

# A Place at the Table: Having a Voice in HIV Planning and Decision Making <sup>[1]</sup>

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The thought of being an HIV [advocate](#) [2] can be intimidating. You know that you want to do *something*, but you may not know what to do or where to start. It can help to realize your voice is important. What you have to say as a person living with HIV (HIV+) is valuable and needs to be heard by those making decisions about how HIV funding is used, what HIV policies are put in place, how research studies like [clinical trials](#) [3] are conducted, and how AIDS service organizations are run.

You may think that there is no way for you to influence or even meet the people making these decisions. However, because of the hard work of HIV advocates over the years, most agencies involved in HIV work now include representatives living with HIV. Many local and national HIV research networks, service organizations, and planning councils receive advice from people living with HIV through advisory groups that provide perspective on issues that are important to the HIV community.

The following is a list of groups you may want to consider joining. Participating in these groups can be rewarding, but it requires time and commitment. Before getting involved, it is important to find out what is expected of you.

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## Community Advisory Boards (CABs)

AIDS service organizations (ASOs), clinical research sites, and some health centers have CABs. Each type of CAB includes people living with HIV and, sometimes, other affected community members. Different types of CABs serve different functions. You can find out who serves on The Well Project's CAB [here](#) [5].

An ASO's CAB can provide valuable input from people living with HIV about the services the organization offers. Many CABs are very active. Others meet infrequently and have little impact on the direction of the agency. You can make a big difference in the effectiveness of an organization's CAB. Contact your local ASO to find out if it has a CAB and how to join.

Government-funded [clinical trials](#) [3] in the US are required to set up CABs to make sure that community interests concerning HIV research are heard at the local level. CAB members offer input about studies, get research results and up-to-date information about ongoing trials, advocate for participants in the trials, and help conduct outreach to sign people up for trials.

CABs can offer a great deal to the HIV community. You can also get a great deal personally from participating in a CAB. In addition to contributing to the community, you may make new friends, get a better idea of what the research project or service organization provides, and educate yourself so that you have more to offer if you look for a job. If you are not sure whether you have anything to offer the CAB, talk to people who are already CAB members. They may help you identify strengths that you are not aware of yourself.

## **HIV Planning Councils and HIV Care Consortia**

Depending on where you live in the US, you could get involved with either a local HIV planning council or HIV care consortium. HIV planning councils and care consortia are groups set up to guide how the US government funds from the [Ryan White Program](#) [6] are spent. Each planning council and care consortium works differently. Many consist of appointed members, while others have a more open membership. Members may include medical providers, public health officials, staff from community-based organizations, and people living with HIV. Even if you are not a member, you can speak before the council or consortium about the needs of your community.

HIV planning councils are located in urban areas with a high number of people living with HIV. They establish priorities for the distribution of government funding based on the services that are most needed by people living with HIV in the area. Planning council members attend full council meetings regularly and usually participate on at least one council committee. The time commitment varies from four to ten hours a month.

HIV care consortia are regional or statewide planning groups in more rural parts of the country. Their goal is to provide a broad-based community response to the HIV epidemic in the region and to ensure that high quality, comprehensive health and support services are available to people living with or affected by HIV.

Most consortia meet at least quarterly, and many members participate on at least one committee. The time commitment varies from one to five hours a month. Contact the appropriate council or consortium to find out about the application process. To locate Ryan White program grantees, click [here](#) [7] (note: Part A = planning councils/urban areas; Part B = care consortia/state programs).

## **Institutional Review Boards (IRBs)**

IRBs - also known as ethical review boards (ERBs) or independent ethics committees (IECs) - exist to protect participants in research studies and [clinical trials](#) [3]. They are made up of people like health care providers, lawyers, statisticians, researchers, clergy members, ethicists, community advocates, and others. Any hospital or research center in the US that conducts clinical or behavioral studies must have an IRB. All trials are reviewed and approved by the IRB before they begin. The IRB protects study participants by making sure trials are safe and ethical. The IRB can stop a trial that is not being run properly.

