an advocate as I am today without her. I will never forget her and what she did for me and my family back then.

“Back then it was hard to get women into health care, but they would bring their infected children to the doctor, and as long as the focus remained on the children, they were participating in support groups and the CAB. There were no women consumers participating on the Miami Ryan White planning council. The only women that were participating in our behalf were the social workers and case managers. A lot of women felt and still feel that they cannot disclose their status openly to a planning council meeting or support group. And women still think that they have to disclose their status to advocate for RW services. At that point, I didn’t care who knew about my HIV status because I had buried both of my babies and wanted everyone to know my pain and my children’s pain.

“I couldn’t stop advocating. I felt that I had to try to empower other women in my community to speak up without disclosing their status. And I met other women who were willing to be educated. Most of the women were very ill and holding on just to be educated and empowered. But, unfortunately, those special ladies passed on and left me to continue the fight. I do what I do for those women. I carry on and continue to fight and not give up for those women who left me here with their loved ones and some of their children so I can tell them the stories of their mothers and their good and bad days.

“I believe that the positive changes in some of the Ryan White programs have occurred because of the voices of women and social workers of these women who advocated for us. We were becoming consumer staff members, advisors, grant reviewers and just respected people living with AIDS. The programs did get more family centered and the CABs fought hard to be part of the program instead of just a CAB on paper. I think some of the CABs still need better organization and purpose, but I know our Miami CAB has come a long way and is very active with clients, family members, parents, care givers, and community representatives. And they are very outspoken regarding the needs and research for better care and treatment for women, children, and youth in the program.

“What I see is that we need a new group of advocates to come and relieve some of us ‘Golden Oldies,’ because I am getting a little burned out and tired. I have been mentoring three women this year to take my spot because I do need to pass the torch. I have come to terms with letting go of some of my advocacy and passing it on because I don’t feel that I have to carry it all by myself, and I know now that my sisters who left me in the ‘90s to carry on would be proud of me.”

# The Ryan White CARE Act at a Glance

The Ryan White Comprehensive AIDS Resources Emergency Act, or CARE Act, is a Federal law first passed by Congress in 1990 and renewed in 1996, 2000, and 2005. The CARE Act provides money to State and local governments and community agencies to help make sure that people and families infected and affected by HIV are able to get quality medical and support services. It pays for those services that are not covered by any other program (for example, Medicaid and Medicare). The CARE Act is divided into five parts, and the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services manages the money according to what the law says. Below is a brief description of each of the parts of the CARE Act. If you have access to the Internet, you can get more information from HRSA's website at [www.hrsa.gov](http://www.hrsa.gov).

## Title I

Title I money is given to metropolitan areas with 2,000 or more HIV/AIDS cases. The cities that receive Title I money are called Eligible Metropolitan Areas, or EMAs. EMAs must have a population of at least 500,000 people and report at least 2,000 AIDS cases during the previous five years. The money is given to the highest-ranking elected government official in the area. The amount of money is determined by a formula based on the estimated number of people living with AIDS over the most recent 10-year period. EMAs can obtain more money, called supplemental funding, if they can show there is severe need in their geographic area. There are 51 EMAs in the country.

EMAs use Title I money to fund certain medical and support services that are not paid for by any other program. These services may include primary care, dental or vision care, case management, mental health care, substance abuse counseling or treatment, transportation, housing assistance, nutrition services, day care, and others. EMAs spend their money based on who is living with AIDS in their area. That means, for example, that if 50% of the people living with AIDS are women and youth, then 50% of the money must be spent on women and youth.

A local volunteer group, called an HIV Services Planning Council, helps each EMA decide which services should be given money, and how much. The planning councils do not decide which agencies get the money, but which services. Based on certain government regulations and their own rules, the planning councils decide on a list of services to be given priority. In order to help make sure that the decisions are fair to as many people as possible, the volunteers on the planning councils must include a mix of professionals, people living with HIV/AIDS, and people who use Title I services. The professionals include public health professionals, housing or homeless service providers, providers of services to prisoners or former prisoners, and medical care and support service providers. Thirty-three percent of the people on the planning councils must be consumers, that is, people who use Title I services.

