

HIV Disclosure Summit

June 28-29, 2012

I. Background

In 2010, the White House released a National HIV/AIDS Strategy (NHAS), which established a new vision for our response to the HIV/AIDS crisis in the United States (US)—a response that turns the US into a place where new HIV infections are rare and every person living with HIV has “unfettered access to high quality, life-extending care, free from stigma and discrimination.” To achieve this vision, the NHAS sets out a number of action steps for federal agencies, including the two existing federal advisory bodies: the Presidential Advisory Council on HIV/AIDS (PACHA), and the Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC). Under “Goal 3: Reduce HIV-Related Health Disparities; Step 3: Reduce stigma and discrimination against people living with HIV,” the Federal Implementation Plan put forth the following directives for PACHA and CHAC:

- PACHA will be tasked with developing recommendations for ways to promote and normalize safe and voluntary disclosure of HIV status in various contexts and circumstances.
- CHAC will solicit public input and make recommendations for normalizing and promoting individuals’ safe, voluntary disclosure of their HIV status. HRSA will publish the recommendations.

As advisors to the President, Secretary of Health and Human Services, HRSA Administrator and CDC Director, the Disclosure Workgroup held a 2-day HIV Disclosure Summit on June 28-29, 2012 with thought leaders from cross-cutting and diverse public and private partners, e.g. people living with HIV and community advocates, social scientists, medical ethicists, researchers, health providers, education leaders, lawyers, policy makers and others. The workgroup created guiding principles and policy recommendations to these Federal officials to consider adopting. The policy recommendations and guiding principles are outlined below and were created to address the structural barriers (federal, state and local) to safe and voluntary HIV disclosure in the US. We believe these recommendations are integral to meeting the broader goals of reducing new infections, increasing access to care, and reducing health disparities, as outlined in the NHAS.

II. Guiding Principles

Preamble

We are committed to ending the HIV/AIDS epidemic. We are committed to honoring the strength and resilience of people living with HIV and their invaluable role in the nation’s ongoing fight against the epidemic. We are committed to ensuring and protecting the right and ability, of all people, to live full, healthy lives.

With these commitments firmly in mind, we recognize and respect:

- the ultimate autonomy of each individual faced with the opportunities and challenges of disclosing her or his HIV status;

- that disclosure of HIV status is not a single, discrete event, but rather an ongoing process that spans a lifetime and a myriad of contexts; and
- the disclosure process necessarily involves multiple parties.

These commitments and the recognition of the characteristics of the disclosure process informed the development of the guiding principles for our discussions and our ultimate recommendations. While this document is focused on the NHAS directives on HIV disclosure, the group also acknowledges that disclosure of all STIs promotes greater communication and sexual health.

Now, therefore, we set forth the following Guiding Principles:

PRINCIPLE NO. 1:

SOCIETY HAS AN OBLIGATION TO CREATE A SAFE ENVIRONMENT FOR DISCLOSURE

There is an obligation and a responsibility for society to create a safe environment for people to voluntarily disclose their HIV status as well as other sexually transmissible infections. Accordingly, any laws and policies that create disincentives to an individual's safe and voluntary disclosure of her or his HIV status, e.g., by increasing HIV stigma and discrimination, should be eliminated. All relevant Federal, state and local laws and policies should incorporate the current state of medical science, best-practices in public health, and evidence-based strategies and priorities for effectively addressing the HIV epidemic and should strive to create and maintain resources and environments conducive to safe and voluntary disclosure.

PRINCIPLE NO. 2:

DISCUSSION OF HIV AND STI STATUS IS IMPORTANT

Confidential and ongoing communication about HIV status and other relevant sexual health conditions (both for those living with HIV and those whose current status is negative or unknown) is essential for individual, family, and community health. An environment that allows for safe, voluntary disclosure empowers persons living with HIV to: 1) access support and care without fear of stigma or persecution; and 2) participate in the organizations and mechanisms of policy, to which they bring invaluable lived-experience. Ultimately, an environment that protects the ability to engage in safe and voluntary disclosure enables all community members to make informed decisions in regard to their own health and conduct.

PRINCIPLE NO. 3:

THE CIRCUMSTANCES AND CONTEXT OF DISCLOSURE MUST BE RESPECTED

A complex constellation of cultural and social factors influences every individual's ability to safely disclose her or his HIV status. These factors must be respected in order to create environments that facilitate safe and voluntary disclosure. Only if we understand and appreciate the external pressures militating against safe, voluntary disclosure, can we create solutions that allow for all people to access the support, treatment and education resources that they need and deserve.

III. Policy Recommendations

In light of the foregoing Guiding Principles, we make the following policy recommendations:

Short-term recommendations

1. **HHS and other federal funders should devote a portion of currently funded programs to facilitate campaigns and education** on safe and voluntary disclosure that encourages

an understanding of HIV in the context of a range of sexually-transmissible diseases that can have a profound impact on health and life. Infuse issues of disclosure in prevention campaigns. Encourage NIH to research what is already known related to effective programs and how to apply their research findings.

