



By Regular Mail and Email

May 17, 2010

Jeff Crowley  
Office of National AIDS Policy  
The White House  
Washington, DC 20502  
Email: AIDSpolicy@who.eop.gov

Re: Additional Recommendations for the National HIV/AIDS Strategy

Dear Mr. Crowley:

The undersigned welcome the opportunity to provide additional recommendations for the National HIV/AIDS Strategy (NHAS). We have reviewed ONAP's recent report summarizing community discussions and their implications for a National HIV/AIDS Strategy. The report does an extraordinary job with the challenging task of synthesizing hundreds of individual comments, written submissions and other input your office has received on essential elements of the NHAS. The purpose of this letter is to identify additional concerns which, while largely raised earlier in communications with ONAP, do not appear or receive the appropriate emphasis in the report that we believe they merit. As ONAP finalizes the NHAS strategy document, it is important that the civil and human rights of people with HIV be a central part of the United States' national strategy.

One striking, though not surprising, aspect of ONAP's recent report summarizing community recommendations for the NHAS was the extent to which HIV stigma was mentioned in the submissions to ONAP – in fact, the report identified “stigma and discrimination” among a few “crosscutting themes.”<sup>1</sup> As indicated by numerous community members, achieving the three primary goals identified by President Obama for the NHAS – preventing new HIV infections, increasing access to care and optimizing health outcomes, and reducing HIV-related health disparities – will not be possible without addressing the continuing, pervasive stigma faced by people living with HIV in the U.S. The comments provided below focus on specific actions (set forth in bold font) that will help reduce HIV stigma and thus help achieve the President's goals, by addressing HIV ignorance, ensuring effective HIV testing, and ending state-supported stigma and discrimination.

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<sup>1</sup> White House Office of National AIDS Policy, *Community Ideas for Improving the Response to the Domestic HIV Epidemic* 5 (2010), available at [http://www.whitehouse.gov/sites/default/files/microsites/ONAP\\_rpt.pdf](http://www.whitehouse.gov/sites/default/files/microsites/ONAP_rpt.pdf); see also *id.* at 22-23, 34, 52, 54, 58, 60, 65-66, 69.

## I. Address HIV Ignorance

Although more than 25 years have passed since physicians reported the first cases of HIV in the United States, HIV-related stigma continues to be prevalent and well documented.<sup>2</sup> The public health consequences of HIV stigma are grave. HIV stigma can lead people to avoid getting tested for HIV, refrain from obtaining needed healthcare, or forego taking antiretroviral medications. “A consequence of HIV-related stigma and discrimination is a negative effect on both HIV prevention efforts as well as care for individuals living with HIV.”<sup>3</sup> Studies have found that one reason that people do not get tested is their fear of stigma and discrimination.<sup>4</sup> Bias against people living with HIV also can “negatively affect the quality of care provided to HIV-positive individuals.”<sup>5</sup>

Stigma against people with HIV stems in significant part from ignorance about HIV transmission, which is still widespread in this country. “Large segments of the public remain uneducated about HIV and how it is transmitted,” which promotes fear and antipathy that can “often translate into biased and discriminatory actions.”<sup>6</sup> The persistence of stigma for people living with HIV and the associated misconceptions about HIV transmission was documented by a recent national survey conducted by the Kaiser Family Foundation.<sup>7</sup> In this national survey, “[n]otable [segments of the public] say they would be uncomfortable with an HIV-positive co-worker (23 percent), child’s teacher (35 percent of parents), or roommate (42 percent), and fully half (51 percent) of adults say they would be uncomfortable having their food prepared by someone who is HIV positive.”<sup>8</sup> According to the survey, “[o]ne third of Americans (34 percent) harbor at least one misconception about HIV transmission, not knowing that HIV *cannot* be transmitted through sharing a drinking glass (27 percent), touching a toilet seat (17 percent), or swimming in a pool with someone who is HIV positive (14 percent).”<sup>9</sup>

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<sup>2</sup> See, e.g., D. Rao et al., *Stigma, Secrecy, and Discrimination: Ethnic/Racial Differences in the Concerns of People Living with HIV/AIDS*, 12 AIDS & Behav. 265-271 (2008); P.A. Vanable et al., *Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women*, 10 AIDS & Behav. 473-482 (2006); G.M. Herek et al., *When Sex Equals AIDS: Symbolic Stigma and Heterosexual Adults’ Inaccurate Beliefs about Sexual Transmission of AIDS*, 52 Soc. Probs. 15-37 (2005); D.A. Lentine et al., *HIV-Related Knowledge and Stigma – United States, 2000*, 49 Morbidity and Mortality Wkly. Rep. 1062-1064 (2000), available at <http://www.cdc.gov/mmwr/PDF/wk/mm4947.pdf>.

