



Designing Peer Driven Disclosure Focused Interventions as a Means for Addressing and Reducing HIV-Related Stigma

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In many ways the stigma of HIV/AIDS has had an even wider reach and a greater effect than the virus itself.

An Epidemic of Stigma and Discrimination Info Sheet
Canadian HIV/AIDS Legal Clinic



Workshop Description

- Disclosure of HIV status is a major concern for all who are impacted by HIV as evidence of the undeniable growing silence about HIV status in this country.
- HIV-related stigma can have devastating consequences for those impacted by the disease and inhibits self-care for those living with the disease which negatively impacts quality of life.

Workshop Description

- This interactive workshop will look at:
 1. Provide two frameworks for designing an effective (peer-led) stigma reduction intervention;
 2. Review evidence (case study) that HIV stigma can be reduced on an individual and community level; Core causes of HIV stigma utilizing a HIV vulnerability framework;
 3. Suggested tips for getting your proposed intervention funded.

The Starting Point: The 7 D's of Basic Program Design

- Define the problem.
- Determine the consequences of the problem
- Determine the source of the problem.
- Define the desired outcome.
- Determine the best approach.
- Determine if it worked.
- Disseminate what worked with others.

Define the Problem

- **HIV-related stigma**

- Is a term that refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with whom they are associated (Herek et al., 1998).
- Is often layered on top of many other stigmas. These layers of stigma have unfortunately helped to extend and deepen the AIDS stigma to many who are infected with or affected by the disease (Herek 1993; Rushing 1995; Sontag 1990).

Consequences of the Problem

- Consequences of stigma can be viewed along a continuum from mild reactions (e.g., silence and denial), to ostracism and ultimately violence. (Boyd et al. 1999; King 1989; Malcolm et al. 1998; Raveis, Seigel, and Gorey 1998; Sowell et al. 1997).

Source of the Problem

PEOPLE



- Elected Representatives
- Spirit-filled People
- Employers & Employees
- Health Care Providers
- Human Service Providers
- Correctional Officers
- Lawyers
- Family & Friends
- Community Members

Desired Outcomes

- **WHY**

1. Decrease HIV/AIDS related stigma.
2. Increase HIV testing and/or linkage to health care by improving the delivery of HIV and other health prevention messages.
3. Decrease HIV transmission and other poor health outcomes.
4. Support the implementation of the National HIV/AIDS Strategy and the community planning process.

Approach: Peer Positions

Environmental Perspective

OVERARCHING INFLUENCE

societal norms and governmental/institutional policies, regulations and investment

SOCIETAL CONSEQUENCES (POSITIVE & NEGATIVE)

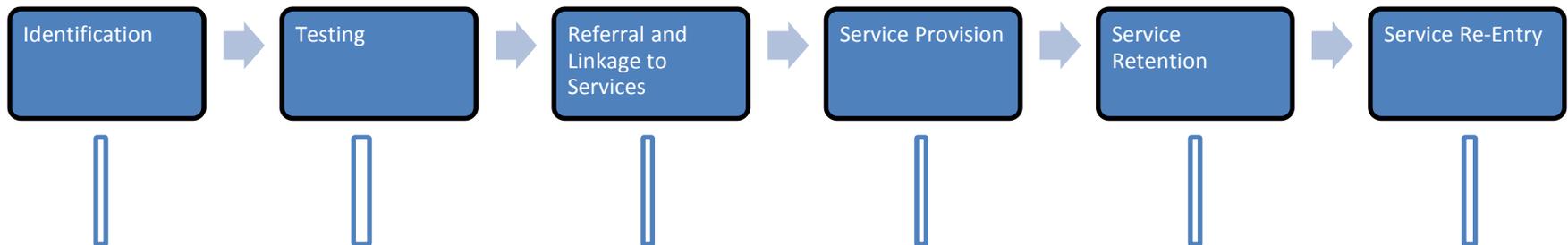
stigma, social determinants of health, legal status, health literacy, and cultural competency

