


DISCLOSURE AND STIGMA FISHBOWL*

▶ ABOUT THIS ACTIVITY

 **Time:** 120 minutes

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

- Discuss HIV disclosure basics;
- Understand that everyone has a unique experience with disclosure;
- Identify the benefits of, and barriers to, disclosure.

 **Training Methods:** Large Group Activity

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

- Introduce the fishbowl activity and explain the rules (15 minutes)
- Tell a disclosure story (5 minutes)
- Facilitate the fishbowl activity (60 minutes - more or less depending on the size of the group)
- Debrief the activity with the group (30 minutes)
- Lead the group in a closing circle activity (10 minutes)

 **Materials:**

- Newsprint, markers
- Chairs
- Flipchart
- Lollipops
- Timer
- Kleenex

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Instructions

1. Introduce activity, by making the following points.
 - a. We are going to have a discussion about disclosure and how it can impact the work that peers do in the community. We are going to do a fishbowl. Has anyone ever done a fishbowl before? In a fishbowl discussion, we have two groups. One group will come inside the circle and sit facing the rest of circle and answer three questions.
 - b. Then we will switch groups and ask the same questions.
 - c. The group that is on the outside of the circle must only listen; let's practice our listening skills, no question, no comments. We've got some lollipops for you, in case you feel the urge to say something!
2. We want to remember our ground rules we have established. This can be an emotional topic and we all have many stories to tell. We want to encourage you to tell the piece of your story related to disclosure, not your whole story. Tears are fine, we've got Kleenex. We want to hear from everyone that would like to speak, so please keep that in mind as you answer questions. When you are talking, you will have a timer. The timer will be set for 2 minutes and when it goes off your turn is up and the next person will give her response to the question. Let's do our best to be respectful and compassionate to each other, recognizing that we all come from a different place with different experiences.
3. Disclosure Meter/Role Model- Go over the disclosure meter with the group. Ask everyone to think about where they feel most comfortable on the meter. As they are thinking about this, tell a story of disclosure for yourself.
4. Fishbowl Activity

* This module comes from the Lotus Women's Peer Education Training Manual, Center for Health Training and Women Organized to Respond to Life Threatening Diseases (WORLD), 2008.

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ABOUT THIS ACTIVITY(CONT.)

Materials (cont.):

- Candles
- CD player
- CD of Christina Aguilera's song "Beautiful" or other song for mixed group.
- Handout - Telling
- Handout - HIV and Disclosure
- Handout - Who Needs To Know You Are HIV+
- Handout - Disclosing to Loved Ones

Note: Handouts are optional and are not required to complete this activity.

Preparation:

- Write the following on flipchart:
Disclosure Meter: How comfortable are you with disclosing your HIV status?
1-NOT AT ALL COMFORTABLE - I will not tell anybody.
2-A LITTLE COMFORTABLE - I will tell a couple of people.
3-GETTING MORE COMFORTABLE- I will tell my family and friends.
4-VERY COMFORTABLE- I disclose to everyone, my family/friends, and I am on TV, newspapers, posters, etc.
- Arrange chairs in a large circle. Ask everyone to take a seat. Put some chairs inside the large circle facing out.

Tips for successfully implementing Fishbowl

- Repeat the question when asking each participant-to keep them on track.
- Rephrase what they say to the group-this helps move the discussion along and also have them reflect on what they are saying. It also helps other participants that are listening.
- Be present, but don't get emotionally engaged. Your role is to facilitate and move the discussion forward.
- Sit with the inside group when asking questions or you can stand outside the outer circle.
- Keep Kleenex in the middle
- Have popsicles or something for the outer circle participants to suck on while they are listening. This helps them to resist the urge to talk.
- Be compassionately firm with time, having each person who speaks hold some kind of timer or use soft chimes.

First group

- Ask those who rated themselves 1-2's to come inside the circle and face outwards towards the outer circle.
- Ask the following questions to the group.
What do you want people in the other group to know about you?
Why are you a 1 or 2?
How do you feel about being a 1 or 2?
What is one thing hard about being a 1 or 2?
What is one thing easy about being a 1 or 2?

Second group

- Ask those who are 3-4's to come inside the circle.
- Ask the following questions to the group.
What do you want people in the other group to know about you?
Why are you a 3 or 4?
How do you feel about being a 3 or 4?
What is one thing hard about being a 3 or 4?
What is one thing easy about being a 3 or 4?

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▶ TRAINING TIP

The instructions for the song are for a women-only group; if a mixed gender group is present select another song if appropriate.

5. Lead the group in a discussion using the following questions:

- What did you learn about yourself?
- What did you learn from the other group?
- What was it like to just listen?
- What was it like to talk and to just be listened to?
- What role do women living with HIV play in fighting stigma?
- How does this role relate to your own comfort level with disclosure?

6. Lead group in closing circle activity, as follows:

- Ask group for any closing comments or question. Thank group for being open and compassionate with others.
- Have the group stand together in a circle. Play the song “Beautiful” by Christina Aguilera while having women lighting candles.
- Facilitator will start by lighting one candle (symbolizing she is lighting a candle for her life) and using that candle to light another candle. Then she can blow out one of the candles (symbolizing that she is blowing it out for stigma).
- Pass the candles to the next person (one lit candle and one unlit candle). Participant will follow the steps as above.
- Pass the candles around the whole circle.

Summary

Wrap up by again thanking everyone for their respect, compassion and participation. Acknowledge that this is a very challenging issue and there is no perfect place to be; it depends on our own personal experiences, situations, and resources, and can change, as those other conditions change. Point out the handouts that they can use to continue exploring their feelings and thoughts about disclosing.

