



AIDS Foundation

May 29, 2008

BY EMAIL

Bernard M. Branson, MD Associate Director for Laboratory Diagnostics Division of HIV/AIDS Prevention Centers for Disease Control and Prevention 1600 Clifton Road MS D-21 Atlanta, GA 30333

#### Re: Comments on Draft of "Implementing HIV Testing in Correctional Facilities"

Dear Dr. Branson:

Thank you for the opportunity to provide comments on the draft Correctional Facilities component of the HIV Testing in Health Care Setting Implementation Guide, entitled "Implementing HIV Testing in Correctional Facilities" (referred to below as the "Guide"). We are submitting these comments on behalf of the undersigned community-based organizations, health care providers, and advocates for people living with HIV. We appreciate your assurances that these comments will be carefully considered, and trust that they will help to make the Guide a more effective and useful document for health care providers working in correctional facilities.

#### I. GENERAL COMMENTS

The undersigned organizations endorse the Guide's reiteration of the legal obligation of correctional officials and health care providers in correctional settings to protect the privacy and confidentiality of HIV-positive individuals, and the concrete steps recommended to accomplish that. These and other provisions of the Guide intended to advance fair treatment of HIV-positive prisoners are, we believe, important steps in advancing voluntary HIV testing in correctional facilities. While we have significant concerns with aspects of the Guide and, as requested, identify a number of additional topics, changes and clarifications needed to make the document more useful, the Guide's recognition of the importance of addressing prisoners' human rights and the need for flexibility in putting the 2006 Recommendations into practice are encouraging indications that the drafters seek to develop guidance that truly accommodates the needs and rights of prisoners with HIV.

We appreciate the opportunity to offer these comments. However, we feel it is important to stress that the very short amount of time allotted for community input seriously burdened the ability to ensure the broad and representative community input that the Guide merits, particularly from individuals who are or have been incarcerated, and their representatives. Input from such reviewers – with direct knowledge about the challenges posed in correctional settings – would be especially valuable in making the document effective and useful. The primary authors of these comments received the Guide on April 30, with a May 16, 2008 deadline for written feedback. In response to our request for more time to submit comments, CDC granted us an extension to May 30th. While the extra time was helpful, the time to prepare comments on a long, detailed document addressing an important and

complex topic was too short. After all, as the overarching purpose of the Guide is to improve the acceptability and administration of HIV testing, diagnosis and care among incarcerated persons -- care that in many instances must continue after release to be effective -- the input of those who are targeted in this effort is critical. We would welcome an opportunity for a more realistic opportunity to review the next draft of this document.

#### II. PRIMARY CONCERNS

#### A. Devote a section to informed consent.

CDC's "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-care Settings" ("Revised Recommendations") emphasize the voluntary nature of HIV screening, the importance of pre-test information, and the necessity to afford patients an opportunity to decline testing if they so choose. However, the Guide fails to address the important issue of informed consent. A separate sub-section should be added to Section II explaining the requirement for informed consent, the considerations that go into ensuring that consent is truly informed, and the information that should be provided in order to obtain informed consent. Anything less would be tantamount to endorsing medical malpractice.

Obtaining informed consent is a legal and ethical pre-requisite to the provision of medical services and procedures, including an HIV test. In the Revised Recommendations, CDC defined "informed consent" as

[a] process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. Elements of informed consent typically include providing oral or written information regarding HIV, the risks and benefits of testing, the implications of HIV test results, how test results will be communicated, and the opportunity to ask questions.

2006 Revised Recommendations for HIV testing, p. 2.<sup>1</sup> The American Medical Association maintains that informed consent consists of the physician discussing with the patient:

- i.The patient's diagnosis, if known;
- ii.The nature and purpose of a proposed treatment or procedure;
- iii. The risks and benefits of a proposed treatment or procedure;
- iv.Alternatives (regardless of their cost or the extent to which the treatment options are covered by health insurance);
- v.The risks and benefits of the alternative treatment or procedure;
- vi. The risks and benefits of not receiving or undergoing a treatment or procedure.

The section on informed consent should explain that informed consent is a legal, not a medical, concept and remove the legally-inaccurate statement that "general informed consent," a term that does not exist in the law, can "encompass informed consent for HIV testing."<sup>2</sup> The Guide should state unequivocally that HIV screening without the patient's knowledge is an especially egregious and unacceptable breach of a person's civil and human rights. The considerations that go into ensuring that consent is truly informed – such as ensuring that the person is capable of providing consent and

<sup>&</sup>lt;sup>1</sup> As the Revised Recommendations make clear, "informed consent" and "HIV-prevention counseling" are not the same thing. See CDC, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings* (Sept. 22, 2006).

