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   #thewellproject
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
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.
Community Advisory Boards (CABs)

- 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

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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
HIV Planning Councils and HIV Care Consortia

- US-specific
- Guide spending of US government funds from 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 appropriate 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*
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
- Many other countries also have ethics committees to protect study participants
  - Design and function of committees 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
  – HIV/AIDS Clinical Trials Network (NIH)
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
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!
  – Be careful not to let advocacy become an opportunity to give yourself power over other people
  – Recognize that you have a voice and ideas to add to the work that has gone before. *Your experiences are valid!*

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• 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
  – www.facebook.com/thewellproject
  – www.twitter.com/thewellproject