April 21, 2011

Board on Population Health and Public Health Practice
Institute of Medicine
500 Fifth Street, NW
Washington, D.C. 20001

Re.: Preventive Services for Women, Inclusion of HIV Testing

Dear Members of the Board,

On behalf of the HIV Testing Reimbursement Subcommittee of the HIV Health Care Access Working Group affiliated with the Federal AIDS Policy Partnership, the undersigned organizations submit the following comments urging that *all* HIV tests should be covered by insurers as a preventive service for women, including transgender women. HIV testing is an essential preventive service for women, and public and private insurers should be required to cover all HIV testing, regardless of the patient's known risk factors, with no cost sharing by the patient.

Women in the United States are Impacted by HIV

While HIV once affected relatively few women, today approximately one quarter of new infections are among women. Women, particularly Black and Latina women, as well as other sub-populations, represent an increasing proportion of infected individuals.[1] HIV has become a women's issue, and yet the dominant approach to HIV screening, which focuses on testing those with identified risk factors, inevitably misses many women who are unable to identify their own risk. In order to move beyond risk-based testing alone, all HIV testing, regardless of known risk, must be included in the list of covered preventive services for women.

Large Numbers of Women are Living with HIV/AIDS

- Women represented 26% of new AIDS diagnoses in the U.S. in 2008.
- In 2006, there were 15,000 new HIV infections and, in 2008, there were 9,813 AIDS diagnoses among women.

Women of Color are Disproportionately Impacted

- Black women accounted for 65% of estimated AIDS diagnoses among women, ages 13 and older in 2008, but only 12% of the U.S. population of women.[2]
- An analysis of national household data from 1999-2006 found that 1.49% of Black women aged 18-49 in the U.S. are HIV-positive.[3]
- One in thirty black women will be diagnosed with HIV in their lifetime.[4]

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[1] Center for Disease Control and Prevention. "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health Care Settings." Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/Rr5514a1.htm.
[2] Henry J. Kaiser Family Foundation. "Fact Sheet: Women & HIV/AIDS in the United States." (November 2010.)
[3] *Id.*
[4] Centers for Disease Control and Prevention "HIV among African Americans." Available at http://www.cdc.gov/hiv/topics/aa/pdf/aa.pdf

- The HIV incidence rate for black women in 2006 was nearly 15 times as high as that of white women and nearly four times as high as that of Hispanic/Latino women.[5]
- Latinas accounted for 17% of estimated AIDS diagnoses, compared to 13% of the female population ages 13 and over.[6]
- Hispanic/Latina women's rate of HIV infection in 2006 was nearly four times the rate of white women.[7]
- Between 2001 and 2004, the estimated annual percentage change in new HIV diagnoses for Asian and Pacific Islander (A&PI) women was 14.3%, higher than any other racial or ethnic group.[8]
- 30.4% of A&PI women living with HIV are unaware of their status, higher than any other racial/ethnic group.[9]
- The HIV infection rate for American Indian/Alaska Native women between 2001 and 2004 was more than twice that of white women.[10]

Young Women are Infected with HIV

- 32% of new HIV diagnoses in women in 2006 were among those aged 13–29 and 31% were aged 30–39.
- In 2006, HIV was the 3rd leading cause of death among Black women ages 25–44.[11]

Most Women Get HIV from Heterosexual Sex

- Heterosexual sex is the source of the vast majority of HIV infections among women. Approximately 90% of 13-24 year old females with new HIV diagnoses in 2008 were infected through heterosexual sex.[12]

Risk-Based HIV Testing Alone is Inadequate, Especially for Women

While the number of new HIV diagnoses among women is too high, the true number of new HIV infections is surely far higher. The CDC estimates that approximately 21% of the more than 1.1 million people living with HIV in the United States, are undiagnosed and therefore unaware of their HIV status. The CDC has further estimated that of all of the people who are undiagnosed in

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[5] Centers for Disease Control and Prevention. "MMWR Analysis Provides New Details on HIV Incidence in U.S. Populations." Available at http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/MMWR-incidence.htm
[6] Henry J. Kaiser Family Foundation. "Fact Sheet: Women & HIV/AIDS in the United States". (November 2010).
[7] Centers for Disease Control and Prevention "HIV among Hispanic/Latinos" Available at http://www.cdc.gov/hiv/hispanics/resources/factsheets/pdf/hispanic.pdf
[8] Racial/ethnic disparities in diagnoses of HIV/AIDS—33 states, 2001-2004. *Morbidity and Mortality Weekly Report* 55. (2006): 121-125.
[9] M.L. Campsmith, P.H. Rhodes, H.I. Hall, and others. "Undiagnosed HIV Prevalence Among Adults and Adolescents in the United States at the End of 2006." *Journal of Acquired Immune Deficiency Syndromes* 53(5) (April 2010): 619-624. Abstract available at: http://journals.lww.com/jaids/pages/articleviewer.aspx?year=2010&issue=04150 &article=00009&type=abstract. Data from article available at http://www.hivandhepatitis.com/recent/2010 /0427_2010_b.html
[10] Racial/ethnic disparities in diagnoses of HIV/AIDS—33 states, 2001-2004. *Morbidity and Mortality Weekly Report* 55. (2006): 121-125.
[11] Henry J. Kaiser Family Foundation. "Fact Sheet: Women & HIV/AIDS in the United States." (November 2010).
[12] Centers for Disease Control and Prevention "HIV Surveillance in Women." Available at http://cdc.gov/hiv/topics/surveillance/resources/slides/women/index.htm

the United States, 47,200 to 59,200 are women.[13] Accordingly, over a third of new HIV diagnoses are made late in the course of the illness.[14]