INDIVIDUAL CONSEQUENCES (POSITIVE AND NEGATIVE)

individual knowledge, attitudes and practices (KAP); self efficacy and self determination

IMPACTS HIV SERVICE CONTINUUM

service access and utilization



Line Positions

Outreach, Educator, Advocate, Navigator, and Case Manager



Case Study: Building Storytellers

- Common Threads is a small group HIV prevention training organized around intense, interactive, skill-building sessions. This training is designed to enhance the ability of women living with HIV/AIDS to share their life experiences (including their experiences with HIV/AIDS and other health disparities) with family members, partners, friends, and community members.



120 National Storytellers

- Albany, NY
- Atlanta GA (2)
- Baltimore
- Baton Rouge, LA
- Charlotte, NC
- Dallas, Texas
- Florida State
 - Ft. Lauderdale, Miami & Tampa
- New York, NY
- Orangeburg, SC
- Philadelphia, PA
- Raleigh, NC
- Washington, DC (2)



Training Outcomes & Successes

- Women reported small group environment (8-12 individuals per training) was supportive to their learning.
- Women reported the safe environment facilitated by peers and clinical support, increased their ability to disclose challenging life experiences including trauma and other vulnerabilities.
- Post training follow-up- women reported significant increases in self-disclosure of their HIV status.



Approach: Building Storytellers

- **WHAT**

1. To teach participants how to make and/or use storytelling tools: storytelling template, HIV testing & diagnosis experience, family history (tree), and personal timeline
2. To provide participants the opportunity to practice and build their confidence and comfort via participant exchange sessions and practice demonstrations
3. To provide practice feedback to improve future presentations



Approach: Building Storytellers

- **HOW!**

- Through mini-lectures, demonstration, discussion, examples, crafting, and practice participants will become acquainted with simple but effective storytelling tools:

- Storytelling Templates
- Family Tree
- Personal Timeline
- Narrative (HIV Testing & Diagnosis Experience)



Case Study: Building Storytellers

- **Key Training Elements**

1. Provide an overview of the AIDS Epidemic and how it impacts women, especially women of African descent.
2. Provide an overview of NHAS goals
3. To provide an overview of Common Threads goals
4. **To introduce the concept of HIV vulnerability and how HIV vulnerability may arise from the interconnectedness of the participants' life experiences.**
5. To role model four (4) storytelling techniques
6. To provide participants with an opportunity to develop and practice presentations.

Women and HIV Vulnerability



IMPACT ON

Prevention, Testing, Linkage to Care and Retention in Care

SOCIAL DETERMINANTS

STRUCTURAL FACTORS

BEHAVIORAL HEALTH



Presentation Outline

Women and HIV Vulnerability



- Learning Objectives
- Identify & Explore Vulnerability Factors
- Exercises



Women and HIV Vulnerability

Learning Objectives

- To learn the definitions for HIV risk and HIV vulnerability
- To become acquainted with factors (or conditions) which can increase one's vulnerability to HIV
- To explore the correlation between life experiences and circumstances and HIV vulnerability.



Defining HIV Risk and Vulnerability

UNAIDS (2007)

- **Risk** is defined as the probability or likelihood that a person may through *their own actions* become infected with HIV. Certain behaviors create, increase, and perpetuate risk. Examples include:
 - unprotected sex with a partner whose HIV status is unknown,
 - multiple sexual partnerships involving unprotected sex,
 - and injecting drug use with contaminated needles and syringes.



Defining HIV Risk and Vulnerability

UNAIDS (2007)

- **Vulnerability** results from a range of factors *outside the control* of the individual that reduce the ability of individuals and communities to avoid HIV risk.
 - These factors may include:
 - lack of knowledge and skills required to protect oneself and others;
 - factors pertaining to the quality and coverage of services (e.g. inaccessibility of service due to distance, cost or other factors); and



Defining HIV Risk and Vulnerability

UNAIDS (2007)

- These factors may also include:
 - societal factors such as human rights violations
 - social and cultural norms.
 - Such violations in the form of practices, beliefs and laws that stigmatize and disempower certain populations, limiting their ability to access or use HIV prevention, treatment, care, and support services and commodities create or exacerbate individual and collective vulnerability to HIV.



