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National Association of People with AIDS Supports Routinely Offered and Voluntary HIV Counseling, Testing, and Referral Services

Founded in 1983, the National Association of People with AIDS (NAPWA-US) promotes the benefits of HIV testing as part of a comprehensive strategy to combat HIV/AIDS. We recognize that HIV testing acceptance is a critical step in the lives of people with HIV. Receiving an HIV-positive test result can be a scary and difficult experience. But for many people, the decision to know is also a path toward a better, healthier, and longer life.

NAPWA has been at the forefront of promoting HIV testing acceptance in diverse communities across the U.S. for nearly as long as HIV testing has existed. In 1995, NAPWA launched **National HIV Testing Day** to promote the importance of early HIV detection, counseling, referral, treatment, and prevention services. Early detection is especially important for people living with HIV so they may take necessary actions to improve their lives and protect others from infection. Eleven years since NAPWA launched **National HIV Testing Day**, hundreds of local communities across the U.S. host annual HIV testing and awareness events that are collectively reaching literally hundreds of thousands of individuals each year.

A Shifting Landscape: HIV Counseling, Testing and Reporting

Voluntary counseling and testing services are integral components of a comprehensive response to the HIV/AIDS epidemic, contributing to timely and accurate disease surveillance, science-based HIV prevention approaches, and high-quality care and treatment strategies. In many jurisdictions, informed written consent to receive HIV testing is required.

An array of HIV testing options currently exist including oral swab, conventional blood tests, and same-day rapid screening. Confidential testing programs track results by name; anonymous testing programs (where available) track results by an anonymous code or number. Counseling and testing occurs in a variety of settings and may be administered by a trained test-counselor or healthcare worker. Most public testing

facilities offer pre- and post-test counseling that may include basic HIV/AIDS information, what an HIV-antibody test result means, ways to prevent the spread of HIV, and service referrals, including partner notification.

Testing programs are under increased scrutiny by public health officials and policymakers to innovate faster and less costly ways to screen more people. In addition, federal funding decisions are increasingly based on reported cases of HIV and AIDS. With no decrease in the number of new infections and more than 250,000 individuals estimated to be unaware of their HIV-positive status, HIV testing alone should not be perceived as the panacea to the nation's HIV/AIDS crisis. In fact, Congress needs to substantially increase funding for HIV prevention and care services in order to meet the needs of people with and at risk for HIV.

The Policy Landscape of HIV Testing and Reporting

- Ten states and the U.S. Virgin Islands allow only confidential HIV counseling and testing services¹
- As of 2005, virtually every state required laboratory reporting of CD-4 and viral-load counts on HIV-positive specimens
- 19 states currently mandate HIV-testing for state prison inmates at either intake or discharge²
- As of 2004, 28 states have enacted specific HIV transmission criminal statutes that may affect individual decisions to seek HIV testing³
- San Francisco recently adopted an expedited consent to testing policy for medical providers and New York officials are debating a similar proposal⁴
- Every state and territory is now moving towards name-based HIV surveillance
- Revised guidelines from the Centers for Disease Control and Prevention (CDC) recommend the routine offer of voluntary HIV testing. CDC is requiring that basic information be provided about HIV and what test results mean.

NAPWA Policy Position on Voluntary HIV Counseling & Testing

As CDC releases updated HIV testing guidelines and government officials consider new paradigms for HIV testing, NAPWA reaffirms its core principles regarding voluntary HIV counseling and testing policies and procedures:

NAPWA SUPPORTS ROUTINELY OFFERED HIV-TESTING

Medical providers should routinely offer voluntary HIV testing to all their patients in order to expand HIV testing acceptance and assist those individuals who are living with HIV but do not yet know it. This has particular bearing on individuals who are sexually active or use drugs but do not believe themselves at risk for HIV, including people with and without healthcare coverage. Healthcare providers should not exempt people whom they consider at low risk for HIV, such as heterosexuals, married individuals, and people over 50, among others, from the offer of voluntary HIV counseling and testing.

NAPWA FIRMLY BELIEVES HIV TESTING MUST REMAIN VOLUNTARY

Mandatory testing strategies threaten to alienate people from the public health sector and the very interventions and services that are urgently needed to halt the HIV pandemic. NAPWA believes HIV testing must remain voluntary and free of coercion in all cases and adhere to modern standards of ethical medical practice. People are more likely to engage in healthcare and prevention services if they understand and elect HIV testing for themselves. In addition, an HIV-positive individual needs to feel safe in order to best deal with his/her new diagnosis. Coercive and mandatory policies work against the needs of public health. NAPWA applauds CDC's revised HIV testing guidelines for affirming individuals' fundamental right to voluntary HIV testing that is free of coercion and provided only with consent.

