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

Last updated: January 14, 2019

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 impact the lives of people with HIV, including:
  – How HIV funding is used
  – What HIV policies are put in place
  – How research studies like 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 representatives living with HIV
  - Local and national HIV research networks, service organizations, and planning councils get advice from people with HIV on what’s important to the HIV community through advisory groups
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 input from people living with HIV about the services the organization offers.
- Some CABs are very active; others meet infrequently and have little impact.
- Government-funded clinical trials in the US are required to set up CABs. CAB members:
  - Offer input into studies.
  - Get research results and up-to-date information about ongoing trials.
  - Advocate for study participants; help conduct outreach to 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 are not aware of yourself!

• Contact your local ASO to find out if it has a CAB and how to join

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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 high number of people living with HIV
• Establish 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 the region
- Ensure that high-quality, comprehensive health, support services are available to people with or affected by HIV
- Meet at least quarterly; 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 being 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 varies by country
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 HIV clinical trial sites where you live; to
  locate HIV clinical trial sites near you, go to:
  – HIV Clinical Trials (CenterWatch)
  – HIV/AIDS Clinical Trials (AIDSinfo.gov)
  – HIV/AIDS Clinical Trials Network (NIH)
Boards of Directors (BOD)

• All not-for-profit ASOs have a Board of Directors (BOD)
  – Responsible for the agency legally and financially
  – 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 meet the financial obligation
  – 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

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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 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**
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 accomplish 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 about issues 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