

From Stigma to Empowerment: HIV Disclosure in 2018

Terri L. Wilder, MSW

Director, HIV/AIDS Education and Training

Mount Sinai Institute for Advanced Medicine

Serina Yancey

Supportive Peer

Mount Sinai Institute for Advanced Medicine



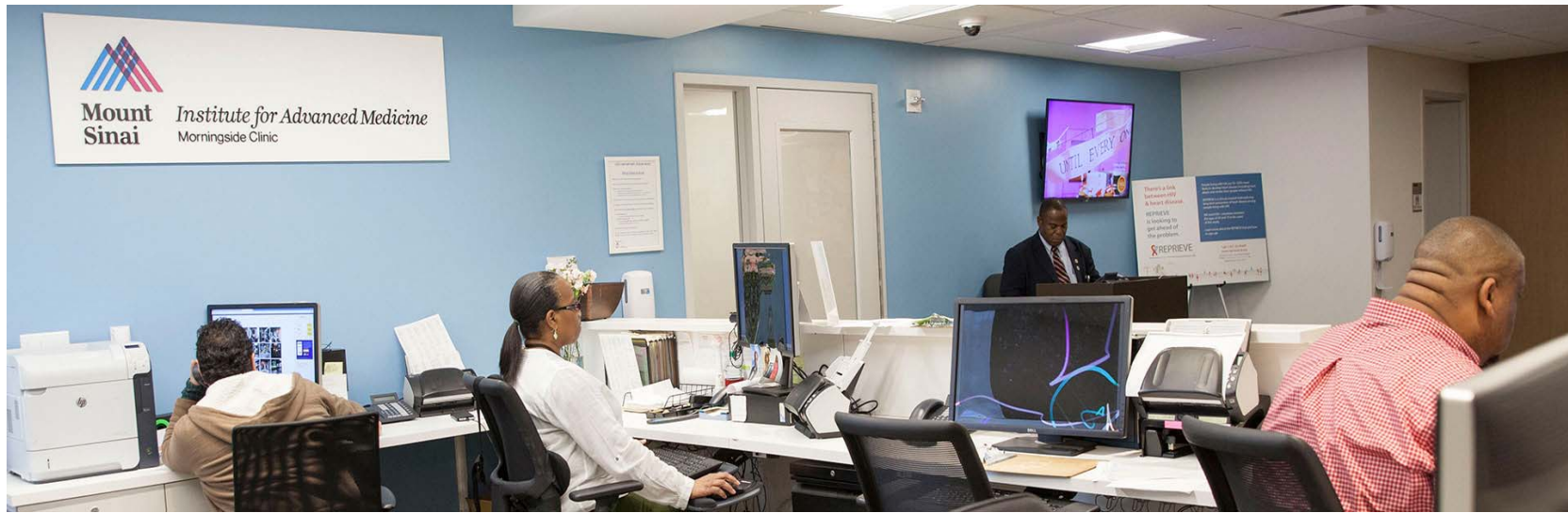
Mount
Sinai

*Institute for
Advanced Medicine*

Introductions



Mount Sinai Institute for Advanced Medicine



The Institute for Advanced Medicine (IAM) provides compassionate, comprehensive care to individuals and families in need of primary care, HIV services, specialty care, supportive services, trauma related treatment, transgender health care and other conditions that impact the overall well-being of our community. We offer our patients an extensive network of caring clinicians and supportive programs to meet their unique needs.

Mount Sinai Institute for Advanced Medicine



WE GOT YOU

SEXUAL HEALTHCARE
INCLUDING PEP & PREP
STI & HIV TESTING,
TREATMENT & CARE



- Care Coordination
- Dental Services
- Pharmacy Services
- Mental Health
- Integrative Medicine
- Coming Home Program
- Hepatitis C/STD Testing

Learning Objectives

- Describe HIV-stigma and its impact on disclosure
- Explain how disclosure can support health outcomes
- Identify effective disclosure strategies that support self-empowerment

What is HIV Stigma?

- **HIV-related stigma** refers to negative beliefs, feelings and attitudes towards people living with HIV, their families and people who work with them. HIV stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture.
- **Stigma** against many vulnerable populations who are disproportionately affected by HIV (such as the stigma of LGBT people, racial, ethnic and tribal minority status) predates the epidemic and intersects with HIV stigma, which compounds the stigma and discrimination experienced by people living with HIV (PLWH) who belong to such groups.