<sup>3</sup> R.A. Brooks et al., *Preventing HIV Among Latino and African American Gay and Bisexual Men in a Context of HIV-Related Stigma, Discrimination and Homophobia: Perspectives of Providers*, 19 AIDS Patient Care & STDs 737 (2005); see also M.A. Chesney & A.W. Smith, *Critical Delays In HIV Testing and Care: The Potential Role of Stigma*, 42 Am. Behav. Sci. 1158, 1159-1165 (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

<sup>4</sup> Vanable et al., *supra* note 2, at 473 (summarizing research).

<sup>5</sup> Brooks et al., *supra* note 3, at 738.

<sup>6</sup> K.R. Waite et al., *Literacy, Social Stigma, and HIV Medication Adherence*, 23 J. Gen. Internal Med. 1367 (2008).

<sup>7</sup> Kaiser Family Foundation, *2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic* (2009), available at <http://www.kff.org/kaiserpolls/upload/7889.pdf>.

<sup>8</sup> *Id.* at 4.

<sup>9</sup> *Id.*; see also *id.* at 21 (Charts 27 & 28).

The Kaiser survey also demonstrated the linkage between misconceptions about HIV transmission and stigma against people living with HIV. People who incorrectly believed that certain activities posed a risk for HIV transmission were significantly more likely to say they would be uncomfortable working with someone who has HIV or having their food prepared by someone with HIV.<sup>10</sup> These levels of ignorance and misconception are intolerable, and perpetuate stigma and discrimination against people living with HIV. This is all the more troubling because that survey also found that “*levels of knowledge about HIV transmission have not improved since 1987.*”<sup>11</sup>

The appallingly high levels of ignorance about HIV need to be addressed aggressively as part of the federal government’s strategy on HIV/AIDS. The failure to talk frankly about HIV, and the consequent public confusion about the implication of “bodily fluids” in HIV transmission, is in good measure a product of a national cultural discomfort with speaking frankly about sex. Previously, in response to widespread ignorance and harmful, misguided fears about people with HIV, the U.S. Surgeon General sent an educational brochure to every household in the U.S.<sup>12</sup> By doing so, the federal Administration made clear that it thought that HIV is something everyone should know about, that speaking openly about sex and HIV is part of reducing stigma, and that knowing about HIV and how to prevent it is everyone’s responsibility, not just the responsibility of the relatively small numbers of individuals who have been tested and know they have HIV.

The federal government must commit itself *now* to providing real leadership on HIV education. The 1988 letter sent by the Surgeon General was a very important, significant step, and it is time to repeat it for the current generation. But clearly much more than distribution of an updated version of that letter is needed in order to make a real difference in the public’s understanding of HIV and to significantly reduce the stigma associated with HIV. Therefore, as part of the NHAS, the following actions should be taken:

**The Administration should commit itself now to determining how to educate the public about HIV/AIDS and to taking the identified necessary educational actions, so that accurate information about HIV transmission is effectively conveyed and harmful, stigmatizing myths about HIV transmission and people living with HIV are effectively refuted. As an immediate first step, ways to effectively achieve this goal must be evaluated. Methods that should be considered include, but are not limited to: (a) sending a mass mailing from the Surgeon General or CDC on HIV, sexual transmission, and how to avoid infection; (b) directing education funds to accurate, age-appropriate HIV-specific education in schools; (c) mandating sexual health care and education programs for juvenile, corrections and detention facilities receiving federal funds; and (d) distributing public service**

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<sup>10</sup> *Id.* at 5, 23 (Chart 31).

<sup>11</sup> *Id.* at 4-5 (emphasis added); *see also id.* at 22 (Chart 29).

<sup>12</sup> *See* U.S. Dep’t of Health and Human Servs. (“HHS”), *Understanding AIDS: A Message from the Surgeon General*, HHS Publication No. (CDC) HHS-88-8404 (1988), *available at* [http://profiles.nlm.nih.gov/qq/B/D/R/L/\\_/qqbdrl.pdf](http://profiles.nlm.nih.gov/qq/B/D/R/L/_/qqbdrl.pdf).

**announcements via mainstream and new media. Then the methods considered most likely to be effective must be implemented.**

II. Ensure Effective HIV Testing

The importance of expanded HIV testing in order to achieve the President's goals was highlighted in ONAP's recent report.<sup>13</sup> But in order to be effective, HIV testing must be provided in ways that ensure that it is voluntary, fully informed, and confidential or anonymous.