In fact, the United States Preventive Services Task Force (USPSTF) has stated, "A large, good-quality U.S. study found that risk factor assessment can identify individuals at substantially higher risk for HIV, but still misses a significant proportion (20% to 26%) of HIV-positive clients who report no risk factors (since some patients may choose not to disclose high risk behaviors and others, especially women, may be unknowingly at risk from an infected sex partner)."[15] This is due, in part, to the fact that risk assessments typically focus on *known* risky behavior of the individual or their sexual partner(s). Yet a partner's infidelity, or past sexual partners, or history of injection drug use, are often unknown. Risk assessments, therefore, regularly fail to capture true risk, particularly for women with no identified risk factors.

As a result, many women who are at risk for HIV infection, or may already be living with HIV, are not being tested and remain unaware of their status despite multiple contacts with the health care system. In a retrospective cohort study in South Carolina, where risk-based testing predominates, of 4,117 persons newly diagnosed with HIV infection between 2001 and 2005, 3,021 (73.4 percent) visited a health care facility one or more times prior to testing HIV positive. Of those with previous visits, 1,311 (43.4 percent) developed AIDS within one year of testing ("late testers"). Of these late testers, 704 (53.7 percent) had AIDS diagnosed at or within 30 days of their initial HIV diagnoses. For all those who had visited a health care facility prior to diagnosis, approximately 80 percent of the health care visits before HIV diagnosis were for conditions not likely to prompt HIV testing in a risk-based testing environment. Thus, risk-based testing failed to diagnose many individuals early in the course of their HIV infection, despite prior encounters with the medical system at times when they were likely already HIV infected.[16]

Importance of the Routine Offer of HIV Testing Regardless of Perceived Risk[17]

Early diagnosis and treatment are central to the fight to slow the HIV epidemic and improve the lives of women living with HIV. Toward this end, health care providers should ***routinely offer*** HIV testing – regardless of perceived risk—and health insurance providers should be required to reimburse the cost of all HIV testing regardless of documentable or known risk factors. In short, *all* HIV tests should be covered by insurers as an essential preventive service.

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[13] Campsmith ML, Rhodes PH, Hall HI, Green TA. "Undiagnosed HIV Prevalence Among Adults and Adolescents in the United States at the End of 2006." *Journal of Acquired Immune Deficiency Syndromes* 53(5) (2010):619–624.
[14] Henry J. Kaiser Family Foundation. "Fact Sheet: The HIV/AIDS Epidemic in the United States," (February 2009).
[15] U.S. Preventive Services Task Force. "Screening for Human Immunodeficiency Virus: Focused Update of a 2005 Systematic Evidence Review for the U. S. Preventive Services Task Force," No. 46. AHRQ Pub. No. 07-0597-EF-1 (April 2007).
[16] Duffus, W., Weis K., Kettinger, L., et. al. "Risk-Based Testing in South Carolina Health Care Settings Failed to Identify the Majority of Infected Individuals." *AIDS Patient Care and STDs* (2009) 23(5): 339-345.
[17] The undersigned use the phrase "routine offer of an HIV test" to mean HIV tests that are offered even in the absence of a known risk factor. We *do not* support HIV testing without patient consent. We *do* believe providers should routinely offer their patients HIV tests as a normal part of medical care ***even in the absence of identifiable risk factors***. The decision to be tested must be made by the patient, after consultation with her medical provider.

Testing Improves Health Outcomes
Early diagnosis allows for medical interventions which can slow disease progression and increase life expectancy. Routinely offering HIV testing regardless of perceived risk would result in increased rates of testing and early diagnosis, allowing people with HIV to live longer, healthier lives.

Testing Reduces New Infections
HIV-positive individuals who are in medical care have lower viral loads and, as a result, reduced infectiousness. A study found that if 10% of asymptomatic patients initiated ART each year, 28% of HIV infections could be prevented,[18] yet clearly treatment will not be initiated unless an individual knows their status. In addition, individuals often decrease their high-risk behavior upon receipt of an HIV diagnosis. People who are aware of their HIV status are 68% less likely to engage in unprotected intercourse with HIV-negative partners than those who are unaware of their status.[19] Routinely offering HIV tests as a regular part of medical care, therefore, can help slow the spread of HIV.

