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

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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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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: more information and skills if you are looking 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*
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*
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
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](http://www.centerwatch.com) (worldwide)
  – [HIV/AIDS Clinical Trials Networks](http://www.aidsclinicaltrials.gov) (US only)
• 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 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 to 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:

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- www.facebook.com/thewellproject
- www.twitter.com/thewellproject
- www.instagram.com/thewellprojecthiv