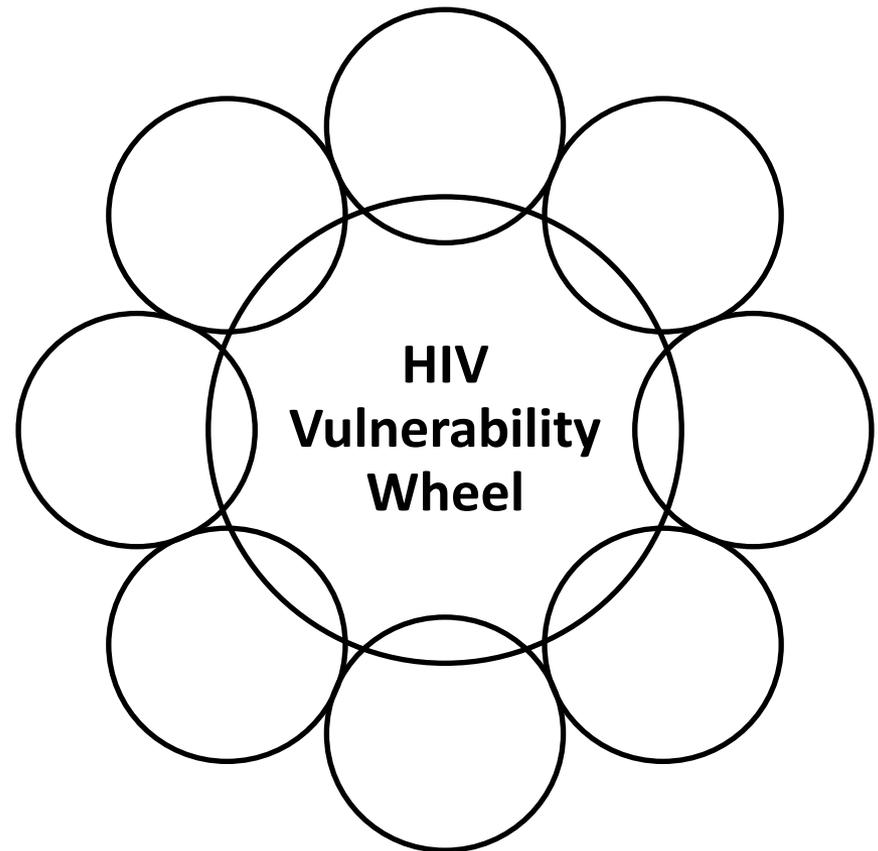
EXERCISE

Identifying HIV Vulnerabilities

Our Community: Women

- **Directions**

- After reviewing the definitions for “risk” and “vulnerability”, attendees will be given a HIV Vulnerability Wheel as illustrated to the right, and asked to identify the types of vulnerabilities that may make women in their communities susceptible to HIV infections





HIV Vulnerability

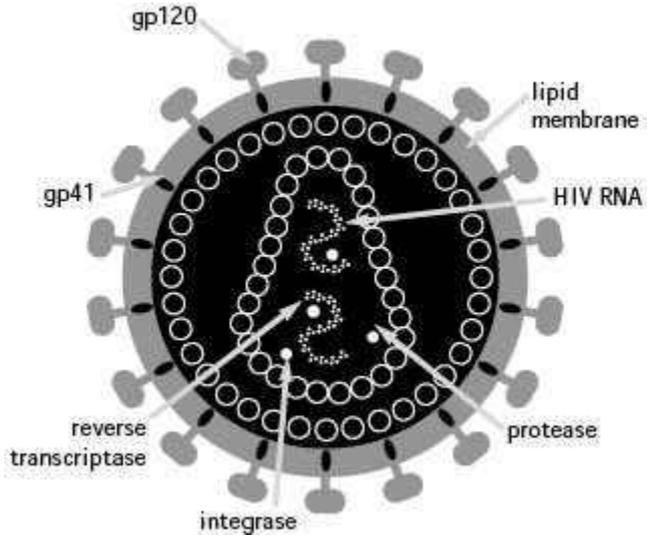
Select Vulnerability Factors

- Genetics
- Race
- Gender
- Sexual Identity and Orientation
- Human Needs
- Family History
- Personal Timeline
- Relationships
- Community Norms
- Stigma
- Trauma
 - Collective
 - Individual
 - Compounded

