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CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

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Press Release

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HIV/AIDS cases among gay and bisexual men of color now exceed cases among white gay and bisexual men

Men of color now account for a greater proportion of AIDS cases among men who have sex with men than do white men, according to a new report in the January 14th issue of CDC's *Morbidity and Mortality Weekly Report*.

Based on an examination of U.S. AIDS cases over the past decade, the CDC study found that men of color represent an increasing proportion of AIDS cases among gay and bisexual men, rising from 31% in 1989 to 52% in 1998. African-American men comprised one-third of AIDS cases among gay and bisexual men, while Latino men represented 18% of cases. While declining from 69% in 1989, white men continued to represent 48% of AIDS cases among gay and bisexual men in 1998.

"The face of AIDS among gay and bisexual men is changing," said Helene D. Gayle, MD, MPH, director of CDC's National Center for HIV, STD, and TB Prevention. "African-American and Hispanic men must recognize that this is not a disease that only affects white gay men – gay and bisexual men of all races are affected."

The report examines the areas hardest hit by AIDS and finds that in recent years (from January 1996 to December 1998), 85% of AIDS cases among gay and bisexual men of color were concentrated in cities with populations over 500,000. The five cities with the highest proportion of cases were New York (12%), Los Angeles (9%), Miami (5%), Washington, D.C. (4%), and Chicago (3%). Trends varied by race *(see attached table)*.

New York City had the highest number of cases among African-American gay and bisexual men, followed by Washington D.C. and Atlanta. Los Angeles had the highest number of cases among Latino gay and bisexual men, followed by New York and Miami. While Asian/Pacific Islanders and American Indian/Alaska Natives represent less than 2% of overall cases among gay and bisexual men, the cities with the highest number of cases among men of these races were Los Angeles and Phoenix, respectively.

Burden of Stigma in Communities of Color

Researchers outline possible factors contributing to the disproportionate toll of HIV and AIDS among gay and bisexual men of color. In addition to economic factors, such as high rates of poverty, unemployment, and lack of access to health care, cultural factors, such as the stigma of homosexuality, may be playing a role.

The study reports the results of a multi-site CDC survey of 8,780 HIV-positive men who have sex with men. Of those surveyed, 24% of African-American and 15% of Latino men who have sex with men identified themselves as being heterosexual. By contrast, only 6% of white men who have sex with men identified themselves as being heterosexual.
Researchers believe the stigma of homosexuality in communities of color may inhibit men of color from identifying themselves as gay or bisexual, despite having sex with other men. According to Gayle, this may prevent men of color from seeking or receiving the HIV prevention and treatment services they need.

Additionally, by not identifying as gay or bisexual, these men may not accept their own risk for HIV, and therefore, may unintentionally put their female partners and children at risk. HIV infection has increased significantly in women of color over the last decade.
"This is a very real and sensitive issue requiring increased dialogue and attention from leaders in communities of color," Gayle said. "The stigma associated with homosexuality in African-American and Latino communities only compounds the traditional factors associated with high rates of disease in our communities. To truly win the battle against HIV, we must be willing to acknowledge and wrestle with the difficult issues."

Gay Men of Color May be More Likely to Contract HIV at Young Age

The CDC study also points to the need to reach African-American and Latino men with HIV prevention programs and messages at an early age.
Because AIDS cases alone are no longer indicative of new HIV infections, CDC also examined data collected from 1996-1998 in 25 states that report HIV diagnoses in addition to cases of full-blown AIDS. Data on HIV diagnoses among men in the youngest age group (13-24) provide the best indication of recent trends in infection in these states.

Among gay and bisexual men diagnosed with HIV during this period, 16% of African Americans and 13% of Latinos were age 13-24, compared with 9% of white men. Although data are not national, they can point to possible trends.

"These data suggest that African American and Hispanic gay and bisexual men are being infected at younger ages than white men," said CDC study author, Janet Blair, Ph.D., M.P.H., "Men of color must be reached early with comprehensive HIV prevention programs, especially in high risk communities."

According to Blair, in addition to expanding prevention programs for men of color, locally based community efforts must also address the need for early HIV testing, diagnosis, and treatment to reduce new infections and improve survival. Since powerful new drug treatments became available in 1996, annual AIDS cases (AIDS incidence) and deaths have declined among all gay men. However, declines have not been as steep among gay and bisexual men of color, as among white gay and bisexual men. Between 1996 and 1998, AIDS incidence among gay and bisexual men dropped 23% among African Americans, 26% among Latinos, and 39% among

whites. AIDS deaths among gay and bisexual men dropped 53% among African Americans, 60% among Latinos, and 65% among whites.