* 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 Lotus Women’s Peer Education Training Manual, Center for Health Training and Women Organized to Respond to Life Threatening Diseases (WORLD), 2008.

DISCLOSURE AND STIGMA FISHBOWL

SESSION HANDOUT # 1 of 4

TELLING

1. A good experience that I had with telling someone else that I living with HIV...
2. A not-so-good experience that I had with telling someone else that I living with HIV...
3. One thing I do well when deciding who to tell is...
4. One thing I will change about disclosing my HIV status in the future is...

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SESSION HANDOUT # 2 of 4

HIV & DISCLOSURE

Preparing for Disclosure

“Disclosure” means telling someone that you are HIV+. Who to tell about your HIV status and how to tell them can be a very complex and personal decision.

There is no one best way to tell someone, just as there is no sure way to gauge their reaction to your news. But it will help to ask yourself a few questions before disclosing:

1. Who do I want to tell and why do I want them to know?
2. How much am I ready to share or are they ready to hear?
3. How will disclosing my HIV status affect me and how will it affect the people around me?
4. Think about the people you rely on for support, like family, friends, or coworkers.
5. Figure out your relationship with each of these people and the advantages and disadvantages of telling them.
6. Determine any issues the person might have that will affect how much he or she can support you. For example, does the person have any health problems of her own? Can you trust her?
7. Look at the person’s attitude and knowledge about HIV. Do they have fears or preconceived ideas about HIV?
8. Think about why you’d want to disclose to this person. What kind of support can this person provide?
9. For each person, decide if the person should be told now, later, or to wait and see.

Deciding who to tell may take a short time or a long time.

There is no right way to do this.

It is a very personal decision that only you can make.

Julianne Serovich, PhD, Professor, Marriage and Family Therapy

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SESSION HANDOUT # 3 of 4

WHO NEEDS TO KNOW YOU ARE HIV+

You do not have to tell everyone that you are HIV+. You should tell people that you may have exposed to HIV so that they can be tested and seek medical attention if required.

These people could be sexual contacts or people with whom you have shared needles. If you do not want to tell them yourself, The Department of Health can inform your contacts without even using your name.

In about 27 states, the law requires that you disclose your HIV status before knowingly exposing or transmitting HIV to someone else. Penalties vary from state to state.

You need to tell your doctors and other healthcare providers to ensure you receive appropriate care. Your doctor also needs to know how you were infected to determine if are at risk for other diseases, such as hepatitis C for injection drug users and other sexually transmitted diseases for women infected through sex.

Who Does Not Need to Know

You do not have to tell your employer that you are HIV+. If you do tell, remember that, as long as you are performing your job, your employer cannot legally discriminate against you. People with disabilities, including HIV, are protected from job discrimination under the Americans with Disabilities Act (ADA).

Who You May Want to Tell

Women often choose to disclose their status to close friends and family. For many, telling those closest to them provides them with both emotional and practical support.

Some people decide to become more public and use their stories to advocate for others with government or media. Others may disclose for educational purposes to neighbors, community and religious groups, schools, other HIV+ people, or healthcare providers.

Many women find a sense of purpose and increased self-esteem by telling their story.

You may want to consider how much of your story you are ready to tell. Many people will ask you how you became infected. If you decide not to share that information, have a reply ready such as, “does it really matter?” or simply state that you are not ready to talk about that.

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SESSION HANDOUT # 4 of 4

DISCLOSING TO LOVED ONES

Disclosing to Children

For moms considering telling their children, it is important to ask yourself why you want to tell them:

- Will they be angry if you keep a secret?
- Do they suspect something?
- Are you sick?

Children can react to the news of HIV in the family in many different ways. Older kids may be upset that you kept a secret from them. Younger children may just want to go back to their toys. Partial truths can be helpful when telling children. You may decide only to tell them as much as you consider appropriate for their age.

Do not forget that kids need support too. If you can, give them the name of another adult they can talk to, perhaps an aunt or grandparent. Several books are available that deal with the issue of disclosure to children. (Find books at Let's Talk.)

Disclosure and Relationships

Women who are dating find it difficult to know when to disclose. Should you tell on the first date or only if the relationship is getting serious? While there is no correct answer, the longer you wait, the more difficult it becomes.

Be aware that women are at risk for violence when disclosing their HIV status, especially pregnant women. If you are worried that your partner may become violent, think about having the discussion with a neutral third party present: a therapist, an HIV advocate, or a health professional.

In close relationships, studies show that living with a secret, such as HIV, can be more emotionally harmful than the rejection that could result from disclosure. Many women who have kept a secret for a long time feel a sense of relief after telling. Community based organizations and AIDS clinics can offer resources to guide women through the disclosure process.

1 Gielen, A.C., et.al. (1997). Women's disclosure of HIV status: Experiences of mistreatment and violence in urban setting. *Women's Health* 25(3). 19-31.

2 Lee, M.B. & Rotherman-Borus, M.J. (2002). Parents disclosure of HIV to their children. *AIDS*, 16(16). 2201-2207: Retrieved July 2003 from http://thebody.com/cdc/news_updates_archive/nov11_02/hiv_disclosure.html.

3 Margolese, S.L. (2002). Telling your story, how to decide: A skills-building workshop designed to increase involvement of people with HIV in education, advocacy, and prevention. XIV International AIDS Conference, Barcelona. Abs. TuPeF5496.

4 Schmidt, C.K. & Goggin, K. (2002). Disclosure patterns among HIV+ women. *American Clinical Laboratory*. 40-43: Retrieved July 2003 from <http://www.iscpubs.com/articles/acl/c0203sch.pdf>.

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