<sup>&</sup>lt;sup>2</sup> See Guide at p. 5.

determining that the information is understood – should be addressed. The information that should be provided in order to obtain informed consent should be stated. The risks and benefits of testing in the correctional setting that should be conveyed to inmates before they are asked to consent to testing should include information on who will have access to their test results; what case reporting is required by law or prison policies if the inmate tests positive; and the implications of the test result (i.e., extent to which a positive test result will or may affect parole, probation, housing or facility placement, program eligibility, work release, medical care and treatment, and post-release supervision.)

In addition, the Guide should provide practical advice for correctional staff to achieve truly voluntary HIV screening in the context of incarceration. The section should also urge correctional health officials to accept the decisions of individuals who decline HIV testing and refrain from harassing or penalizing them in any way because of that decision. Because living conditions in correctional setting are often violent and rarely private, individuals can have various, legitimate concerns about accepting testing or disclosing their HIV status. With policies to mitigate such concerns and active promotion of the availability of HIV testing and healthcare services, facilities may gain the trust of some people over time.

#### B. Include opt-in approaches among alternatives to opt-out screening.

The Guide appropriately recognizes that routine opt-out screening may not be universally workable and therefore that alternative approaches are acceptable to promote awareness of HIV status among inmates. However, oddly absent from the list of alternatives is "opt-in" screening. The Guide should include a discussion of opt-in screening and its benefits (including, but by no means limited to, ensuring that no one is tested without their knowledge). Because incarceration is by its very definition coercive, it is especially important that the Guide include discussion of the benefits of voluntary HIV testing in this setting. For many inmates in short-term custody, an HIV test while incarcerated will be the portal to health care which will necessarily continue or commence after release; ensuring that inmates experience this process as voluntary, respectful, beneficial, and unrelated to their pending criminal matter will have a direct, significant impact on their engagement with the long-term care essential to their health, the health of their partners, and the public's health. With experience in states such as New York and Illinois demonstrating that low rates of HIV testing acceptance in some settings results largely from voluntary screening not being readily offered or discussed, it is clear that it is health care providers willingness to offer and engage in testing, not the elimination of patient protections, that is most critical to increased HIV diagnosis.<sup>3</sup> Testing that is not fully informed and consensual, while permitted in some jurisdictions, breaches civil and human rights and makes future engagement with the medical and public health sector enormously challenging.

<sup>&</sup>lt;sup>3</sup> To address this problem, the "offer of voluntary [opt-in] HIV testing" has been mandated in some instances For example, both Illinois and New York state law require healthcare providers to offer HIV testing to pregnant patients, a requirement resulting in virtually universal, voluntary acceptance of HIV testing. Illinois state law also requires state prisons to offer (and to document the offer and acceptance or rejection) of voluntary HIV testing for all new inmates, and increased HIV testing in those correctional facilities by 475% between 2005 and 2007 after a mandated offer was required by law.

### C. Include specific recommendations appropriate for different populations and correctional settings.

The Guide should more directly acknowledge, at the outset, the various different configurations of correctional settings in this country, which means that one testing program framework will not be best or even effective in every setting. More detailed recommendations are needed in relation to various populations and settings within correctional systems. For example, the Guide should include specific recommendations for expanded testing in juvenile detention centers; work-release programs; maximum security; facilities for females; transgender populations; and gang-involved populations, among others.

In particular, the special challenges posed by the emotional/cognitive distress of arrest and lock-up, often in an environment of drug and alcohol withdrawal, and the attendant risks of depression and suicide, inform whether consent can legally and ethically be obtained. Short-term incarceration also warrants a separate section addressing HIV screening in that situation. Inmates who are incarcerated only briefly may not learn their test results while still in jail and may be unreachable after release. This is especially likely if the inmate is not capable of providing informed consent when first incarcerated (e.g., due to drug use or emotional distress). For short incarcerations, offering rapid testing to all inmates may be the most practical and successful approach to increase HIV testing. Inmates who affirmatively agree to be tested are more likely to make efforts to learn their test results. Rapid testing and already-formed linkages to medical care and other services in the community will be especially important for testing in the short-term incarceration context.