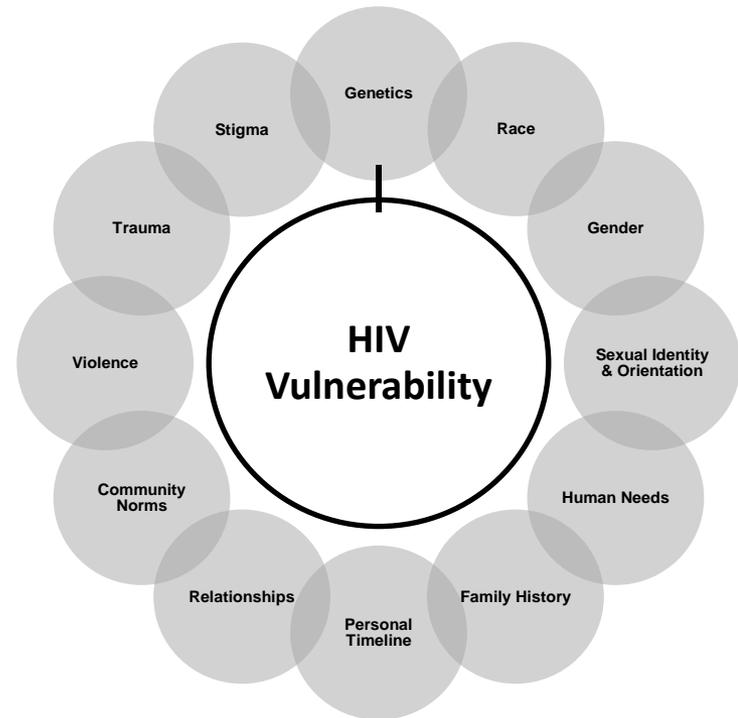


Similar Pattern

HIV Virus & HIV Vulnerability



The HIV Virus
thebody.com





Similar Pattern

HIV Virus & HIV Vulnerability

- **Gp20**
 - The dome prevents gp120 from being recognized by the human immune response. As the HIV virus and the human CD4 cell come together, the gp120 binding site "snaps open" at the last minute. Source: Dan Stowell (2006)
- **HIV Vulnerability Factors**
 - We often do not know, nor recognize that these factors maybe increasing our vulnerability for acquiring HIV and other related health conditions such as other sexually transmitted diseases and Hepatitis C.



HIV Vulnerability

Factor: Genetics

- The researchers found that a genetic trait — found in 60 percent of African-Americans and 90 percent of Africans — makes HIV infection 40 percent more likely. The trait is virtually nonexistent in whites. The benefit that the Africans got from a mutation that gave them some resistance to malaria has, statistically at least, rendered them some increased susceptibility to HIV.

SOURCES: Matthew J. Dolan, M.D., researcher, Wilford Hall United States Air Force Medical Center and San Antonio Military Medical Center; Sunil K. Ahuja, M.D., professor, University of Texas Health Science Center in San Antonio; Rowena Johnston, Ph.D., vice president, research, Foundation for AIDS Research, New York City. July 17, 2008, *Cell Host & Microbe* . Copyright © 2008 ScoutNews, LLC. All rights reserved.