An Efficient Use of Resources
The benefits of early detection outweigh the costs of routinely offering HIV testing.[20] Firstly, early testing results in longer life expectancy.[21] Second, early testing saves health care costs by preventing further transmission, as discussed above. Third, early detection that flows from the routine offer of HIV testing saves money as health care costs are far higher among those individuals with more advanced disease: approximately $14,000 annually for individuals at the earliest stage of disease as compared with $36,500 per year for those with the most advanced disease.[22]

HIV Testing Should Respect the Rights of Those Tested

Medical providers should routinely offer HIV testing to all patients aged 13-64, and to those younger or older who are sexually active, regardless of perceived risk. Any test that follows from such a routine offer must be voluntary and uncoerced. Expanded HIV testing that does not ensure informed consent threatens subjecting women to violence from their partners, rejection from their families or communities, and/or alienating women from the health care system.

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[18] Long, Elisa F., Brandeau, Margaret L., Owens, Douglas K. "The Cost-Effectiveness and Population Outcomes of Expanded HIV Screening and Antiretroviral Treatment in the United States." *Annals of Internal Medicine,* 153:12, (2010): 778-789
[19] Marks, G. et al. "Meta-Analysis of High-Risk Sexual Behavior in Persons Aware and Unaware They Are Infected in the United States". *AIDS* 39 (2005): 446-53.
[20] Sanders, G.D., Bayoumi, A.M., Sundaram V., et al. "Cost-effectiveness of Screening for HIV in the Era of Highly Active Antiretroviral Therapy." *New England Journal of Medicine*, 352 (2005): 570-585.
[21] *Id.*
[22] Guttmacher Institute. "Bulk of Health Care Costs for People with HIV Are For Drugs, Hospitalization." *Perspectives on Sexual and Reproductive Health*, 38:2 (June 2006). Available at http://www.guttmacher.org/pubs/journals/3811906.html

The Routine Offer of HIV Testing Depends on Reimbursement

Despite the clear advantages of routinely offering HIV testing, it is not standard practice for medical providers to offer an HIV test as a routine part of care. Doctors cite competing priorities and lack of time as reasons for not testing. Of course with no mechanism to ensure reimbursement for HIV testing that flows from a non-risk-based routine offer, it will never be prioritized. Reimbursement is critical to motivating providers who are pressed for time and resources to test patients whom they may not perceive to be high risk.[23] Thus, to ensure that the routine (non-risk-based) offer of an HIV test becomes part of the standard of care for women and that providers are reimbursed for such testing, all HIV testing (whether risk-based or non-risk-based) and appropriate counseling should be included in the mandatory preventive services package.

We thank you for your consideration of these comments, and your review of this important topic, and we welcome the opportunity to discuss these issues further with you. Please feel free to contact Carl Schmid (cschmid@theaidsinstitute.org, 202/462-3042) or Alison Yager (ayager@hivlawproject.org, 212/577-3001 x239).

Sincerely yours,

ActionAIDS, Philadelphia, PA
AIDS Alabama, Birmingham, AL
AIDS Alliance for Children, Youth & Families, Washington, DC
The AIDS Institute, Washington, DC and Tampa, FL
AIDS Foundation of Chicago, Chicago, IL
AIDS United, Washington, DC
Alaskan AIDS Assistance Association, Anchorage, AK
The American Academy of HIV Medicine, Washington, DC
Asian & Pacific Islander Wellness Center, San Francisco, CA
Association of Nurses in AIDS Care, Akron, OH
Cascade AIDS Project, Portland, OR
Center for Health Justice, Los Angeles, CA
Community Access National Network (CANN), Washington, DC
Georgia AIDS Coalition, Snellville, GA
Harlem United, New York, NY
HIV Law Project, New York, NY
HIV Dental Alliance, Atlanta GA
Housing Works, Brooklyn, NY and Washington, DC
Inova Juniper Program, Springfield, VA
International Association of Physicians in AIDS Care, Washington, DC
International Women's Health Coalition, New York, NY
Los Angeles Gay & Lesbian Center, Los Angeles, CA
Lower East Side Harm Reduction Center, New York, NY
Memphis Center for Reproductive Health, Memphis, TN

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[23] Gever, J. "Physicians Reluctant to Follow CDC Call for Routine HIV Testing." *medpageToday*, November 20, 2008. Available at http://www.medpagetoday.com/HIVAIDS/HIVAIDS/11874

Multicultural AIDS Coalition, Boston, MA
National Alliance of State & Territorial AIDS Directors (NASTAD), Washington, DC
The National Black Leadership Commission on AIDS, Inc., New York, NY
Okaloosa AIDS Support and Informational Services, Inc. (OASIS), Ft Walton Beach, FL
Project Inform, San Francisco, CA
Racial and Ethnic Health Disparities Coalition
Sexuality Information and Education Council of the U.S. (SIECUS), Washington, DC and New York, NY
South Carolina Campaign to End AIDS, Columbia, SC
Treatment Access Expansion Project, Jamaica Plain, MA
United Methodist Church, General Board of Church & Society, Washington, DC
United Methodist Global AIDS Fund Committee, Denver, CO
U.S. Positive Women's Network (PWN), Oakland, CA
TheWellProject, Inc., Oakland, CA
Women Organized to Respond to Life-threatening Diseases (WORLD), Oakland, CA
Women Together For Change, Inc., Kingshill, Virgin Islands
The Woodhull Sexual Freedom Alliance, Washington, DC