Finally, the guidance needs to address the complexities of pregnant prisoners' choices in treatment decisions for themselves and to prevent vertical HIV transmission, and their right to autonomy in decision-making, even when incarcerated. At present, the guidelines present as a given that all pregnant women will commence ARV to prevent transmission, regardless of personal health and choices. As the NIH guidelines on prevention of perinatal transmission make clear, a particular course of treatment is elected by, not mandated for, the pregnant woman.

## D. Explicitly clarify that correctional facilities have a court-recognized legal obligation to have medical services in place that respond to the serious medical needs of inmates, including those with HIV.

As the U.S. Supreme Court recognized more than thirty years ago in *Estelle v. Gamb*le, "deliberate indifference to serious medical needs" in the prison context is a constitutional violation. "An inmate must rely on prison authorities to treat his medical needs; if the authorities fail to do so, those needs will not be met."<sup>4</sup> Accordingly, delaying or switching the provision of HIV medications on the basis of cost consideration rather than medical efficacy, when the change or delay has a negative impact on an inmate's health, violates inmates' protected rights to adequate medical care.<sup>5</sup> For example, the

<sup>&</sup>lt;sup>4</sup> Estelle v. Gamble, 429 U.S. 97, 103-04, 97 S.Ct. 285, 290-91 (1976). See also, e.g., McNally v. *Prison Health Services,* 46 F.Supp. 2d 49 (D. Maine 1999)(where an HIV positive detainee repeatedly informed prison medical personnel that he was following a strict regimen of HIV medication and was deprived of that medication for three days, a jury could find that the defendant was deliberately indifferent to the inmate's serious medical needs).

<sup>&</sup>lt;sup>5</sup> See, e.g., Taylor v. Barnett, 105 F.Supp. 2d 483(E.D. Va. 2000)(claim of inmate with AIDS that prison doctor switched his HIV medications not for medical purposes, but for cost considerations, causing serious side effects and shortening his life, stated a claim for violation of his 8<sup>th</sup> amendment rights to adequate medical care).

suggestion in the Guide in Section V.B.1 (concerning linkage to medical care during incarceration) that an inmate's initial visit with an HIV provider need not be face-to-face, and that HIV-positive inmates' access to competent medical care can be determined by "available resources," is contrary not only to prevailing medical and ethical standards, but to prevailing law.

# E. Address the role of HIV testing as part of a broader HIV prevention and health care program, including screening and treatment for viral hepatitis, STDs and tuberculosis, and the value of condom access and programs that promote inmate health and voluntary testing.

U.S. prison officials have a "special duty" to curb the spread of HIV and hepatitis C among the more than 11 million people who spend time in the prison system each year, because about one-third of U.S. residents who have hepatitis C and 15% of individuals with HIV are incarcerated in any given year.<sup>6</sup> Currently, 95% of U.S. prisons do not make condoms (male or female) available to inmates. Few facilities even provide condoms to inmates at discharge or for conjugal visits. Yet, according to a 2002 survey of U.S. prisoners, inmates indicate that roughly 44% of prisoners participate in sex while imprisoned.<sup>7</sup> In addition, researchers estimate that about 70% of people who have sex while in prison had their first same-sex partner while incarcerated.

#### F. Add a separate section on planning and implementation.

The target audience for the Guide should be urged to convene locally with state correctional health officials, policymakers, wardens, discharge planners, community-based organizations servicing HIV-positive ex-offenders, Medicaid and ADAP officials, housing and substance abuse treatment providers, peer educators, ex-offenders, and other stakeholders to review applicable polices and laws and identify ways to take action on these and other relevant recommendations. Many of the undersigned organizations created and endorsed a document designed to help stakeholders assess local needs and determine next steps toward expansion of voluntary HIV testing services. This document – *Expanding the Availability and Acceptance of Voluntary HIV Testing: Fundamental Principles to Guide Implementation* (available at www.hivtestingprinciples.org) – and other practical resources should be made available to correctional officials to establish responsive policies and practices. In particular, corrections officials will need to contemplate issues specific to their settings, including:

- Approaches appropriate for the length of stay of inmates/detainees
- Cost and available resources
- Inmates'/detainees' demographics (age, gender, sexual orientation, etc.)
- Healthcare infrastructure
- Integration (or lack thereof) among HIV, STD, TB, and viral hepatitis services
- Needed training and technical assistance
- Approaches appropriate for types of correctional settings (medium or maximum security; juvenile detention; work release; parole, etc)
- Available re-entry services with expertise serving HIV-positive ex-offenders
- Systems development (policy development; staff buy-in; etc)

<sup>&</sup>lt;sup>6</sup> Opinion, *Prisons Should Make Condoms Available To Prevent Spread of HIV, Hepatitis C*, New York TIMES (4/29/2005)

This new section might highlight examples of jurisdictions that have applied creative models to expand voluntary HIV testing services as part of their response to HIV among individuals affected by the criminal justice system. Specific examples should mention the process used to achieve buy-in among facility and/or correctional system workers and decision-makers. In addition, the role of correctional facilities in ensuring that individuals released from their custody receive appropriate discharge planning, linkages, and referrals cannot be overstated. In order to achieve stability and uninterrupted healthcare in community settings, discharge planning must coordinate closely with Medicaid, AIDS Drug Assistance Programs, community health centers, and other community-based social service agencies. The need for correctional health programs to coordinate between and among various public and private entities should be strengthened in the Guide.

The advantages of correctional-CBO collaborations are many, and should be underscored in the Guide. Using community-based service providers with the training and experience to offer quality counseling and testing services avoids unnecessary expenditures of time and money on training and utilizing staff to perform these services, while conserving scarce dollars for those services that must be provided in-house. Further, the use of non-correctional staff in HIV testing and related services increases the likelihood that inmates, fearful of confidentiality breaches and other negative institutional consequences of positive test results or disclosures of risk behavior, will accept testing and engage in post-test counseling.

Finally, the implementation guidance should include specific materials and tools, such as model scripts, that will promote best practices and ensure rapid implementation of a high-quality, sound program. Identification of tools would include references to videos that can be used in group settings to provide basis information to inmates prior to test offers, and sources for these and other materials.

#### III. ADDITIONAL COMMENTS ON DRAFT TEXT

#### A. Introduction of Draft

1. Add a preamble to the Introduction (p. 3):

The introductory section should open with a broad statement acknowledging the role of voluntary HIV counseling and testing services in a broader continuum of interconnected and interdependent approaches needed to adequately respond to the HIV/AIDS epidemic. In the context of corrections, that continuum includes, but is not limited to:

- HIV, STD, TB, and viral hepatitis prevention education, including peer-based services
- HIV, STD, TB, and viral hepatitis prevention education for visitors
- Voluntary, accessible HIV, STD, TB, and viral hepatitis screening
- Accessible and high-quality HIV medical care and treatments
- HIV-specific discharge planning
- HIV-specific community re-entry services
- Surveillance
- Enforced HIV confidentiality policies
- Enforced universal precaution policies
- Trained and informed staff

We strongly believe that any perception that HIV testing expansion alone is sufficient to address the HIV-related needs of correctional populations could do more harm than good.

#### **B. Section II of Draft**

This Section correctly recognizes that alternatives to opt-out HIV screening will be appropriate in some correctional facilities, for various reasons. As noted above, greater discussion of alternative approaches to HIV testing should be provided in this document. Moreover, this Section should be revised to reflect the existence of appropriate alternatives and to more accurately reflect the information provided in the Section, as follows:

- Section II should be re-titled "HIV Screening in Correctional Medical Clinics" (p. 5): This re-titling is appropriate both to better reflect the Section content and because most of the first paragraph applies to HIV testing generally, not only opt-out screening.
- A sub-section "A. Opt-out HIV Screening" should be created (p. 5): This Section should start with the last two sentences of the first paragraph and contain the current sub-sections "A" and "B."
- 3. Recognition of the potential drawbacks of opt-out screening should be added (p. 5): The current text lists potential benefits of opt-out screening, but lacks any reference to potential detriments to such screening. The text should refer to such potential detriments as the risks of testing inmates for HIV without their knowledge; of failing to foster communication and trust between the inmate and the medical care provider; and of failing to impart important information (including the possibility of testing negative while in a highly infectious early stage of the infection) to all tested inmates.
- 4. The tips for implementing opt-out HIV screening should be revised and expanded (p. 5): The Guide needs to provide specific guidance on how to ensure that HIV testing in correctional settings is "free from coercion." The inherently coercive nature of correctional settings poses a special challenge for implementing a non-coercive testing program – especially if the testing program is opt-out – yet the Guide fails to provide guidance on that important issue. The Draft needs to acknowledge the high risk of coercive testing in the correctional setting context and discuss the need for special approaches in this setting in order to avoid coercive testing.

