A Place at the Table: 
Having a Voice in HIV Planning and Decision Making

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Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime

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Your voice is important!

• What you have to say as a person living with HIV is valuable, and needs to be heard by those making decisions that affect the lives of people living with HIV, including:
  – How HIV funding is used
  – What HIV policies are put in place
  – How research studies such as clinical trials are conducted
  – How AIDS Service Organizations (ASOs) are run
Having a Voice in HIV Decision Making

• Because of the hard work of HIV advocates over the years, most agencies involved in HIV work now include people living with HIV
  – Local and national HIV research networks, service organizations, and planning councils get advice from people living with HIV on what’s important to the HIV community through advisory groups
• Information is mostly about US

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• ASOs, clinical research sites, and some health centers have CABs
• **Each type of CAB includes people living with HIV**
• An ASO's CAB can provide valuable comments from people living with HIV about the services the organization offers
• Some CABs are very active; others meet infrequently and have little effect
• Government-funded clinical trials in the US must set up CABs.

CAB members:
– Offer comments about studies
– Get research results and up-to-date information about ongoing trials
– Advocate for study participants; help sign people up
Community Advisory Boards (CABs)

- Participating in a CAB can also help you:
  - Make new friends
  - Get a better idea of what the project or organization provides
  - Educate yourself so that you have more to offer if you look for a job

- If you’re 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 didn’t know you had!

- Contact your local ASO to find out if it has a CAB and how you can join

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HIV Planning Councils and HIV Care Consortia

- US-specific
- Guide spending of money from US Ryan White Program
- Some appoint members; others have 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 present about the needs of your community to the council or consortium
- *Locate a planning council or care consortium:* This site lists all programs receiving Ryan White funding: [https://careacttarget.org/grants-map/all](https://careacttarget.org/grants-map/all)
- Contact local council or consortium to find out about the application process

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HIV Planning Councils

- Located in urban areas with a large number of people living with HIV
- Set priorities for distribution of government funding based on services most needed by local people living with HIV
- Members attend full council meetings regularly and usually participate on at least one council committee
- *Time commitment: 4-10 hours/month*

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HIV Care Consortia

• Regional or statewide planning groups in more rural areas
• Provide a broad-based community response to the HIV epidemic in their region
• Ensure that high-quality, comprehensive health, support services are available to people living with or affected by HIV
• Meet at least every three months; many members participate on at least 1 committee
• *Time commitment: 1-5 hours/month*
Institutional Review Boards (IRBs)

IRBs are also known as Ethical Review Boards (ERBs) or Independent Ethics Committees (IECs)

- Exist internationally
- Protect study participants by making sure trials are safe and ethical – an IRB can stop a trial that is not run properly
  - Made up of health care providers, lawyers, statisticians, researchers, clergy members, ethicists, community advocates, others
  - All US research hospitals or centers conducting studies must have IRBs
  - All trials are reviewed and approved by the IRB before they begin
- Other countries also have ethics committees
  - Design and function vary by country

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Institutional Review Boards (IRBs)

- As a member of an IRB, be prepared to:
  - Spend many hours reading trial designs, attending meetings, talking with other IRB members
  - It is important that people living with HIV be involved in IRBs; other members and researchers need to hear your concerns and priorities
  - *Time commitment: big.* An IRB is probably not the easiest way to get started in community advocacy, but it is an excellent way to learn a *lot!*

- 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:
  - CenterWatch (worldwide)
  - HIV/AIDS Clinical Trials Network (US only)

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Boards of Directors (BOD)

- All not-for-profit ASOs have a Board of Directors (BOD)
  - Legal and financial responsibility for organization
  - Sets policy, hires and fires the executive director
  - Makes sure the organization is serving its chosen mission
  - *Time commitment: 2-4 hours/month – meetings, activities*

- Many boards require members to give or raise a certain amount of money
  - Some BODs make exceptions so that they can include people who have valuable things to offer but cannot help raise money
  - If you would like to join the board of a local ASO, set up a meeting with the board's chairperson (sometimes called the president) or the organization's executive director

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Tips for Successful Advocacy

• Community involvement is an important way of helping HIV groups serve their purpose
• Being an advocate on a board/planning council can be very rewarding
  – It allows you to give your opinion 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
Tips for Successful Advocacy

• Tips to help balance your physical and emotional health with your advocacy efforts:
  – *Remember, you and your health come first*
  – Think about what you want to achieve before joining a group
  – Limit yourself to only those projects you can complete
  – Work with people who understand the issues and support your efforts
  – Try not to let disagreements become personal
  – Learn from long-time advocates
  – Think before you speak!
  – Do not let advocacy help to give yourself power over other people
  – Recognize that you have a voice. *Your experiences are valid!*
  – Try to get people with diverse experiences onto the board or council
To learn more about these topics, please read the full fact sheets:

- How to Be an Advocate for Yourself and Others
- A Place at the Table: Having a Voice in HIV Planning and Decision Making
- Stress Management

For more fact sheets and to connect to our community of women living with HIV, visit:

- [www.thewellproject.org](http://www.thewellproject.org)
- [www.facebook.com/thewellproject](http://www.facebook.com/thewellproject)
- [www.twitter.com/thewellproject](http://www.twitter.com/thewellproject)