HIV Vulnerability

Factor: Race

- **Disproportionate burden**

- Since the beginning of the epidemic people of color, particularly people of African descent have been disproportionately affected by HIV/AIDS

- Probable Reasons

- Collective historical trauma as a result of slavery and its aftermath
- Racism and discrimination which contribute to poor health and early death due to:
 - Higher rates of poverty
 - Higher rates of incarceration
 - Higher rates of illness (health disparities)

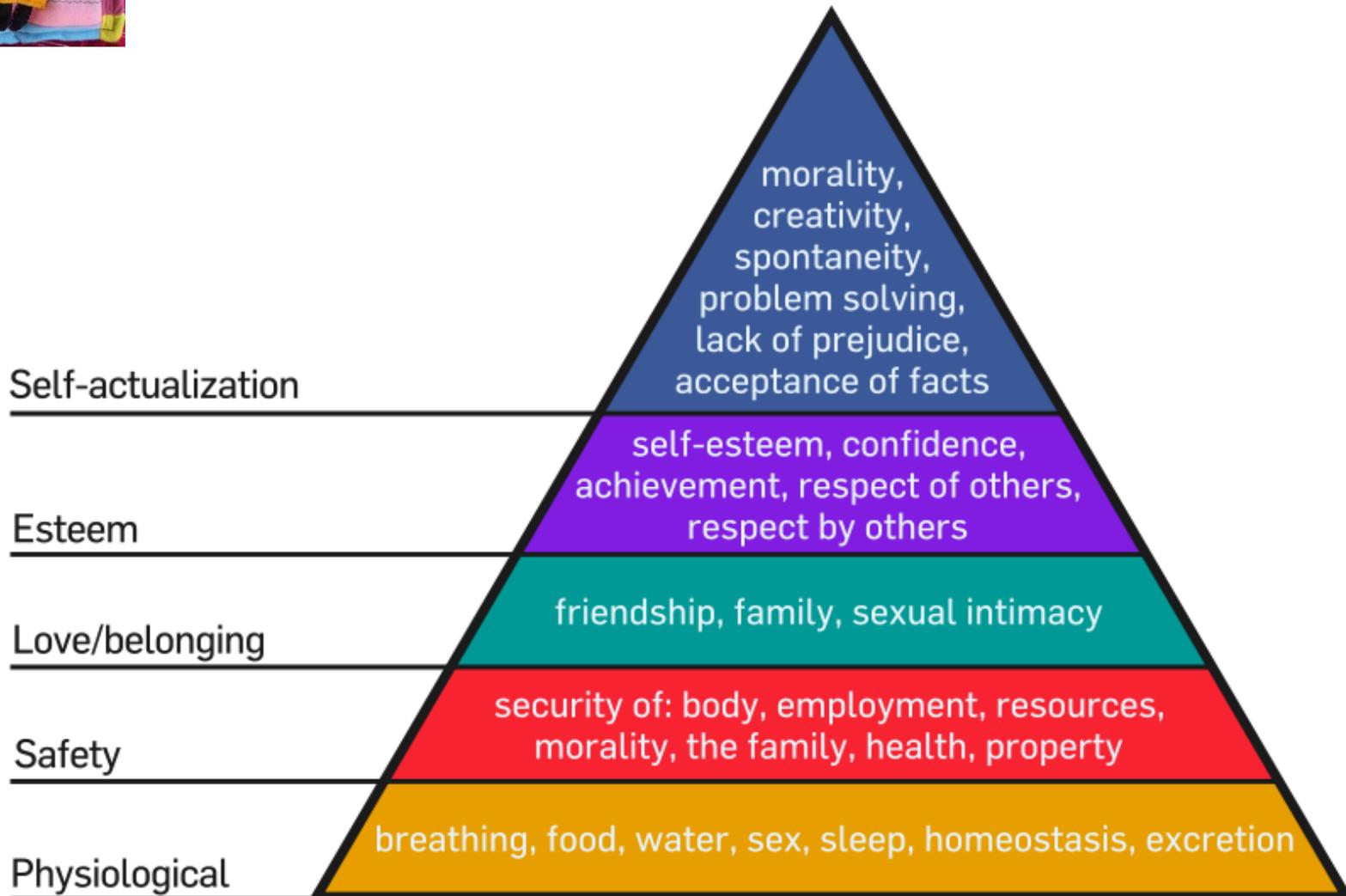


HIV Vulnerability

Factor: Gender

- Gender, as a factor for women, can lead to the following conditions which may cause vulnerability:
 - Lack of money
 - **Economic inequality and disempowerment**
 - Women who do not have sufficient financial resources to support themselves may exchange sex for money as it may be one of the few options available to them to earn money and support themselves and their children.
 - **Underinsured or uninsured**
 - Women often have lower incomes than men or work lower paying jobs with minimal benefits and as a result, women have less access to HIV care and affordable medical insurance.