The term "general informed consent" is misused here and in other parts of the Guide. General consent covers procedures, conditions, and outcomes for which the risks and benefits are generally well known. The meaning of the term "other legal authorization for medical care" is unclear. As discussed above, informed consent is needed before an individual is tested for HIV.

In accordance with the Revised Recommendations, the "Tips" for opt-out screening should state that patients should be provided "an explanation of HIV infection and the meanings of positive and negative test results" and "an opportunity to ask questions and to decline testing." (See Revised Recommendations, p. 7-8.)

The last bullet should reference the legal obligation upon correctional facilities – under the U.S. Constitution – to provide medical care to inmates, by re-wording such as the following: "Inmates diagnosed with HIV infection will need to be linked promptly with appropriate clinical care and support services. Each facility MUST [should] be prepared to meet the legal obligation for provision of medical care that could be triggered by a positive test result." 5. The sub-section on "Alternative approaches" should be expanded and revised (p. 5-8): As discussed under "Primary Concerns," above, "opt-in screening" should be added to this section.

The meaning and intent of the section on "Demographic screening" (p. 7-8) is unclear. Moreover, we question the benefits of expending resources to develop demographic screening criteria. The suggestion that incarceration systems collaborate with local public health entities to develop strategies (p. 8) seems potentially more productive than either "Demographic screening" or "Custody-based criteria for screening" (p. 8) and therefore should be listed before those two approaches.

#### C. Section III of Draft

1. This section recognizes that confidentiality of HIV information is especially difficult and important in correctional settings and contains some very important and useful guidance on protecting confidentiality. However, the suggestion in the opening paragraph of Section III that federal OSHA requirements may require disclosure of an inmate's HIV status following a possible occupational exposure is confusing and misleading. Under OSHA, covered employers and employees does not include the United States or any State or political subdivision of a State. As virtually all correctional facilities are operated by such government entities and therefore governed by individual state laws rather than the OSHA provisions mentioned here, the reference provides no useful guidance and should be deleted.

2. Additional text should be added to the "Confidentiality and privacy considerations" (p. 10):

Measures to "prevent unauthorized persons from viewing inmate health care data . . . " (p. 10) are extremely important for inmates diagnosed as having HIV. Specific suggestions should be added under this bullet point, to ensure that its importance is recognized and privacy is ensured. For example, "Maintain documents containing inmate health care information in folders or other containers so that the information is not visible to others;" "Maintain health care information about each inmate separately from information about other inmates (e.g., do not maintain health care information about more than one inmate in the same log book)."

3. The "Suggestions for providing HIV services" should be revised (p. 10): The two sentences in the last bullet should be split into two separate points. The phrase "before seeking consent for HIV testing from inmates" should be appended to the sentence "Inform inmates specifically who will have access to their medical information."

4. The "Special recommendations for adolescents confined in adult correctional facilities" should be revised (p. 11):

The significance of the first bullet should be explained – i.e., add that "therefore it is especially important that adolescents be informed of their rights and that those rights be respected."

The statement that adolescents should be informed that "their HIV status will not adversely affect their medical care or legal rights" is unclear and misleading and should be deleted. Unfortunately, a diagnosis of HIV can adversely impact an individual's medical care and will affect their legal rights (e.g., state laws may require reporting of that diagnosis to public health officials, HIV-specific laws may put the inmate at risk of criminal prosecution if he or she engages in certain conduct after learning that diagnosis).

The last bullet in this section needs to be revised to make clear that state laws differ as to who is an emancipated minor and for what purposes (e.g., some states specifically grant minors the right to consent to services related to sexually transmitted diseases without parental consent or notification). That bullet could be re-worded as follows: "Before implementing HIV testing, determine whether state law requires parental consent or notification for HIV testing and/or HIV-related health care services for minors. If required by law, obtain consent for testing and/or health care services from the appropriate adult prior to providing that service."

