


ADVOCATING WITH PROVIDERS*

▶ ABOUT THIS ACTIVITY

 **Time:** 35 minutes

 **Objectives:** By the end of this session, participants will be able to:

- Describe problems clients have with their healthcare providers.
- Describe ways peers can help their clients advocate for themselves with their health care providers.

 **Training Methods:** Brainstorm, large group discussion

 **In This Activity You Will...**

- Ask participants to brainstorm a list of difficulties in communicating with providers for themselves or for clients. (5 minutes)
- Divide up the list and ask the groups to come up with solutions. (20 minutes)
- Discuss the solutions. (10 minutes)

 **Materials:**

- Flip chart
- Markers
- Handout –Working with Healthcare Providers
- Handout – Health Care Providers Don't Receive Any More Training
- Handout – Solutions to Dealing with Physicians or Health Care Providers
- Cheat Sheet - Problems Clients May Have with Physicians or Health Care Providers

 **Preparation:**

- Prepare handouts

Instructions

1. Introduce this session on patient advocacy. Ask participants what advocacy means to them.
2. Acknowledge that advocacy can take several forms, but that it is basically about speaking up in order to make positive change happen. In today's session, we'll be focusing on helping our clients to advocate for themselves with their doctors and other health care providers. Remind participants that these skills are also useful for them.
3. Brainstorm: What problems do you or your clients have with your doctors or other health care professionals? On flip chart paper, record participants' responses. Refer to Working with Health Care Providers if needed.
4. Next, ask participants to brainstorm possible solutions to each problem they came up with. Designate a fresh flip chart page for each "problem" and record participant responses. (Some "problems" that came up during the brainstorm may be similar and can be grouped together on the "solutions" sheets.)
5. Distribute handout and review any items that have not been discussed.
6. Ask if participants can see how they would use any of the suggestions, and if so, which ones.
7. Hand out a list of suggestions developed by AIDS Community Research Initiative of America's (ACRIA) on how HIV infected patients can advocate for themselves with their health care providers. Acknowledge that most, if not all, of these have already come up in today's discussion.

* This module comes from the Comprehensive Peer Worker Training, Peer Advanced Competency Training (PACT) Project Harlem Hospital Center, Division of Infectious Diseases, 2008.

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▶ TRAINING TIP

Link the concept of advocating with providers to other areas where peers need the same skills such as assisting clients that they work with and when working on a multidisciplinary team. Also draw a link with their personal lives. Acknowledge that this is difficult for every one and that these suggestions might need to be implemented gradually

Summary

Wrap up session.

Sources: The Chronic Disease Self-Management Workshop: Leaders Manual, Stanford University, 1999 and AIDS Community Research Initiative of America (ACRIA) Update, Winter 2004/05

* This module is part of the online toolkit Building Blocks to Peer Success. For more information, visit http://www.hdwg.org/peer_center/training_toolkit. This module comes from the Comprehensive Peer Worker Training, Peer Advanced Competency Training (PACT) Project Harlem Hospital Center, Division of Infectious Diseases, 2008.

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SESSION HANDOUT # 1 of 3

WORKING WITH HEALTH CARE PROVIDERS

So – What's the First Step?

- Get involved with your care!

Educate Yourself

- Through treatment newsletters.
- Through the internet
Learn how to use the internet and find places where you can go online – your AIDS service organization, the library, etc.
- Get subscriptions to treatment magazines and newsletters – most are free!
- Go to your local AIDS service organization and talk to the treatment specialist or enroll in a treatment education program.
- Talk to other HIV-positive people who are going through some of the same things that you are.

What to Think About when Choosing a Doctor or Other Health Care Provider

- Does the provider have at least two years of HIV experience?
- Do they keep up to date? Do they read journals, attend conferences and seminars, and receive other HIV-related medical education?
- Is the provider sensitive to your particular issues – drug use, gender, sexual orientation, religious or spiritual beliefs?

It's Your First Visit – Bring Your Medical History

- If you can get your records from your previous provider, it makes things easier.
- You have a legal right to copies of all your medical records.
- Keep a copy of all your records.

Take Some Time Before Seeing the Provider

- Make a list of everything you'd like to ask about. This way, you won't forget the important things or the little things that have been bugging you.
- You probably won't get the chance to ask everything, but think of it as a wish list.

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SESSION HANDOUT # 1 of 3 (cont.)

