



**The Committee on Civil and Human Rights and
The Committee on Mental Health, Disabilities and Addiction**

Negative Mental Health Consequences of Discrimination and Bias Incidents

Testimony of The Center for HIV Law and Policy

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I thank the Committees for the opportunity to testify today. I also want to thank the Governmental Affairs Division, the Committees and their staff for the excellent briefing paper provided to frame this hearing. I am the Founder and Executive Director of The Center for HIV Law and Policy and have been working in the field of HIV law and discrimination for nearly 35 years. My comments reflect the experiences of people living with HIV who are on the margins and who, because they are low income, either rely on or are disproportionately ensnared in the criminal, detention, foster care and publicly funded health care systems.

There is bountiful evidence of the impact of discrimination. We know that refusing someone a job, denying them access to a service, treating them differently in the criminal legal system or in the level of respect afforded them in the delivery of essential health care on the basis of their identity or disability does far-reaching damage beyond the already profoundly disturbing immediate one.¹

Even if it weren't self-evident, the evidence of discrimination's impact on an individual's mental health also is well established.² Studies show that perceptions of discrimination among Black, Latino and Mexican Americans not only have a measurable impact on mental health, but that impact appears to worsen for immigrants the longer they are in the country, and the full weight of discrimination in this country becomes apparent.³

Experiences that teach and reinforce the self-perception that one is "less-than" is strong fertilizer for feelings of self-loathing. For people living with HIV, that also translates into a

¹ Patterson SE et al. The impact of criminalization of HIV non-disclosure on the healthcare engagement of women living with HIV in Canada: a comprehensive review of the evidence, *Journal of the International AIDS Society* 2015, 18:20572 <http://www.jiasociety.org/index.php/jias/article/view/20572> | <http://dx.doi.org/10.7448/IAS.18.1.20572>.

² R. Kessler, K. Mickelson, D. Williams, *The Prevalence, Distribution, and Mental Health Correlates of Perceived Discrimination in the United States*, 40 *J. OF HEALTH AND SOCIAL BEHAVIOR* 208-239 (1999).

³ *Self-Reported Discrimination and Mental Health Status Among African Descendants, Mexican Americans, and Other Latinos in the New Hampshire REACH 2010 Initiative: The Added Dimension of Immigration*, Gilbert C. Gee, PhD, Andrew Ryan, MA, David J. Laflamme, PhD, MPH, and Jeanie Holt, MS, RN., 96 *Am J Public Health*, 1821–1828 (Oct. 2006).

disinclination to get into care or to stay in care after diagnosis.⁴ For people with complicated lives and few resources to manage those complications, people who overwhelmingly are poor, Black, Brown, female or living with a host of other disabilities and issues, the anticipation of discrimination is enough to cause stress and the understandable decision to avoid yet another source of judgment and trauma.⁵

You already know that this is the case; as the briefing paper acknowledges, unconscious or implicit bias in healthcare is well documented,⁶ and nearly 70% of individuals diagnosed with a chronic illness report that their ability to access health care has a great deal with who they are.⁷

The unconscious stereotyping and related assumptions based on a patient's association with a group rather than as an individual reflects a clinician's failure to try and understand the patient based upon their own merits. Implicit bias has been shown to adversely influence medical and clinical outcomes and may manifest itself in everything from medication non-adherence on the part of the patient to missed diagnosis on the part of the clinician.⁸ Just in the past year, I have done trainings and had discussions with medical and dental students who believe they have a right to refuse to treat a person living with HIV if they have a high viral load, and physicians who believe that a couple of missed appointments and a suspicion that a mother is breast feeding is enough to remove her children

⁴ *Perceptions and Impact of HIV Stigma among High Risk Populations in the US Deep South*, Susan Reif, Elena Wilson & Carolyn McAllaster, Journal of HIV and AIDS (2018).

⁵ American Psychological Association, *Stress in America: The impact of discrimination*, March 10, 2016, available at: <https://www.apa.org/news/press/releases/stress/2015/impact-of-discrimination.pdf>, p. 8.

⁶ Blair, I.V.Ph.D., Steiner, J.F. MD, MPH and Havarnek, E.P. MD, *Unconscious (Implicit) Bias and Health Disparities: Where Do We Go From Here?*, 15 *Permanent Journal* 71-78 (2012) Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140753/>.

⁷ Id.

