

Continuing Education for Peers and Supervisors: Disclosure May 3, 2010

PEER Center
Peer Education & Evaluation Resource Center



Boston University School of Public Health



Minority AIDS Initiative/HRSA: Peer Education Training Sites & Resource Evaluation Center

- To improve HIV-related health outcomes for communities of color and reduce health disparities through HIV peer education by:
 - Training HIV peer educators on HIV care, treatment and support
 - Replicating successful peer education programs through training of trainers
 - Building capacity in existing HIV/AIDS peer programs or in organizations developing a peer program

People to People
MO Alliance: American Red Cross- St. Louis Chapter

Kansas City Free Health Clinic



PEER Center,
Boston University
Boston, MA
PEER Center
Peer Education & Evaluation Resource Center

PACT Project
Harlem Hospital
New York, NY



Lotus Project
Center for Health Training
WORLD
Oakland, CA

RI
CT
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Agenda

- Welcome – Sally Neville



- Helping clients with disclosure –
Alicia Downes



- Supporting peers in disclosing to clients –
LaTrischa Miles



- Role of the Supervisor – Janie Riley



- Questions & Discussion
- Evaluation

Disclosure

- Disclosure of HIV status is a difficult decision for peers and clients.
- Risks/Benefits
- Impact on others
- Impact on self

Objectives

- Identify risks and benefits of disclosure for self and clients
- Develop strategies to assist clients in weighing the risks and benefits of disclosure
- Develop strategies to support clients through the disclosure process
- Utilize resources to support self through disclosure to clients, family, co-workers, community

Poll Question: Are you a peer, supervisor or program administrator?

- *Are you a peer, a supervisor of peers, program administrator?*

Disclosure is a Continuum

- Self-disclosure: reveal something about ourselves that is not readily apparent
- Decisions to self-disclose vary with circumstances
- Outcome of self-disclosure varies as well

Benefits of Disclosure

- Encourages a person to be open to receive trusted support from others
- Reduces anxiety, fear and worry
- Helps a person feel better about themselves
- Helps a person be more authentic with people they trust
- Decreases the need to be secretive (e.g., hiding medications), enabling them to receive support for adherence

Benefits of Disclosure

- Helps reduce stigma associated with HIV
- Fosters community with others who are HIV+
- Reduces mental stress
- Adheres to Legal Disclosure laws for some states (e.g. CA, MO)

Poll Question: your experience with disclosing your status

- *In general, my experience in disclosing my status has been:*
 - 1) *Positive*
 - 2) *Negative*
 - 3) *Neutral*

General Guidelines for Telling Others You Are HIV Positive

- Disclosure is personal and private; it is a choice.
- Know why you want to disclose
 - What do you want from them?
- Anticipate the person's reaction
- What's the best you can hope for?
- What's the worst you might have to deal with?

General Guidelines for Telling Others You Are HIV Positive

- Prepare – get informed about HIV disease.
- Leave resources (i.e., articles or a hotline phone number) for the person you tell.
- Get support.
- Talk it over with someone you trust, and come up with a plan.
- Accept the reaction.
- You can't control how others will deal with your news.

Source thebody.com

Peer Educator's Disclosure to Clients

- There is no perfect roadmap for how to disclose to clients.
- Peers must feel comfortable with their own HIV diagnosis before disclosing to clients.
- Reasons why a peer should disclose:
 - To help establish a connection/bond to advance peer goals to provide emotional, practical support and treatment education
 - To explain confidentiality to the client in regards to HIPAA laws and remind the client in turn to respect your privacy.

Peer Educators and Self-Care

- Supporting and coaching clients in the area of disclosure can be stressful for peers.
- Clients may have strong feelings that come up.
- Peers may feel pressure (*from themselves or the client*) to give advice, and in turn, feel frustrated when clients don't follow through.

Peer Educators and Self-Care

- Go at the client's pace and know your limits.
- Set beginning and ending times when meeting with clients to help hold your boundaries.
- Remember that disclosure is a decision for your client to make; not you.