Many countries other than the US have ethics committees designed to oversee studies of human subjects and protect participants. The specific design and function of these committees or boards varies from country to country.

If you are interested in being a member of an IRB, be prepared to learn a lot and spend many hours reading trial designs, attending meetings, and talking with other IRB members. It is important that people living with HIV be involved in the IRB process so that other members and researchers hear your concerns and priorities. However, be aware that this is a big commitment. If you are new to community advocacy, an IRB is probably not the easiest way to get started.

To find out about IRB opportunities and application requirements, contact clinical trial sites where you live.

- To locate HIV clinical trial sites near you go to
  - [HIV Clinical Trials](#) <sup>[8]</sup> (CenterWatch)
  - [HIV/AIDS Clinical Trials](#) <sup>[9]</sup> (AIDSinfo.gov)
  - [HIV/AIDS Clinical Trials Network](#) <sup>[10]</sup> (NIH)

## Boards of Directors (BOD)

All not-for-profit ASOs have a BOD. The BOD is responsible for the agency legally and financially. It also sets policy, hires and fires the executive director, and makes sure that the organization is serving its chosen mission. If the BOD has few or no members living with HIV, it may be less in touch with the everyday concerns and challenges of the people it is meant to serve. You can find out who serves on The Well Project's BOD [here](#) <sup>[11]</sup>.

Since one of the main responsibilities of the BOD is the financial stability of the organization, many boards require members to give or raise a certain amount of money. Some BODs make exceptions so that they can include people who cannot meet the financial obligation but have other valuable things to offer.

Most BODs meet monthly or every other month for a couple of hours. Being a board member can require a commitment of two to four hours a month for meetings and other activities.

If you would like to be a member of the board of a local ASO, set up a meeting with the board's chairperson (sometime called the president) or the agency's executive director.

## Tips for Successful Advocacy

Community involvement is an important way of helping HIV groups serve their purpose. Being an advocate on a board or planning council can be very rewarding. It allows you to voice your opinions and stand up for what you feel is important to you and your community. However, it also adds extra responsibilities and takes up some of your time. The following tips may help you to balance your physical and emotional health with your advocacy efforts:

- Remember you and your health come first
- Think about what you would like to accomplish before joining a group
- Avoid taking on too many projects and limit yourself to only those you think you can see through
- Find people to work with who understand the issues and will support you in your efforts
- Try not to let disagreements become personal. Conflict is often a necessary part of any kind of advocacy, and you may meet resistance to your ideas. Try to stay focused on the

issue even if you feel you are being personally attacked.

- Learn from long-time advocates
- Think before you speak. It can be scary to speak up, especially the first time you disagree with someone in power. Assess how you might feel beforehand so that you are prepared.
- Recognize that you have a voice and ideas to add to the work that has gone before. At times, you may feel shut out by some people who have been involved in HIV advocacy for many years. Your experiences are valid.
- Be careful not to let advocacy become an opportunity to give yourself power over other people

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## Additional Resources

Select the links below for additional material related to community advocacy.

[Positive Women's Network USA](#) [23]

[HIV Prevention Trials Network \(HPTN\): Community Program](#) [24]

[Community Advisory Board Fact Sheet \(HPTN\)](#) [25]

[Center for Women and HIV Advocacy \(HIV Law Center\)](#) [26]

[Women's Resource Advocacy Connection \(Center for HIV Law & Policy\)](#) [27]

[The Toolkit: Women Taking Power Over HIV/AIDS \(The Women's Collective\)](#) [28]

[Peer Advocacy \(WORLD\)](#) [29]

[Youth Activism \(Advocates for Youth\)](#) [30]

[Make It Matter: 10 Key Advocacy Messages to Prevent HIV in Girls and Young Women \(UNFPA\)](#) [31]

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- [25] <https://www.hptn.org/sites/default/files/2016-05/Community%20Advisory%20Board%20Fact%20Sheet.pdf>
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