Factor: Human Needs - Maslow's Hierarchy of Needs





HIV Vulnerability

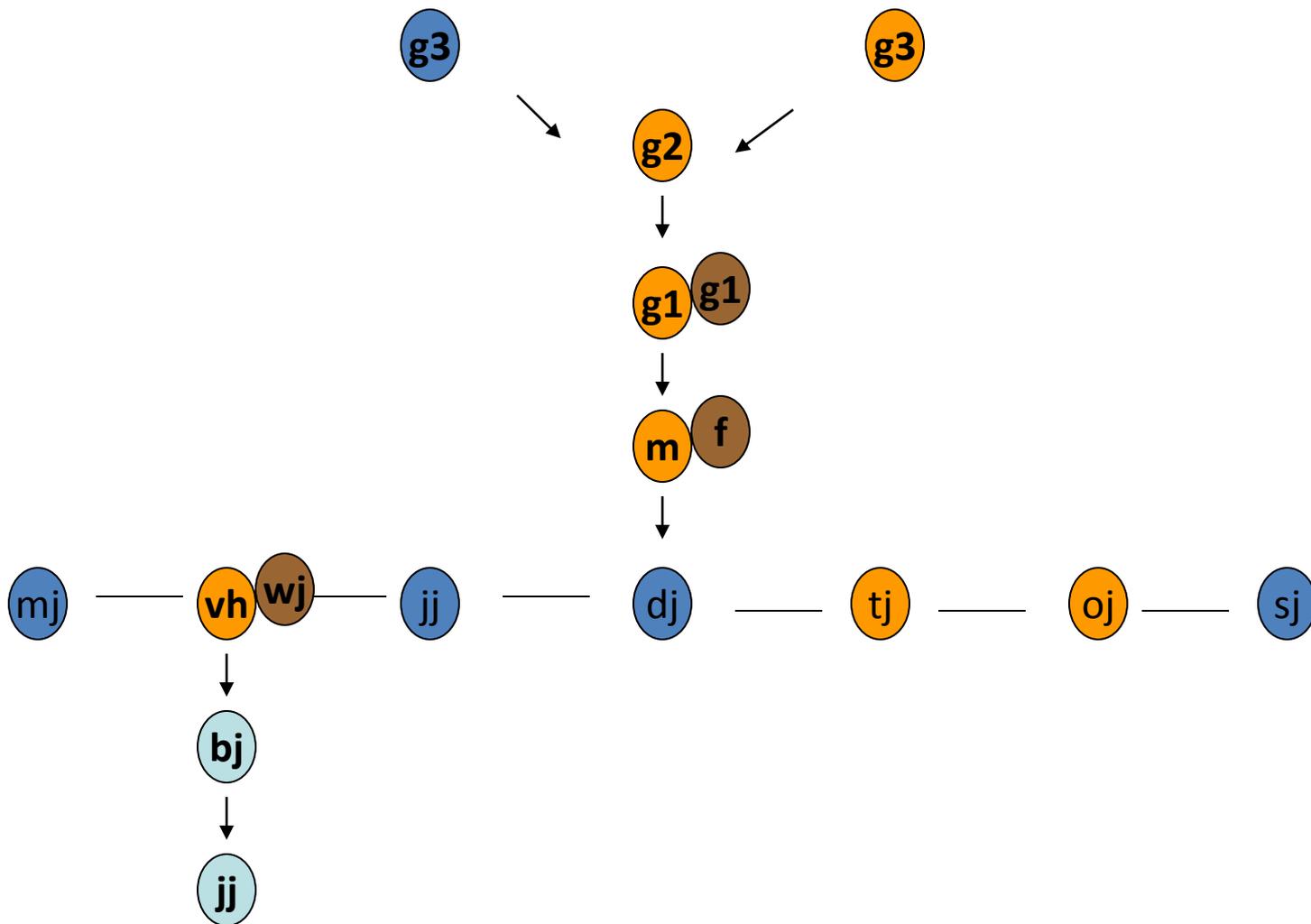
Factor: Family History

- A family tree can show family connections between individuals and document their effects
- A knowledge of our family history can help us to determine HIV vulnerability



My Family Tree

Maternal (Buford)





HIV Vulnerability

Factor: Personal Timeline

- **Internalized Oppression**
 - The result of internalized oppression is shame and the disowning of our individual and cultural reality. Internalized oppression can result in the development of destructive coping skills.



My Personal Timeline

Highlighting Vulnerabilities, Risk-Taking & Recovery

- Age 4** First exposure to violence
- Age 9** Molested by next door neighborhood
- Age 13** Sexually molested by male relative
- Age 16** Exposed to marijuana
- Age 18** Started binge drinking
- Age 19** First experience with partner violence
- Age 32** **Diagnosed w/ HIV**
- Age 36** Entered Rehab & Family Counseling
- Age 37** Volunteer
- Age 39** Pass the NY Bar Examination
- Age 42** Work in HIV Field (local organization)
- Age 48** Work in HIV Field (national organization)
- Age 53** Work (consulting business)



HIV Vulnerability

Factor: Relationships

– Role Assignment

- **Family care giver**

- Women are most likely to assume the role of the family care givers. As a result, women are more likely to sacrifice their own health care in order to care for their family, especially their children.

- **Partners**