This recommendation responds to each of our guiding principles by: 1) developing the research base to inform laws and policies (Principle #1); 2) educating Americans about safe and voluntary HIV disclosure and encourage their ongoing discussions (Principle #2); and 3) addressing the circumstances that may influence those discussions (Principle #3).

2. **Federal funders should develop and/or disseminate a quantitative and qualitative research agenda** and fund studies on the benefits and challenges of disclosure.

Developing a comprehensive research agenda on disclosure will: 1) help better inform laws and policies regarding HIV/AIDS (Principles #1 and #2); 2) develop strategies for encouraging safe and voluntary disclosure in a variety of contexts (Principles #2 and #3).

3. **The Surgeon General should write a letter to the American People** containing up-to-date information about HIV/AIDS and the importance of frank discussions about maintaining sexual health. Much has changed since Surgeon General Koop's 1988 letter; a new letter will help correct many persistent misconceptions about HIV, its transmission, and the prognosis for those whose infection is detected early and are provided with appropriate access to HIV-related healthcare

We envision this letter as addressing each of our guiding principles, by using the authority of the Surgeon General to provide up-to-date information about HIV that will: 1) inform laws and policies based on best evidence and best practices in 2012 (Principle #1); 2) encourage all Americans to discuss, as appropriate, HIV with their partners, families, friends, and medical professionals (Principle #2); and 3) identify the factors that may impede or facilitate those discussions (Principle #3).

4. **The Secretary of Health and Human Services should appoint an HHS representative** to work with the associate attorney general to create a working group to examine laws and policies that discriminate against people with HIV and formulate recommendations for the elimination of those laws, and develop recommendations for laws and policies that would support and protect people living with and vulnerable to HIV.

This recommendation is directly responsive to Principle #1. Such an analysis will enable policymakers to make the required changes to ensure that laws do not create disincentives to disclosure and suggest ways that laws might be reformed to create a supportive atmosphere for disclosure. Such efforts can also underscore the importance of safe and voluntary HIV disclosure, while recognizing how context may influence the ability to do so (Principles #2 and #3).

5. **Establish a dedicated position within the office of the Associate Attorney General** for HIV Law and Policy.

This recommendation is similarly responsive to Principle #1 and is intended to provide leadership on the role of law in fostering a supportive environment for safe and voluntary HIV disclosure. As such, this recommendation may also serve to support the recognition of the importance of HIV disclosure in a variety of contexts (Principles #2 and #3).

Long-term recommendations

6. **HHS and medical providers should prioritize disclosure support as a component of mental health services within clinical settings.** Include disclosure education, training

and support under the definition of “peer navigator/support.” Recognizing that disclosure is a continuous and voluntary process, we need to fund the supportive work around disclosure in the clinical setting over a person’s lifespan. In addition, the following approaches should be supported:

- a. Part of the clinical care model should include a comprehensive discussion of HIV and STI disclosure outcomes with a trauma-informed approach to care. Approaches to disclosure in the clinical setting which merely involve informing the newly-diagnosed of the existence of a law mandating disclosure and/or advising and admonishing the person to disclose to all sexual partners should be discouraged.
- b. To support this, AETCs should be allowed to train peers and count peer training. In addition, medical professionals need to be trained. Accordingly, nursing and medical education should include skills building on supporting and facilitating disclosure.

Providing this support recognizes the importance of HIV disclosure (Principle #2) and addresses some of the potential barriers to voluntary HIV disclosure (Principle #3). More disclosure education may ultimately help in creating a more supportive atmosphere for safe and voluntary HIV disclosure (Principle #1).

7. **HHS should develop sex-positive prevention messages** rooted in evidence-based research but also reflecting and tailored to people’s real lives; create culturally relevant messages developed by people living with HIV.

The recommendation responds to Principle #3 and seeks to address some of the factors that may facilitate or impede HIV discussions. Messages developed in accordance with this recommendation are also likely to advance Principle #2, by discussing the importance of HIV discussions.

8. **HHS should develop ways to encourage and incentivize states to address state and local laws that create barriers to disclosure of HIV status and access to care.** To further support this, we recommend that HHS conduct an objective analysis on the impact of these laws on access to testing and care.

These recommendations are directly responsive to Principle #1 by identifying a specific way to understand how state law may either support or discourage discussion of HIV status and by creating incentives to develop legal environments that are supportive of safe and voluntary disclosure.

Participants

Brooks, Douglas, co-chair
Dempsey, Antigone, co-chair
McClain, Matthew (Facilitator)

Ahmadi, Halima
Birnbaum, Jeffery
Crowley, Jeffery (presenter)
Fullem, Andrew
Futterman, Donna
Hanssens, Catherine
Hopkins, Ernest
Johnson, Ronald
Knight, David

Nichol, Alison
Rios-Ellis, Britt
Rutland, Will
Schoettes, Scott
Scruggs, Linda
Wolf, Leslie

HHS Federal Observers

Cheever, Laura
Hayes, Kaye
Harrison, Timothy
Joppy, Melvin
Talev, Caroline