Providing pre-test information prior to HIV testing is necessary to satisfy legal requirements for informed consent, as well as medical ethical requirements. In addition, pre-test counseling that explains the nature of HIV testing and gives patients information about HIV disease provides many patients with important information they do not already know.<sup>14</sup> An additional benefit of pre-test counseling is that such counseling increases testing consent rates among patients.<sup>15</sup> Pre-test provision of information about HIV transmission provides an excellent opportunity to educate patients about HIV and how to begin to change risk behaviors, to the benefit of the individual patients and public health generally – and evidence shows it is feasible and effective even in emergency department settings.<sup>16</sup>

Furthermore, the pre-test dialogue between practitioner and patient is important for developing or enhancing trust between the patient and the care provider, and with greater trust comes an increased likelihood that the patient will seek and continue needed treatment. Studies show that patients' rates of adherence to prescribed treatment are higher where their trust in their physician is high.<sup>17</sup> This is especially important given the low rates at which

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<sup>13</sup> White House Office of National AIDS Policy, *supra* note 1, at 21-24.

<sup>14</sup> A. Hutchinson et al., *Understanding the Patient's Perspective on Rapid and Routine HIV Testing in an Inner-City Urgent Care Center*, 16 AIDS Educ. & Prevention 101, 111-12 (2004).

<sup>15</sup> See, e.g., L. Samson & S. King, *Evidence-Based Guidelines for Universal Counseling and Offering of HIV Testing in Pregnancy in Canada*, 158 Can. Med. Ass'n J. 1449, 1451 (1998); R. Kropp et al., *Unique Challenges to Preventing Perinatal HIV Transmission Among Hispanic Women in California: Results of a Needs Assessment*, 17 AIDS Educ. & Prevention 22, 35 (2005). Nearly 40% of the participants in Kropp's study were unaware that ZDV treatment could reduce the risk of mother-child transmission, but 92% indicated that such knowledge would increase their willingness to be tested. *Id.* These findings led the authors of the study to conclude that "[t]o improve HIV test acceptance by Hispanic women, culturally appropriate pretest counseling with information on treatment to reduce perinatal HIV transmission is needed." *Id.* at 36.

<sup>16</sup> Routinely recommending HIV counseling and testing is workable and effective in the emergency room; testing in that setting can be increased by streamlining counseling to the needs of the individual patient, providing some information in writing, and involving non-physician staff in counseling. See, e.g., R. Rothman, *Current Centers for Disease Control and Prevention Guidelines for HIV Counseling, Testing and Referral: Critical Role of and a Call to Action for Emergency Physicians*, 44 Annals of Emergency Med. 31 (2004).

<sup>17</sup> F.L. Altice et al., *Trust and Acceptance of and Adherence to Antiretroviral Therapy*, 28 J. of AIDS 47-58 (2001) (finding trust in a personal physician was the strongest predictor of willingness to initiate antiretroviral treatment in a population of primarily African-American and Hispanic inmates and was

patients newly diagnosed as having HIV are linked to follow-up care in some settings.<sup>18</sup> Therefore, ensuring that a patient receives the information that an individual considering an HIV test would reasonably want to know will increase the likelihood of patient-provider trust and of treatment adherence if the patient gets a positive HIV test result.

Opt-out testing which omits any discussion of risk behaviors disingenuously suggests that everyone, even the celibate, are at risk and thus is counter-productive to the goals of preventing HIV transmission and ending HIV stigma. Moreover, such testing saves little time and no money.<sup>19</sup> On the other hand, providing all of those offered testing with culturally and linguistically appropriate information about HIV and risk-reduction strategies will help to reduce misperceptions and related stigma.

It is estimated that half of all new infections are caused by individuals in the acute infection stage (people with high viral loads who typically do not know that they are infected and will usually test negative in standard antibody screening),<sup>20</sup> yet most people are unaware of this. Testing personnel must counsel those who test negative about the possibility that they could in fact be living with HIV and at their most infectious. Eliminating post-test counseling for these individuals is “streamlining” with a very high cost – and little or no public health justification.

Any HIV testing protocol also must humanely reflect the real-world circumstances of the target population and community. For example, for those entering the state prison system in Alabama and South Carolina, a positive HIV test result will have more of an impact on that individual’s life while incarcerated than what they did to warrant imprisonment. The impacts include being excluded from prison work programs and being required to wear armbands, badges, or uniforms that declare their HIV status to everyone, including visitors to the facilities.<sup>21</sup> At best, proposals for universal opt-out testing in such environments are ethically questionable. (See also Point III, below.)