#### **D.** Section IV of Draft

- Sub-section D ("Other considerations") should be expanded (p. 14): This section appropriately notes that some inmates may be "under the influence of drugs or alcohol use or withdrawal, or emotional distress" at intake. The text should specifically state that inmates should not be tested if they are not capable of providing informed consent to the HIV test, whether due to alcohol or drug use, emotional distress, or other reasons.
- 2. Sub-section F ("Providing HIV test results") should be revised (p. 16-18): Subsection 1 should include a recommendation that additional information be provided, in person, to inmates who test negative. People who test negative need counseling so they fully understand that they might still be infected and highly infectious and understand how to avoid transmitting the virus. The HIV tests typically used look for antibodies to the virus, which usually develop six weeks to six months after infection. Before the antibodies develop, a person infected with HIV will not test positive, but may be highly infectious. (See, e.g., Pope, M. & Haase, A.T. (2003) Transmission, Acute HIV-1 Infection and the Quest for Strategies to Prevent Infection, Nature and Medicine, 9, 847-852; Pilcher, C.D. et al. (2004) Acute HIV Revisited: New Opportunities for Treatment and Prevention, Journal of Clinical Investigation, 113, 937-945.) Studies have estimated that almost half of all HIV transmissions occur when a person with acute HIV infection unknowingly transmits HIV to others. (See, e.g., Cates, W. et al. (1997) Primary HIV Infection: A Public Health Opportunity, American Journal of Public Health, 87(12), 1928–1930; Wawer, M.J. et al. (2005) Rates of HIV-1 Transmission per Coital Act, By Stage of HIV-1 Infection, in Rakai, Uganda, Journal of Infectious Diseases, 191, 403-409.) This Guide should state that this risk needs to be explained to all persons tested, so that those who test negative understand that they may still have HIV and how transmission can be avoided.

Subsection 2 should be revised by deleting the suggestion that prison staff can notify inmates of test results simply by "providing a notice that indicates 'your test results are normal" (p. 16). In addition to the serious disadvantages noted in the draft text, conveying results in that way fails to notify the inmate that he or she may be infected and infectious despite the negative test result.

Subsection 3 should incorporate into this document the guidance on prevention counseling provided in the Revised Recommendations, rather than simply referencing the Revised Recommendations, so that this document will be more useful to its intended audience.

#### E. Section V of Draft

1. Subsection A.3 should be revised (p. 19-20):

This subsection refers to the fact that HIV antibody test results may be negative or indeterminate while the person tested actually has acute HIV infection. As mentioned above, that possibility should be included in information provided to all inmates prior to HIV testing and at the time negative results are reported to an inmate.

This subsection refers to initiation of antiretroviral therapy for pregnant inmates infected with HIV. The text should specifically mention that the informed consent of the inmate will be needed prior to initiating treatment (for example, by re-wording the third sentence to read "Initiation of antiretroviral therapy is indicated (regardless of the inmate's CD4 count a the time) to minimize the risk of mother-to-child HIV transmission, so informed consent for such therapy should be promptly sought."

2. Subsection B.1 should be expanded (p. 21):

This subsection should specifically reference correctional facilities' legal obligation to provide adequate medical care to inmates. The Guide should direct corrections officials to the DHHS *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* (January 29, 2008), regarding the importance of HIV expertise in clinical care, including primary care, to define the nature of their obligation to inmates with HIV or AIDS. <u>http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf</u>

3. Subsections B and C should be revised to reflect privacy and confidentiality issues (p. 21-22):

The second paragraph of Subsection B.1 – on linking inmates to HIV specialists – should specifically reference the need to ensure that such linkages are handled in ways that protect inmate privacy and the confidentiality of inmate's HIV-related information. Subsection B.2 and Subsection C also should specifically reference the need to ensure that linkages to medical providers, community care providers, and HIV case management services are handled in ways that protect inmate privacy and the confidentiality of inmate's HIV-related information.

4. Subsection B.2 should be expanded (p. 21-22):

Subsection B.2 should reference the importance of linkage to medical care to prevent disruption of care, which can cause the inmate to develop drug resistance and pose risks to the former inmate's health.

#### F. Section VI of Draft

1. This Section raises some very important issues and is a valuable addition to the document.

2. The "Challenges that could increase inmate refusal for routine testing" should be expanded (p. 24-25):

An additional "challenge" is that failure to inform inmates of the risks as well as the benefits of HIV testing before obtaining consent for the testing may result in distrust of medical staff by the inmates. The following "solution" should be suggested: "Ensure that the information needed in order to obtain legally valid informed consent is provided to all inmates prior to seeking consent for testing."

