



AIDS RESEARCH Community Handbook

Tools for HIV/AIDS Treatment & Prevention Research Advocates

Getting Started: Being a Community Advocate

The following was originally collected by Julie Davids for Project TEACH, with help from Charles Nelson, Kiyoshi Kuromiya, and Jane Shull.

1. It is important that you are doing this: Serving as a community representative is hard work. Other people have more experience than you, and may know more about the topic or the unspoken rules of meetings and power. But you are an expert about your life and your community, and you can learn everything else. It can be scary to speak up, especially the first time you disagree with a powerful person. Remember that you are doing the right thing and speaking the truth, and you need to be heard. No one was born knowing how to do this, and it will get easier. It is a challenge and you will have to take risks, but it will also teach you about yourself and help people have longer and better lives.

2. Pick an issue or an organization to focus on -- and follow it wherever it goes. No one can know everything, or do everything. Whether you are interested in tuberculosis, or TPAC, or teenagers with HIV, read all you can or ask people who know the most about the issues. Then start going to meetings where decisions are made that affect peoples' lives. You will become the expert and feel more comfortable speaking up.

3. Don't get isolated: It is usually a good idea to avoid being the one person living with HIV (or community advocate) on a committee or panel. Demand that there are at least two, and ask to help select the other person or people -- then meet ahead of time and between meetings to plan strategy. Get a list of who else is on the committee, before you go to a meeting, and ask around about the other people. If you hear good things about someone, call up and introduce yourself and ask any questions you may have. Don't judge people by their title or position, but by their reputation and your experiences with them. Some researchers or bureaucrats will give you good information and explain things clearly. Some "community members" may not be trustworthy or share your beliefs and goals.

An affinity group is a group of people who work together on a certain issue. You could form an affinity group to support you on this committee -- even if the other people are not on this committee -- as they may have access to information and could help you figure out what to do. A support person can be someone who will really stick with you, help you keep track of the process and your role in it, and let you complain. It should be someone you like and trust, and can be someone who has been in your position or a similar situation.

Make contacts, and use them. Once you have found good people on your committee, or in the outside world who know about the issues, talk to them often. If you have a question about a term or idea that comes up in a meeting or on a conference call, and you do not feel comfortable asking about it right away, write it down and ask it later.

4. Do your homework: If you are sent information before a meeting, read it or find someone to help you go through it. Write down any comments or questions or anything that seems strange. If you need more background information on the topic, call an expert or ask someone who has been in your position before. Sometimes you will be sent too much information, and your contacts can help you decide what is important.

Other homework includes thinking about what is likely to happen at the meetings. What might you have to speak up about? What will you say? How will others respond? What are arguments against your position, and how will you take them on? Discuss this with your contacts and others who are working on the issues, or who have worked with the people on your committee before!

5. Don't try to do everything: You cannot be on every committee and board and do a good job. Share the load with your peers - - if they are new to this, make sure they fight for training and support them as they learn and grow. Know your limits, and do not spread yourself too thin!