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a strong predictor of preventive services use among African Americans); *see also* A.S. O’Malley et al., *The Role of Trust in Use of Preventive Services Among Low-Income African-American Women*, 38 *Prevention Med.* 777-785 (2004) (survey found that trust in a personal physician was strongly associated with use of preventive health services among low-income African-American women); *see also* D.H. Thom et al., *Further Validation and Reliability Testing of the Trust in Physician Scale*, 37 *Med. Care* 510-517 (1999); D.G. Safran et al., *Linking Primary Care Performances to Outcomes of Care*, 47 *J. of Fam. Prac.* 213-218 (1998); E. Etchells et al., *Bioethics for Clinicians: 1. Consent*, 155 *Can. Med. Ass’n. J.* 177-180 (1996).  
<sup>18</sup> M. Lyons et al., *Emergency Department HIV Testing and Counseling: An Ongoing Experience in a Low-Prevalence Area*, 46 *Annals of Emergency Med.* 22-28 (2004) (finding that only 35% to 64% of emergency department patients newly diagnosed with HIV are successfully linked to follow-up care post-diagnosis).

<sup>19</sup> D.R. Holtgrave, *Costs and Consequences of the U.S. Centers for Disease Control and Prevention’s Recommendations for Opt-out HIV Testing*, *PLoS Med.* (2007), available at <http://www.plosmedicine.org/article/info:doi%2F10.1371%2Fjournal.pmed.0040194>.

<sup>20</sup> C.D. Pilcher et al., *Acute HIV Revisited: New Opportunities for Treatment and Prevention*. 113 *J. of Clinical Investigation* 937-945 (2004).

<sup>21</sup> *See* American Civil Liberties Union & Human Rights Watch, *Sentenced to Stigma: Segregation of HIV-Positive Prisoners in Alabama and South Carolina* (2010), available at <http://www.aclu.org/files/assets/health0410webwcover.pdf>; *see also infra* note 26.

Therefore, as part of the NHAS, the following actions should be taken:<sup>22</sup>

**Remove opt-out and/or mandatory HIV testing as a condition for receipt of federal Ryan White Act or CDC funding. HIV testing programs must be tailored to different clinical settings, populations, and patient needs, such as those in dependent or abusive relationships, recent immigrants, and young people without strong systems of social support.**

**Create incentives to encourage states to adopt local policies that mandate counseling and offering voluntary HIV testing, regardless of *perceived risk*, that is combined with STI counseling and testing as part of a broader sexual health care approach. Mandatory counseling and offers of voluntary testing should be included in primary care services, including routine gynecological and sexual and reproductive health services, and other key points of entry for ongoing primary care.**

**Increase funding for model programs that streamline the HIV testing process while documenting informed consent, increased voluntary testing, and corresponding increased entry into care. Funding incentives should be based on a protocol's effectiveness in identifying additional people with HIV and ensuring their linkage to care, not on eliminating patient-centered approaches to care that encourage individual responsibility and protect patient autonomy.**

### III. End State-Supported Stigma and Discrimination

Various forms of state-supported stigma and discrimination persist in the U.S. One of the most egregious is prosecutions of individuals based on their HIV status. Criminalizing conduct based on HIV status stigmatizes people with HIV, fuels ignorance about HIV transmission, and serves as a disincentive to being tested for HIV (because only those who know they have HIV are subject to prosecution).

About half of the states have HIV-specific laws criminalizing sexual contact by people with HIV; most of them hinge prosecution on the failure of an HIV-positive person to disclose his or her HIV status and obtain consent from a sexual partner and do not require that HIV was transmitted.<sup>23</sup> Importantly, none of these laws do anything to deter

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<sup>22</sup> Many of the recommendations that follow in this section were also included in *Critical Issues for Women and HIV: Health Policy and the Development of a National AIDS Strategy* (2009), available at <http://www.hivlawandpolicy.org/resources/view/426>, which was submitted to ONAP in 2009.