3. The "Challenges associated with increase[d] number of tests conducted" should be expanded (p. 25-26):

The "challenge" of providing adequate HIV-related medical care – including prompt access to HIV specialists and HIV medications and subsequent monitoring – for an increased number of inmates identified as having HIV should be listed. The following "solution" should be suggested: "Ensure that systems and increased staffing to promptly and effectively link inmates to quality HIV care are in place before HIV testing is expanded."

Some facilities will face an additional "challenge" due to the lack of prison staff who can communicate with non-English speaking inmates to obtain informed consent for testing, to provide test results, and to provide confidential health care and other post-test services. The lack of such staff may result in inmates being reluctant or unable to access services and poses the risk of inmates being tested without informed consent. The following "solution" should be suggested: "Ensure that sufficient staff who can communicate with non-English speaking inmates are available and are trained to provide pre-test information, confidential test results, and confidential medical and other post-test services before HIV testing is expanded."

With respect to the fourth identified "challenge," we believe that some of the proposed "solutions" should be deleted. For reasons discussed above, we do not believe that negative HIV test results should be conveyed in a manner such as "all results are normal." Also as discussed above, as part of obtaining informed consent, all inmates should be provided not only with materials explaining the test, but also with the other information needed in order to obtain legally valid informed consent.

The final "challenge" should reference emotional or mental factors that may render an inmate incapable of providing informed consent, by revising the "solution" to read "Delay medical evaluations for inmates under the influence of substances (e.g., drugs or alcohol) or incapable of providing informed consent due to mental or emotional difficulties until they are capable of making decisions about their health care."

Thank you again for the opportunity to provide comments. We look forward to working with you to improve and finalize this Guide.

Sincerely,

David Munar, Vice President, Policy and Communications, AIDS Foundation of Chicago, <u>DMunar@aidschicago.org</u>, 312-334-0933

Catherine Hanssens, Executive Director, The Center for HIV Law and Policy, <u>chanssens@hivlawandpolicy.org</u>, 212.430.6733

Bebe Anderson, HIV Project Director, Lambda Legal, <u>banderson@lambdalegal.org</u>, 212.809.8585

#### On behalf of the following organizations:

AIDS Foundation of Chicago, Chicago, IL

AIDS Law Project of Gay and Lesbian Advocates and Defenders, Boston, MA

AIDS Law Project of Pennsylvania, Philadelphia, PA AIDS Legal Council of Chicago, Chicago, IL The AIDS Project of the ACLU, New York, NY AIDS Project Los Angeles (APLA), Los Angeles, CA The Bridging Group, Oakland, CA The Center for HIV Law and Policy, New York, NY Common Ground - the Westside HIV Community Center, Santa Monica, CA Community HIV/AIDS Mobilization Project (CHAMP), New York, NY; Providence, RI Copasetic Women Over Fifty, New York, NY Family Health Project, New York, NY Gay Men's Health Crisis (GMHC), New York, NY HIV/AIDS Law Project, Phoenix, AZ HIVictorious, Inc., Madison, WI Hispanic AIDS Forum, Inc., New York, NY Hyacinth AIDS Foundation, New Brunswick, NJ Lambda Legal, New York, NY The Legal AID Society, Prisoners' Rights Project, New York, NY National AIDS Fund, Washington, DC National Association of People With AIDS (NAPWA), Silver Spring, MD National Lesbian and Gay Task Force Action Fund, Washington, DC National Prison Project of the ACLU, Washington, DC New York AIDS Coalition, New York, NY New York City AIDS Housing Network (NYCAHN), Brooklyn, NY Pennsylvania Institutional Law Project, Philadelphia, PA The Pride Connections Center of New Jersey and Hudson Pride Connections, Jersey City, NJ Sisterhood Mobilized for AIDS/HIV Research and Treatment (SMART, Inc.), New York, NY SisterLove, Inc., Atlanta, GA

Spiritually for Wellness and Bridge Over Troubled Water Restoration Urban Ministries Inc., Philadelphia, PA

SUNY Downstate Medical Center, HEAT Program, Brooklyn, NY

Test Positive Aware Network, Chicago, IL

Treatment Access Expansion Project, Silver Spring, MD

Women Organized to Respond to Life-threatening Diseases (WORLD).Oakland, CA

The Woodhull Freedom Foundation, Washington, DC