## *Title II*

Title II money is given to all 50 States, the District of Columbia, Puerto Rico, Guam, the US Virgin Islands, and US Territories and Associated Jurisdictions. The money is most often given to State health departments. Like Title I, the amount of money is determined by a formula that includes the estimated number of people living with AIDS in the entire state and the estimated number of people living with AIDS in the state that do not live in an EMA. They include this last part because Title II money is meant to make sure that everyone has access to quality care, whether they live in a city, suburb, or rural area. States with fewer than 90 people living with AIDS get a minimum of \$200,000 and states with more than 90 cases get a minimum of \$500,000. Supplemental funding also is available to states with what are called emerging communities, or those reporting between 500 and 1,999 AIDS cases over the most recent 5-year period. The CARE Act also requires that States with more than 1% of the total AIDS cases reported in the US during the previous two years contribute a match with their own money, according to another formula.

Title II money may fund the same services as Title I, but there are a few different rules. For example, money may be used for daycare for children who are affected by HIV even if they are not HIV positive. Title II money also may be used to pay for health insurance programs that help keep people covered by their private health insurance, and for states to reduce the number of cases of mother-to-child (perinatal) HIV transmission. Title II money also must be spent based on who is living with AIDS in that state.

Most states have volunteer groups that help them decide which services should be given money, and how much. These groups, most often called an HIV Care Consortium, are like the Title I planning councils. They include a mix of professionals, people living with HIV/AIDS, people affected by HIV/AIDS, and people who use Title II services. They too decide on a list of priority services.

A special part of Title II is called the AIDS Drug Assistance Program (ADAP), which helps people with no insurance or not enough insurance pay for HIV-related medications. ADAP also may be used to pay for other services that improve access to, adherence with, and monitoring of drug treatments. Congress, based on another formula, tells the states how much of the Title II money should be spent on ADAP. Three percent of this money is reserved for supplemental funding to those states and territories that can demonstrate a severe need.

## *Title III*

Title III money is given to individual organizations that apply for funding based on the need in their community for early intervention services. These organizations, which may include community or migrant health centers, hospital medical centers, or city or county health services, compete with others from across the country to provide medical care. The money is given to those organizations with the best proposal for spending the money, which is most often meant for people who do not usually receive services, or those who live in geographically remote areas. Money also is provided for organizations to plan for the development of services (Title III planning grants) or to improve their ability to provide these services (Title III capacity building grants). In 2004, there were 166 early intervention grants, 58 planning grants, and 59 capacity building grants.

Title III money is to be used for outpatient medical services and support services that help keep people in medical care. These services may include HIV counseling and testing, primary or specialty medical care, dental or vision care, case management, medications, or nutritional services.

## *Title IV*

Title IV money is given to individual organizations that apply for funding based on the need in their community for services to women, infants, children, and youth living with HIV, and their families. A separate Title IV program specifically funds services that address the unique needs of youth. Again, organizations compete for these funds. In 2004, there were 73 Title IV grants and 17 Title IV youth grants.

Title IV money is to fund medical and support services that help keep women, infants, children, and youth in care, and to support services for families affected by HIV. These services may include HIV counseling and testing, primary or specialty medical care, case management, medications, transportation, or childcare. In addition, there is an emphasis on preventing perinatal transmission and providing access to clinical research.

## *Part F*

Money under Part F is used for several different programs: Special Projects of National Significance (SPNS) for evaluation programs, AIDS Education and Training Centers (AETC) for the education and training of health care providers treating people living with HIV/AIDS, the Dental Reimbursement Program that reimburses dental education programs for providing dental care, and the Community-Based Dental Partnership Program for education programs for dental care and provider training in community settings. In 2004, there were 88 SPNS projects, 11 regional and four national AETCs, 65 Dental Reimbursement Programs, and 12 Community-Based Dental Partnerships.



AIDS Alliance advances the partnership between consumers and providers – we are the voice of women, children, youth and families living with HIV and AIDS.



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