- Men can assume a position of power in the form of domination and control over women, minimizing the amount of input and consent from women.



HIV Vulnerability

Disorder Associated with Trauma

- **Definition**

- **Posttraumatic stress disorder (PTSD)** is a severe anxiety disorder that can develop after exposure to any event that results in psychological trauma. This event may involve the threat of death to oneself or to someone else, or to one's own or someone else's physical, sexual, or psychological integrity, *overwhelming the individual's ability to cope.*



HIV Vulnerability

Community Norms

- **Definition**

- **Norm**

- Informal guideline about what is considered normal (what is correct or incorrect) social behavior in a particular group or social unit. In this case “community”.
 - Norms form the basis of collective expectations that members of a community have from each other, and play a key part in social control and social order by exerting a pressure on the individual to conform. In short, "The way we do things around here."

<http://www.businessdictionary.com/definition/norm.html#ixzz2DQZQ4RaZ>



HIV Vulnerability

Stigma

- **Definition**
 - **HIV-related stigma**
 - Is a term that refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to AIDS or HIV, and the individuals, groups, and communities with whom they are associated (Herek et al., 1998).
 - Is often layered on top of many other stigmas. These layers of stigma have unfortunately helped to extend and deepen the AIDS stigma to many who are infected with or affected by the disease (Herek 1993; Rushing 1995; Sontag 1990).