History of HIV and Stigma

- In 1988, Herek and Glunt coined the phrase “AIDS-related stigma” to describe the intense negative public reaction to persons presumed to be living with HIV.
- Two major sources of this stigma: the belief that AIDS is a deadly disease and its association with already stigmatized communities, especially gay men and communities of color.
 - Perceived as lethal and incurable
 - Perceived to be the responsibility of the bearer

Stigma in 2018

- HIV-related stigma is a global problem.
- Stigma reinforces existing social inequalities based on gender, race, ethnicity, class, sexual orientation, and culture.
- Stigma can undermine HIV prevention efforts (i.e. HIV testing, PEP, and PrEP) and discourage people with HIV from engaging in healthcare.
- Stigma can also impact a person's decision to disclose their HIV status.

How does stigma impact HIV disclosure?

- Fear of stigma may keep people from disclosing their status to family, friends and sexual partners.
 - This can increase isolation and undermine the ability to access and adhere to treatment, and undermine prevention efforts such as using condoms and not sharing drug equipment.



What is HIV Disclosure?

Disclosure means telling someone that you are living with HIV.





Pros (+)

- Receive support
- Become part of a larger community
- Access to healthcare and other community resources

Cons (-)

- Fear of rejection
- Fear of being ostracized by family/friends
- Fear of discrimination (loss of employment, housing, etc)
- Person might not keep the information confidential
- Fear of physical violence

Things to think about before you disclose.....









WHAT?





HOW?

WHEN?



HIV vs AIDS CHEAT SHEET

A FEW COMMON LANGUAGE MISTAKES REGARDING HIV

AVOID

SAY

“AIDS”
(WHEN REFERRING TO HIV)

“HIV”
(WHEN REFERRING TO HIV)

“DIED OF/FROM AIDS”

“DIED OF/FROM AN AIDS-RELATED ILLNESS”

“AIDS PATIENT”
“HIV PATIENT”
“SUFFERING FROM HIV”
OR **“AIDS VICTIM”**

“PERSON LIVING WITH HIV”

**BREAK THE BAD LANGUAGE HABIT AND THINK BEFORE YOU SPEAK.
WITH YOUR HELP WE CAN END HIV STIGMA.**

THE **STIGMA** PROJECT

HIV DISCLOSURE ETIQUETTE

CHEAT SHEET

YOUR FRIEND JUST TOLD YOU THEY HAVE HIV. HERE ARE A FEW SUGGESTIONS ON HOW TO PROPERLY RESPOND.

AVOID

"HOW LONG DO YOU HAVE?"

"HOW DID YOU GET IT?"

"WHO GAVE IT TO YOU?"

"WHY AM I NOT SURPRISED?"

"I'M NOT GONNA GET IT AM I?"

SAY

"YOU'RE NOT ALONE."

"HAVE YOU STARTED TREATMENT YET?"

"I'M HERE FOR YOU."

"HAVE YOU FOUND A GOOD DOCTOR?"

"I APPRECIATE YOU TELLING ME THAT."

ASKING QUESTIONS ABOUT HIV IS IMPORTANT TO LEARNING & UNDERSTANDING IT. BUT REMEMBER THERE'S A TIME & PLACE, AND RIGHT NOW YOUR FRIEND NEEDS YOU TO BE STRONG & SUPPORTIVE, NOT OFFENSIVE.