⁸ Id.

from her custody. Yet in every discussion I have ever attended about reducing disparities in treatment access, engagement and outcomes, I have never heard serious discussion of treating health care providers as part of the problem to be solved. To the contrary, and to an unfortunate degree right here in New York City, a number of prominent health care administrators and physicians continue to argue that the best way to get more of the poor and people of color in this city in HIV care is to reduce the amount of communication and patient engagement employed at the diagnosis stage. In view of the minimal nature of the requirement in the case of HIV testing, the objections to the inconvenience of speaking with patients ignore the other issues at play – a discomfort with talking about sex, a lack of trust in the capacity of disadvantaged patients to understand and make choices that work for them, and an inability to understand the extent to which distrust of providers affects decisions to access care.

I am heartened that the Briefing Paper concludes its discussion with observations about discrimination in the health care setting. As the authors of the Briefing Paper state, “Victims of discrimination, bias and harassment often internalize and normalize the behavior so that they come to believe that they are less worthy because of their characteristics.”⁹ Many people at risk, and even those who have been diagnosed, assume that they will not be treated with respect and that “the system” does not prioritize their best interests, and avoid health care as a consequence.

A basic but frequently ignored fact of life is that for individuals to do those things that require them to stay healthy, they need to believe that they have a life worth living, that they are worthy of respect and autonomy. The persistent failure to recognize this in the field of HIV testing and care may be one of the most important contributors to ongoing racial and economic disparities in HIV care.

⁹ Council of the City of New York, Briefing Paper of the Governmental Affairs Division, OVERSIGHT: NEGATIVE MENTAL HEALTH CONSEQUENCES OF DISCRIMINATION AND BIAS INCIDENTS (Dec. 12, 2018).

For example, while supporters of proposals for reducing and now eliminating patient engagement and consent in testing decisions promote this as a “stigma reduction” measure, the fact is that it is not the test, but the consequences of the test and the enduring distrust of health care professionals that drives the avoidance of testing and care. A recent study in New York City, which arguably has one of the best arrays of competent LGBTQ-friendly service providers of any city in the U.S., found that a third of a cohort of sexually active gay men and transgender women had not tested for HIV and that expectations of stigma that accompany a positive test was a major reason for that avoidance.¹⁰

Recognizing discrimination’s damage to mental health is important, as are services to address that damage. However, I hope that our primary goal here today is to make those services less necessary by focusing on new ways to identify and stop the daily onslaught of discrimination and indignities that people of color, women, seniors, people with disabilities including HIV and the poor experience. Despite the fact that racism in its many forms contributes to poor health outcomes, health professionals and policymakers have yet to employ concrete anti-racism measures to address persistent health inequities in the United States.

It is my hope that this hearing will inspire the creation of programs and policies that effectively reduce the human suffering, both in terms of new HIV infections and the quality of life, that is the direct result of unrelenting discrimination. We can start by considering the extent to which we have policies or laws that disadvantage these communities or treat them with the assumption that they are less than: less able to make their own decisions, less worthy of autonomy, less capable of understanding what’s best for them in terms of health care and other life decisions.

An example of this is the pending proposal of New York health care providers and large ASO’s who also provide health care to eliminate even personal notice that an HIV test is going to be

¹⁰ Sarit A. Golub and Kristi E. Gamarel, *The Impact of Anticipated HIV Stigma on Delays in HIV Testing Behaviors: Findings from a Community-Based Sample of Men Who Have Sex with Men and Transgender Women in New York City*, AIDS Patient Care and STDs (2013).

administered, eliminating the very minimal requirement of telling a patient they will be tested and asking them if that's okay or if they would like to opt out. This small piece of communication, which is no more than what is provided before testing anyone for any significant disease, has been described by providers at places such as Montefiore Medical Center as a "significant barrier" to getting people tested. As one legal services provider told me recently, "the real reason that most people aren't getting tested is because medical providers are bad at talking about HIV/sex/drugs and just don't do it, so people don't get tested. The doctors and hospitals are failing to convince people to get tested so the solution is to just let the medical world off the hook and test everyone without their consent."

Even just a few specific, concrete commitments to action that can reduce the mental cruelty of discrimination could have a real impact. Examples are:

- Requiring regular trainings in cultural humility and capacity and patient engagement skills for all staff in hospital and clinical settings
- Universalizing patient feedback systems to rate systems and provider quality of services and provider's communication with/treatment of patient
- Incorporating ethics training in the treatment of patients with disabilities, including infectious diseases, as part of provider education, certification and CME requirements
- Increasing the role, and funding, of peer navigators and counselors to support patient engagement and monitor the cultural capacity of primary and ER care providers.

Thank you for your consideration of these comments.