Poll Question: Your confidence level in supporting clients' disclosure decisions

- How confident are you in your ability to support (assist, help) clients in making decisions to disclose?

1. Very confident

2. Confident

3. Somewhat confident

4. Not confident

Considerations for Peer Educators as They Work with Clients around Disclosure

- Peers can help clients consider why they want to self-disclose.
- Encourage clients to arrange a comfortable, appropriate time and place for the discussion.
- Clients may anticipate how the support person might react to their self-disclosure.
- Encourage clients to ask for what they want and do not want from the person they are self-disclosing to.

Considerations for Peer Educators as They Work with Clients around Disclosure

- Clients may want to decide if they want the person to whom they are disclosing to do any or all of the following during the discussion:
 - to give advice
 - ask questions about living with HIV or
 - just listen and not ask questions
- Peer educators may share their own story of self-disclosure.

Poll Question: How can a peer help this client?

- A client is struggling with disclosure to children, how can a peer help?
 - A. Convince the client to only tell older children
 - B. Role-play different scenarios with the client
 - C. Tell the client to consult a therapist first
 - D. Advise the client to be open, honest, only answering questions asked

Tips for Peers who Help Clients Disclose

- Be there to support the client at time of disclosure
- Give a sense of hope – share your story or give facts
- Answer questions and dispel myths
- Provide facts about HIV/AIDS – educate
- Offer to connect with resources
- Offer to follow up by phone in a couple weeks
- Know the laws in your state and document the disclosure visit with the client

Tips for Peer Educators to Help Clients Disclose

- Remember that clients may go back and forth in their decision making, and that is no reflection on you as a peer.
- Use your supervisor as a sounding board.
- To relieve stress, talk with your supervisor and other supportive co-workers about your feelings.
- Keep in mind: Burnout, over-commitment and extending yourself beyond what is expected does not provide balance.

Questions so far?

- We will take any questions from participants before moving on to the role of the supervisor

Poll Question:

How might your supervisor help?

- You are a peer and your client has not disclosed to his or her partner with whom he or she has been having unprotected sex. You have been supporting the client to disclose and the client hasn't.
- *How might your supervisor help?*

Answers: How might your supervisor help?

Answers

- A. Demand that you have your client disclose to the partner immediately.
- B. Tell you exactly how you should handle the situation and hold you to it.
- C. Give you a chance to express your feelings and worries, and brainstorm to approach the situation.
- D. Encourage you to work harder for the client and meet with her as often as possible.

How can supervisors help?

Supervisors may:

- Assist peers in determining what to disclose to clients.
- Help peers use disclosure as a tool to help clients,
- Introduce models to define disclosure process.
- Help peers address feelings that arise when helping clients disclose their HIV status
- Support peers in balancing dual role (peer/helper).

Peers may:

- Ask supervisors for assistance.
- Have a different opinion and share it.

Tips for Supporting Peers' Disclosure

- Encourage and support peers to consider their boundaries and what feels comfortable to them.
- Widen definition of disclosure to include any personal information shared.
- Support peers in telling their stories to clients while also respecting clients' unique situations.

Supporting Peers' Ongoing Use of Disclosure

- Clients are usually inspired and motivated by peers' stories.
- In the course of a demanding work schedule, peers may lose sight of the power of disclosure and its profound effects.
- Supervisors can remind peers to consider telling their own stories as a way to help.

How Models Can Help

- While models are not definitive, they can act as road maps for peers and/or clients.
- Models can normalize the process of disclosure.
- They can also help peers regain patience with clients who are finding disclosure to be difficult.

Stages of Change & Disclosure

- Pre-contemplation: Not even thinking of disclosing (or not disclosing).
- Contemplation: Considering disclosure.
- Preparation: Beginning to think, talk about and plan how to disclose.
- Action: Disclosing to one or more people.
- Maintenance: Maintaining relationships within context of disclosure.
- Reconsidering (Relapse): May review disclosure choices and consider new ones.