WORKING WITH HEALTH CARE PROVIDERS (CONT.)

- Check off five things that you really want to ask about, so that you're sure to get to them. Things like:
 1. New symptoms or recent sicknesses you may have had.
 2. Medicines, natural or over-the-counter remedies, or vitamins you are taking
 3. Any life changes, like changes in your diet, where you are living, your job, or how busy or active you have been.
 4. Let your provider know about any emergency room visits.
 5. Questions you have about your medicines or new medicines you have heard about.

Stop Your Provider the Moment You Don't Understand Something

- Lots of times, things snowball – the provider starts saying something and you are not really sure what it's about. But you're a nice person, so you nod, and the provider keeps talking, and suddenly you realize that you really don't know what they're talking about at all.

Take Notes

- If you find it hard to listen or hear what your provider says (and who doesn't?), bring paper and pen to write things down.
- Keep notes of the important points of your visit.
- You can bring a friend or family member to help you remember what the healthcare provider said. You can even bring a tape recorder (although the tape recorder might make the provider nervous).
- Ask your provider to write treatments or instructions down on paper.

Ask About Your Medicines

- What is the name and purpose of the medicine?
- Will there be any interactions with any other medicines you are taking?
- What is the dosage of the drug and how often should it be taken?
- Are there any foods you have to take with the medicines?
- What are the possible side effects? And how can you deal with them if you get them?
- Is there written material about the drug that you can take home with you?

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SESSION HANDOUT # 1 of 3 (cont.)

WORKING WITH HEALTH CARE PROVIDERS (CONT.)

Communication Skills/Conflict Resolution

- **Open Up:** Don't feel embarrassed about bringing up sensitive health issues. If your provider makes you feel uncomfortable when you discuss your lifestyle or a particular issue, you may need to find another provider.
- **Be Honest:** Don't be tempted to tell your providers what they want to hear – for example, that you are taking your medications regularly and in the correct way when you're really not.

What to Do When Your Provider Isn't Available

- If your doctor isn't in when you call, you can often get help from the nurse, physician's assistant (PA), or someone else who works there. That's one reason why it's good to know the names of everyone on the medical team.
- If it's a serious problem and you must speak with your doctor, be clear that you will be waiting for a return call – and be sure to be available at the number that you leave.

Source: AIDS Community Research Initiative of America (ACRIA) Update, Winter 2004/05 – Vol. 14, No. 1

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SESSION HANDOUT # 2 of 3

HEALTH CARE PROVIDERS DON'T RECEIVE ANY MORE TRAINING THAN THE REST OF US IN HOW TO BE HUMAN BEINGS

- Some are kind, some aren't so smart, some are malicious, and some are really great people.
- They may be nervous and hate that they sometimes don't really know what to do.
- They hate that they don't have a cure to offer you.
- They rarely try to cause harm.
- They're often overwhelmed, but rarely admit it. They carry their arrogance mostly to protect themselves, not to hurt you.
- As in any other relationship, calling them on their stuff can sometimes help communication.
- If it's not working, move on if you can!
- Never forget that the healthcare provider works for you. It's your body, your health, your blood tests, your HIV. You are paying the provider's rent for her every time you walk in the door.

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SESSION HANDOUT # 3 of 3

SOLUTIONS TO DEALING WITH PHYSICIANS OR HEALTH CARE PROVIDERS

Ask questions especially for jargon/ technical terms

Be comfortable

Don't be embarrassed

Follow-up

Resources – 101 and websites

There are no stupid questions

Non- medical solutions to side effects

Need to respect peer knowledge/pay attention to peer

Use other resources/references

Document and keep copies

Tell them to use accessible language

Don't talk down

Ask provider to give more information instead of just a prescription

Explain the benefits versus risks of medications and procedures

Communicate with other providers

Provide more information about toxic medications

View peers as individuals

Make self heard and ask why

Listen

Realize consequences

Go to same-sex physician if you prefer

Be truthful/blunt and to the point

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SESSION TRAINER CHEAT SHEET

PROBLEMS CLIENTS MAY HAVE WITH PHYSICIANS OR HEALTH CARE PROVIDERS

Speaking to doctors about side effects and damages

Doctors may not pay attention to the role of a peer worker

Uncomfortable speaking about sexual issues

Not enough time

Compatibility with patient they are working with

Dealing with over-worked physicians

Different language/jargon/technical terms

Not getting respect