NAPWA SUPPORTS COUNSELING AND INFORMED, WRITTEN CONSENT TO TESTING

With advances in technology, HIV testing is able to take place in a wide variety of settings, with results increasingly available in shorter periods of time. These advances make counseling and informed written consent even more important because there may be less time for vulnerable individuals to identify support from peers, family, and/or social service providers. The provision of counseling and informed, written consent to testing must therefore be preserved in keeping with high ethical standards designed to protect basic human rights. Counseling and informed consent are integral to promoting HIV prevention efforts and reducing HIV-related stigma, which persists in the U.S. and abroad. Only by continuing to promote factual information about HIV disease through a variety of interventions, including counseling, can stigma against people living with HIV be reduced.

NAPWA CALLS ON GOVERNMENT OFFICIALS TO GUARD AGAINST ABUSES AND BREACHES OF CONFIDENTIALITY IN HIV TESTING SETTINGS

HIV remains a highly stigmatized condition in the U.S. and around the world. In addition, consent is a fundamental human right for any medical procedure, including testing for HIV. NAPWA considers any instance of HIV testing without the individual's prior knowledge and explicit consent (including opportunities to decline testing) a human rights violation. Policies that eliminate counseling and/or informed written consent to testing may be especially prone to human rights violations. Government officials must monitor, address, and forcefully respond to instances of ethical abuse in HIV testing. Failure to do so will undermine anti-AIDS efforts and alienate HIV-positive people. Those at highest risk and at greatest need for HIV testing—men who have sex with men, substance users, sex workers, sexually active young people, racial and ethnic minorities, incarcerated populations, among others—are especially vulnerable to institutional abuses and are least likely to report and respond to violations. While NAPWA supports CDC's initiatives for expanded HIV screening, we must be assured that the removal of written informed consent does not result in involuntary HIV testing without the ability to decline.

NAPWA CALLS ON PUBLIC HEALTH OFFICIALS TO DEVELOP AND PILOT NEW MODELS TO EXPEDITE AND IMPROVE VOLUNTARY HIV COUNSELING AND TESTING SERVICES

NAPWA believes that voluntary counseling and testing modalities can and must be modernized to take into account new technology, advances in HIV medical care, increases in HIV incidence and prevalence, and new knowledge and innovations in responding to the HIV/AIDS pandemic. NAPWA supports efforts to streamline and expedite the offer and attainment of consent to testing so long as basic ethical standards are not only preserved but enhanced. An ethical framework for testing ensures that testing is voluntary and free of coercion; that patients are afforded an opportunity to

decline testing without penalty; that test subjects receive basic information about HIV and understand what a test result means; that all people tested can receive their testing results; and that people are provided needed counseling, referrals, and healthcare services, including HIV care and treatment. NAPWA calls on medical providers, researchers, and public health officials to develop, pilot, and broadly disseminate information on updated and proven effective models to streamline voluntary HIV counseling and testing modalities.

NAPWA CALLS ON POLICYMAKERS TO CREATE MEANINGFUL LINKAGES FROM TESTING TO AVAILABLE, ACCESSIBLE HEALTHCARE

HIV testing must be accompanied by HIV care and treatment services. Moreover, the most meaningful way to expand HIV testing acceptance is to guarantee healthcare and support services for all individuals who receive an HIV-positive result, regardless of their level of income or insurance status. Government officials must ensure that healthcare safety-net programs—such as Medicaid, Medicare, and the Ryan White CARE Act—are adequately funded to meet the needs of thousands of low-income and uninsured individuals who, thanks to expanded promotion of testing, will become aware of their HIV-positive status and need assistance obtaining lifesaving healthcare, treatments, and support services.

About NAPWA

NAPWA-US is the nation's first national AIDS organization and the world's oldest national network of people living with HIV/AIDS. NAPWA supports voluntary HIV counseling and testing nationally and abroad through National HIV Testing Day; U.S. Mayor's Initiative; Service Provider Networks for Latino (SABER) and Black (PAAN) communities; partnerships with OraSure Technologies, Black Entertainment Television, WKYS radio, Kaiser Family Foundation and the Centers for Disease Control & Prevention; and programs in four countries. Through these efforts, NAPWA has been at the forefront of promoting HIV testing acceptance in diverse communities across the U.S. for nearly twelve years.

¹ States offering only confidential HIV testing include: Alabama, Idaho, Iowa, Mississippi, Nevada, North Carolina, North Dakota, South Carolina, South Dakota, Tennessee, Virgin Islands. *Current Status of HIV Infection Surveillance*, The Centers for Disease Control & Prevention, as of April 2006.

² Hammett, Theodore M., PhD, HIV/AIDS and Other Infectious Diseases Among Correctional Inmates: Transmission, Burden, and an Appropriate Response, *American Journal of Public Health*, June 2006, Vol. 96, No. 6, 974-978.

³ States include: Alabama, Arkansas, California, Colorado, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maryland, Michigan, Missouri, Montana, Nevada, New Jersey, New York, North Dakota, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Utah, and Virginia. Source: State Criminal Statutes on HIV Transmission – 2004.

<http://www.aclu.org/HIVAIDS/HIVADIS.cfm?ID=17769&c=21>, accessed 8/18/06.

⁴ <http://www.aclu.org/hiv/privacy/25751prs20060602.html>,

http://www.aclu.org/images/asset_upload_file662_24735.pdf, both accessed 8/19/06.