<sup>23</sup> See Lambda Legal, *State Criminal Statutes on HIV Exposure* (2009), available at [http://data.lambdalegal.org/publications/downloads/fs\\_state-criminal-statutes-hiv-exposure.pdf](http://data.lambdalegal.org/publications/downloads/fs_state-criminal-statutes-hiv-exposure.pdf). People with HIV are being prosecuted throughout this country – under both HIV-specific laws and more general criminal laws – for conduct that is either consensual or poses no significant risk of HIV transmission. See, e.g., Center for HIV Law and Policy, *Prosecutions for HIV Exposure in the United States, 2008-2010* (2010), available at <http://www.hivlawandpolicy.org/resources/view/456>.

risk-taking behavior that actually is driving the epidemic: unprotected sex between persons who don't know their HIV status. Rather, the statutes punish only those who have taken the step of actually getting tested for HIV. Consequently, it is not the risk of transmission, but the fact of an HIV test, that is the predicate to prosecution.

Recent research increasingly has raised concerns about the rise in criminal prosecutions of people living with HIV and the negative consequences of these prosecutions.<sup>24</sup> An increasing number of public health experts, human rights scholars, and other individuals view HIV criminalization laws and prosecutions of people with HIV for being sexually active as evidence of the continuing stigmatization of people living with HIV/AIDS. Recent research demonstrates that there is no evidence that criminal prosecutions have any positive public health impact whatsoever.<sup>25</sup>

Given the serious harms that flow from these prosecutions, the federal government should take steps to discourage them.

Another egregious form of state-supported stigma and discrimination is the treatment of inmates and detainees with HIV. The inhumane treatment of inmates of correctional facilities, such as the Alabama and South Carolina state prison systems, must be addressed. Prisoner advocates have labored for years for the voluntary elimination of policies that treat those with HIV as toxic and unfit for work and early release programs, forced to wear armbands, and segregated in a manner than is reminiscent of barbaric treatment of other marginalized populations from decades ago.<sup>26</sup> The federal government should take leadership in seeking and achieving an end to such policies. Moreover, serious deficiencies in the treatment of immigrants held in detention facilities – including failure to provide vital medications and other needed medical care – require federal attention.<sup>27</sup>

Therefore, as part of the NHAS, the following actions should be taken:

**The CDC should distribute information about HIV transmission risks and myths to criminal justice personnel, state health departments, and the general public (see also Point I, above).**

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<sup>24</sup> See, e.g., Z. Lazzarini et al., *Evaluating the Impact of Criminal Laws on HIV Risk Behavior*, 30 J. Law, Med. & Ethics 239-253 (2002).

<sup>25</sup> S. Burris et al., *Do Criminal Laws Influence HIV Risk Behavior? An Empirical Trial*, 39 Ariz. St. L.J. 467-519 (2007).

<sup>26</sup> In Alabama, prisoners with HIV must wear white armbands and live in special units. In South Carolina, HIV-positive men have blue dots on their badges and are housed in a maximum-security prison; female prisoners carry the name of the HIV/AIDS dorm on their uniforms. South Carolina bars HIV-positive prisoners from participating in work-release and from some in-prison jobs and Alabama limits such opportunities. The restrictions on these prisoners also effectively ensure that, due to program exclusion, they will serve more time behind bars than their uninfected counterparts. See ACLU & Human Rights Watch, *supra* note 21.

<sup>27</sup> Human Rights Watch, *Chronic Indifference: HIV/AIDS Services for Immigrants Detained by the United States* (2007), available at <http://www.hrw.org/en/reports/2007/12/05/chronic-indifference>. Some specific steps that the Administration can and should take to address these problems are set forth at pages 4 to 6 of this Human Rights Watch report.

**The Department of Justice should issue guidance discouraging prosecutions in the absence of a specific intent to transmit HIV.**

**The CDC should explore incentive mechanisms – much as it has done in its push for adoption of its 2006 HIV testing recommendations for health care settings – that will encourage states to take corrective action. Incentives could include research grants that would monitor changes in testing and risk behavior following repeal of HIV criminal laws; prevention project grants in correctional facilities in states that eliminate barriers to testing, such as the threat of prosecution for having consensual sex after diagnosis; or other incentives related to the removal of legal and other barriers to HIV testing.**

**Federal funding for law enforcement and HIV testing programs should be restricted to state entities that can demonstrate the existence of non-discrimination policies for the housing, program participation, and service availability afforded inmates with HIV and other disabilities.**

We hope that the information and suggestions contained in this letter will guide formulation of the National HIV/AIDS Strategy. We believe that taking the concrete actions set forth above will help ensure that implementation of the NHAS is successful.

Sincerely,

Rose Saxe, Staff Attorney, AIDS Project, American Civil Liberties Union

Catherine Hanssens, Executive Director, The Center for HIV Law and Policy

Bebe J. Anderson, HIV Project Director, Lambda Legal