Expanded Prevention Urgently Needed

CDC's prevention initiatives to address the growing epidemic among gay men of color include, expanded surveillance to better track the path of local epidemics, increased efforts to reach individuals with HIV counseling and testing linked to prevention and treatment services, and continued expansion of community-based prevention programs. One important element of prevention efforts for gay and bisexual men is the provision of anonymous HIV testing sites. Access to anonymous testing may help ensure that stigma and fear do not prevent individuals from seeking HIV testing. CDC has been working with organizations throughout the country to implement locally designed, targeted prevention programs specifically for men of color who have sex with men, including several designed to reach men who don't identify as gay. To expand these efforts in 1999, CDC awarded an additional $7 million in grants for HIV prevention services specifically targeted to gay and bisexual men of color.

"We must continue to combat complacency about HIV infection, " said Gayle, "HIV remains a serious, lifelong and incurable disease—a disease that can and must be prevented."
The above mentioned $7 million is part of a larger initiative. Since October 1998, HHS has been working in a partnership with the Congressional Black Caucus to address the severe and ongoing crisis of HIV/AIDS in communities of color, given the disproportionate impact of the disease in racial and ethnic communities. As part of this effort, HHS spent an additional $156 million in fiscal year 1999 to attack HIV/AIDS in racial and ethnic minority communities. The partnership also includes the deployment of special Crisis Response Teams of HHS experts to work alongside local officials, public health personnel and minority community-based organizations in highly affected communities to help them address their communities of color HIV/AIDS crisis.

Metropolitan statistical areas (MSA's)* with the highest number of AIDS cases among 64,685 men who have sex with men - United States, 1996-1998**

Race/Ethnicity	MSA	# of Cases	% of Racial/Ethnic Total
Black, non-Hispanic (N=19,983)	New York, NY	2,034	10.2
	Washington, D.C.	1,135	5.7
	Atlanta, GA	951	4.8
	Los Angeles-Long Beach, CA	947	4.7
	Chicago, IL	848	4.2
	Total	5,915	29.6
Hispanic (N=10,944)	Los Angeles-Long Beach, CA	1,728	15.8
	New York, NY	1,570	14.3
	Miami, FL	879	8.0
	San Juan-Bayamon, PR	568	5.2
	San Diego, CA	365	3.3
	Total	5,110	46.6
White, non-Hispanic (N=32,679)	New York, NY	2,138	6.5
	Los Angeles-Long Beach, CA	1,931	5.9
	San Francisco, CA	1,456	4.5
	Houston, TX	1,003	3.1
	Dallas, TX	902	2.8
	Total	7,430	22.8

*Includes only those metropolitan areas with a population ≥500,000. Metropolitan areas are named for a central city or county, may include several cities and counties, and may cross state boundaries.

**Less than two percent of cases were represented by the following two groups: Asian/Pacific Islanders (384 cases) and American Indian/Alaska Native (55 cases). Additionally, 140 men were reported without race identified.

Ryan White Care Act

In August 1990, the Ryan White Comprehensive AIDS Relief Emergency (CARE) Act was enacted to provide care and treatment for the thousands of Americans living with HIV/AIDS. The rate at which the AIDS epidemic was growing threatened to implode existing health care and service infrastructures. The CARE Act was reauthorized in 1996 due to the continued growth of the AIDS epidemic. The following paper was developed by the Public Policy Committee of AIDS Action to outline the organization's policy regarding the reauthorization of the CARE Act.

The Ryan White CARE Act, without question, plays the most critical role in ensuring access to appropriate care and services for Americans living with HIV/AIDS. CARE Act funds are used to provide primary medical care, AIDS drugs, viral load testing, treatment information, adherence support, case management, and other essential support services for tens of thousands of individuals living with HIV/AIDS. While each of the CARE Act's components addresses a specific need, they complement each other and play a critical role in making Ryan White the health care and social service safety net of last resort. The Ryan White CARE Act is needed to ensure that our nation can continue to meet service needs and successfully support access to life saving therapies. The structure of the CARE Act has worked effectively to: dramatically improve the quality of life for people living with HIV disease and their families; reduce use of costly inpatient care; and increase access to care for underserved populations, including people of color.

Why is the Ryan White CARE Act needed?

Each year, the number of people with HIV-disease grows, and the need for appropriate HIV care services grows. As of June 30, 1998, 665,357 cases of AIDS have been diagnosed in the United States and over 401,000 Americans have died. More than 260,000 Americans are living with AIDS and many hundreds of thousands more are HIV positive but do not yet have AIDS. As the AIDS epidemic continues to spread into rural, urban, and suburban communities across the country and more Americans with HIV/AIDS seek care, the already over-burdened public health infrastructure is buckling under the weight of the increased demand. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, originally enacted in 1990 and reauthorized in 1996, is the cornerstone of the federal response to

the critical need for health care and care-related services for Americans living with HIV/AIDS. This program was created to provide assistance to localities that are disproportionately affected by the HIV/AIDS epidemic and to make financial assistance available to the States and other public or private non-profit organizations for the development, organization, coordination, and operation of more effective, and cost efficient systems to deliver essential services to individuals and families with HIV disease.