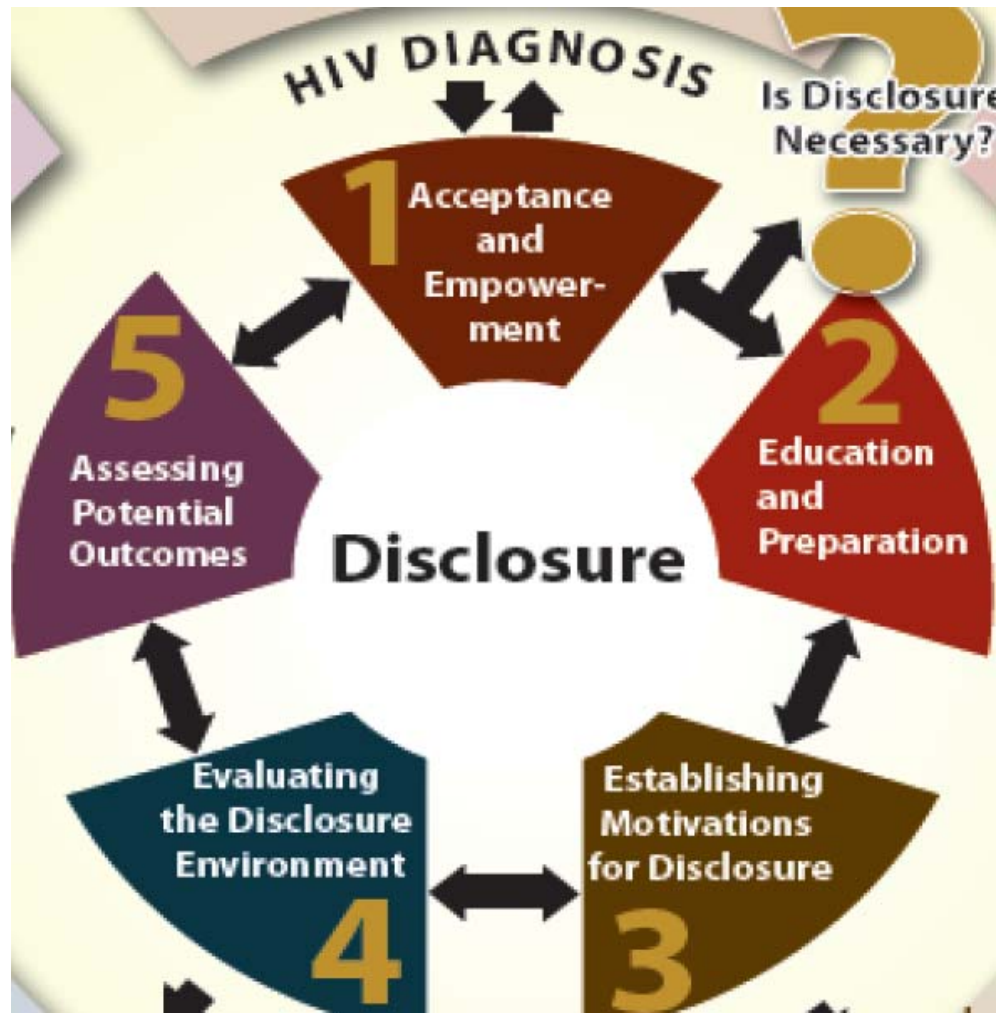
THESTIGMAPROJECT

Health and HIV Disclosure

- HIV status disclosure is associated with improved health outcomes.



- Having at least one person who knows your status can make a difference in your ability to manage stress and to take care of yourself.



Disclosure Exercise

- You're chatting with a friend you are very close with but who doesn't know that you have HIV. They makes an offhand hurtful comment about people with HIV. How comfortable would you feel with each of the following approaches?
 - Correct the misinformation in their statement.
 - Tell your friend about your HIV status.
 - Say nothing to your friend, but discuss the situation at your next support group meeting.
 - Decide not to act.

Action Planning



Conclusion/Take Home

- HIV disclosure is a process.
- Education and action planning can help you prepare for disclosure.
- Stigma is associated with negative health outcomes.
- We must fight stigma everyday!



Sharing your HIV status with those you trust can help with the stresses of having HIV, AND CAN ACTUALLY IMPROVE YOUR OVERALL HEALTH.



Discussion



Acknowledgements

The Association Between HIV Disclosure Status and Perceived Barriers to Care Faced by Women Living With HIV: The ELLA Study

Mona Loutfy, Margaret Johnson, Sharon Walmsley, Anna Samarina,
Patricia Vasquez, He Hao-Lan, Marie-Josée Fournelle,
Marisol Martinez-Tristani, Jean van Wyk

5th International Workshop on HIV and Women
• Seattle, WA, USA •
21 February 2015

Thank You!



Stay in touch!

Terri L. Wilder, MSW

Terri.Wilder@mountsinai.org

Serina Yancey

Serina.Yancey@mountsinai.org