EXERCISE

HIV Vulnerability

Select Vulnerability Factors

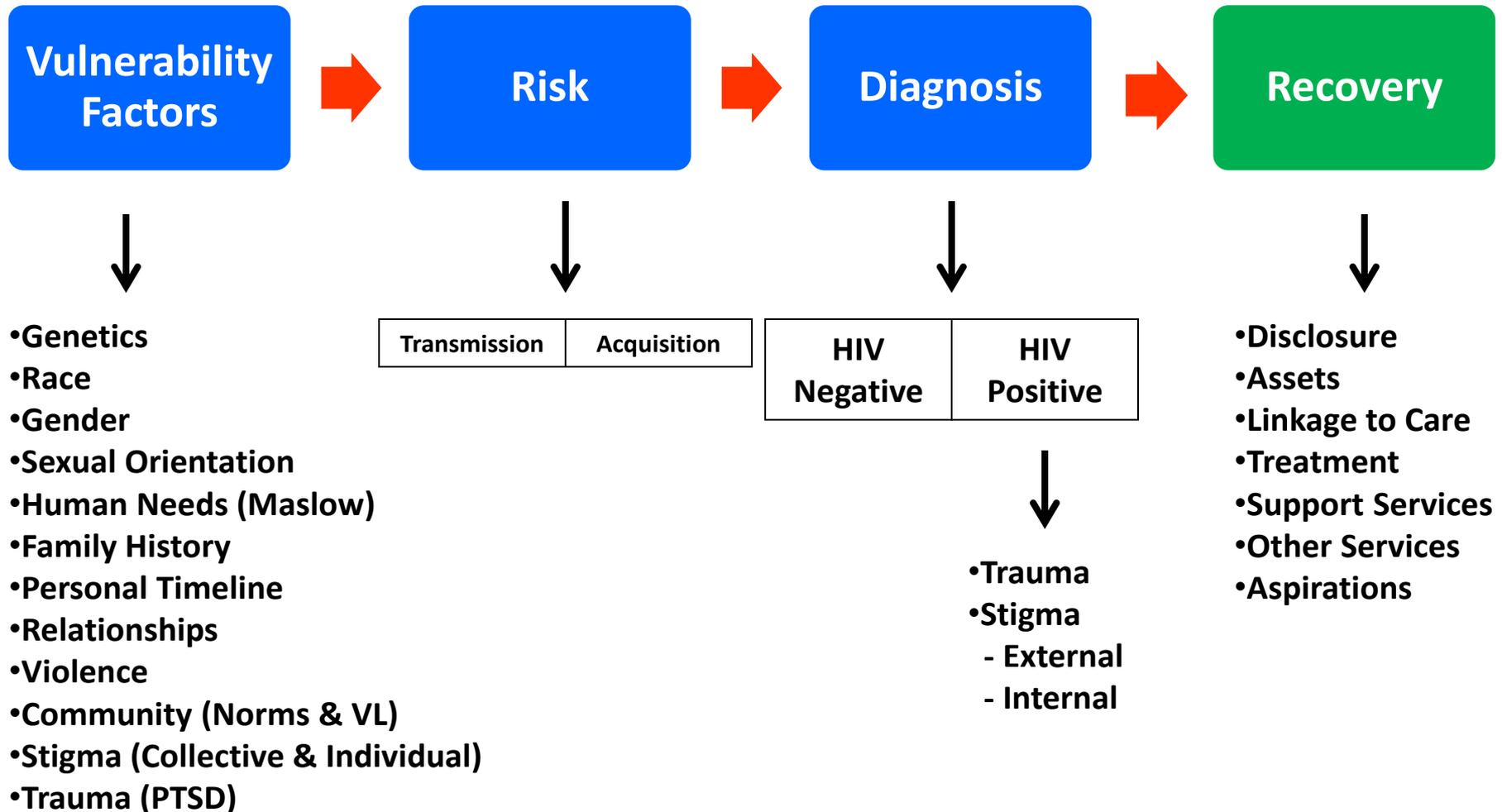
- **Directions**

- After completing the HIV Vulnerability Wheel, attendees will be given three cards and asked to write down three selections from the previous exercise. Thereafter, attendees will be asked to place their cards under the factors they think best represents their vulnerabilities.

- Genetics
- Race
- Gender
- Sexual Identity and Orientation
- Human Needs
- Family History
- Personal Timeline
- Relationships
- Community Norms
- Stigma
- Trauma



HIV Vulnerability Framework



From Paper to Program

- Discussion: Suggested tips for getting your proposed intervention funded.

Contact Information

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