HIV, Grief and Disclosure

- Disclosure can be more difficult if a peer and/or client has not gone through a grief process related to change in health status.
- Stages of grief can help peers or clients identify where they are in the process.
- Peers can teach the stages to clients and/or use it to empathize with clients.

Grief Stages/HIV

- Shock/Denial/Unreality
 - Fear and/or Bargaining
 - Anger and/or Shame
 - Depression and/or Sadness
 - Acceptance (esp. Self-Acceptance)
 - Finding Meaning/Rediscovering Purpose
- (Disclosure issues come up in all stages)*

Countertransference and Disclosure

- Peers cannot do this work and not be affected.
- Peers may experience intense feelings towards clients with disclosure-related issues.
- Peers may have a bias towards disclosing.
- Identifying feelings and beliefs in supervision can help peers “meet clients where they are at.”

Suggested Strategies for Supporting Peers

- Hold weekly or bi-weekly supervision (Coaching)
- Have team discussions about disclosure
- Role-play different scenarios
- Encourage participation on speakers bureau
- Suggest other professional trainings in the community

Ways to Help Peers with Self-Care

- Train peers on countertransference
- Provide a go-to person peers can talk to when you are not available
- What should the peer do when under stress?
 - Seek supervision or support from other peers
 - Seek counseling when needed
 - Journal
 - Take time off
 - Don't isolate yourself; talk about your feelings

Public Disclosure: How Supervisors Can Help

- Check in with peers about their readiness for public disclosure.
- Raise awareness about both the positive and potentially negative emotional effects of public disclosure.
- Give peers a place to talk about feelings; normalize and provide helpful feedback.
- Discuss different forms of public disclosure--ie., media, internet, print media.

Lessons Learned

- Many HIV+ persons feel a need to tell their story.
- They also benefit from hearing other people's stories.
- Talking to each other about disclosure provides a forum in which change feels possible for them.

Lessons Learned

- Disclosing allows HIV+ persons to share their experience with others.

Poll Question: Your confidence level in supporting clients' disclosure decisions

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Resources about disclosure

Core Competencies: Peer Role | PEER Center - Windows Internet Explorer

http://peer.hdwg.org/training_toolkit/peer_role

File Edit View Favorites Tools Help

PEER Core Competencies: Peer Role | PEER Center

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Peers in action

Core Competencies: Peer Role

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Building Blocks to Peer Success

The modules below go into depth about the many different aspects of a peer's role. Portions of this training must be adapted for local conditions: navigating the health care system, confidentiality, the peer job descriptions and employee benefits. Several training programs use local provider panels to describe the services they offer. This needs to be supplemented with a discussion about how peers find out about other local resources. The confidentiality training modules should be supplemented with information about specific state laws. Job descriptions and benefits discussions should also reflect local conditions.

- What is a Peer?
- Workplace Issues
- Stages of Change
- Disclosure**
 - Disclosure Benefits and Risks
 - Disclosure and Stigma Fishbowl
 - Peer Disclosure
 - Supporting Our Clients Through Disclosure

Internet 100%

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Lesson plan modules on disclosure on PEER Center website



☐ Disclosure

- Disclosure Benefits and Risks
- Disclosure and Stigma Fishbowl
- Peer Disclosure
- Supporting Our Clients Through Disclosure

☐ Multidisciplinary Team

☐ Navigating the System

☐ Self-Care

☐ Are You Ready to Be a Peer?

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http://peer.hdwg.org/training_toolkit/peer_role

Resources

Websites:

- PEER Center: <http://peer.hdwg.org>
- Kansas City Free Health Clinic: <http://www.kcfree.org>
- PACT project Harlem Hospital: <http://www.peernyc.org>
- WORLD: <http://www.womenhiv.org>
- **TARGET Center:** <http://careacttarget.org/>

Thank you!

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