What is the Ryan White CARE Act?
The Ryan White CARE Act is a life-line for thousands of individuals who have little or no access to appropriate and compassionate HIV/AIDS care. The CARE Act is not a "welfare" program or an "entitlement". It is a unique partnership between federal, local and state government; non-profit community organizations, health care and supportive service providers; and people living with and affected by HIV/AIDS, working together to meet the care challenges posed by the HIV/AIDS epidemic in each community. CARE Act programs have saved lives, preserved health, dramatically cut costs of care, and led to the development of a continuum of medical and support services that have improved the quality and duration of life and reduced the need for expensive hospitalization or skilled nursing home care for people with AIDS.

The CARE Act consists of 5 titles. While each addresses a specific need, they complement each other to provide a continuum of comprehensive services.

Title I provides emergency formula and competitive grants to those metropolitan areas most heavily affected by the HIV/AIDS epidemic. Jurisdictions qualify for Title I funding if they have a population of at least 500,000 and report a cumulative AIDS caseload of at least 2,000 over the most recent 5 years. There are currently 49 eligible metropolitan areas (EMAs). In 1996, Congress changed the eligibility criteria to slow the number of newly qualifying jurisdictions. In 1999, two new jurisdictions (Las Vegas, NV and Norfolk, VA) will qualify for Title I funding.

Title I funds may be used for outpatient medical care, substance abuse and mental health treatment, and other critical support services. Local planning councils assess and prioritize local needs and develop plans for the delivery of comprehensive HIV/AIDS health care services.

Title II provides formula grants to the state health departments in all 50 states, the District of Columbia, and the territories. Each state must have a comprehensive plan for the delivery and

organization of HIV services in the state, including how Title II funds will be used to augment present services. Title II funds may be used to operate HIV care consortia, fund state health insurance continuation, home-based care services, and to purchase AIDS-related drugs for low-income individuals through the AIDS Drug Assistance Program (ADAP). Additionally, since fewer jurisdictions can qualify for Title I funds, Title II funds are also used by states to provide the same range of HIV/AIDS services throughout the state that could be provided under Title I.

In 1996, Congress created a separate funding line in order to appropriate funds directly to the **AIDS Drug Assistance Program (ADAP). These funds are used specifically for the purchase of HIV/AIDS-related drugs.** This action resulted from the impact that the increase in demand for additional services under Title II and the recent breakthroughs in expensive, new combination drug therapies. A direct appropriation to ADAP preserves core Title II funds giving states greater flexibility in providing comprehensive care services. These care services are critical to ensuring the success of new therapies. These new treatments must be taken under strict regimens and require state-of-the-art medical care and monitoring. The benefits of these therapies can be realized only with access to appropriate medical care and services.

Title III provides competitive grants to existing community-based clinics and public health providers serving traditionally underserved populations, to deliver early intervention and ongoing comprehensive HIV/AIDS health care services, including HIV counseling and testing, primary care, and prescription drugs. In some areas of the country, particularly rural areas Title III is the only source of medical care and other critical HIV services.

Title IV provides competitive grants to pediatric, adolescent and family HIV care programs to provide coordinated care services and access to clinical research by linking care services to clinical research programs.

Title V provides competitive grants for projects of national significance. Title V also provides funds to educate and train health care providers in HIV/AIDS care through the AIDS Dental Reimbursement Program and the AIDS Education & Training Centers (AETCs). As the training arm of the Ryan White CARE Act, the AETCs ensure that health care providers have access to the most up to date information and training on competent and compassionate HIV/AIDS care and the HIV/AIDS Dental program helps to provide training in and access to much needed HIV dental

care.

Why is increased funding needed for the RW CARE Act?
The CARE Act was constructed, and has successfully served, as the health care and social service safety net of last resort for Americans living with HIV/AIDS. In recent years, the program has received significant funding. However, escalating case loads and increases in the demand for services pose continued threats to the capacity of Ryan White funded programs to meet the needs of people living with HIV who little or no options.

The advent of promising, highly expensive new drugs and the associated increase in demand has added to the huge health care burden that the CARE Act must shoulder. The AIDS Drug Assistance program (ADAP) under Title II continues to face seemingly insurmountable challenges to meeting the demand for new and potentially lifesaving and life-extending drug therapies. As a result, additional funds are required specifically for the ADAP program so that, at least in the short term, it can continue to address this explosive growth in demand from uninsured and underinsured people with HIV/AIDS.

The high cost of these new drug therapies, however, is only one piece of a larger and even more challenging problem. **The promise of new therapies made available through ADAP can only be fully realized in the context of providing appropriate and competent medical care and supporting services.** Titles I, II (core services), III, IV, and V play a critical role in achieving this goal.

All of the Titles of the Ryan White CARE Act must be sufficiently funded to ensure that the health care and support services infrastructure established through the CARE Act can continue to meet the broader service needs of individuals living with HIV/AIDS and successfully support the provision of effective medications. To accomplish this, increased funding for every Title of the CARE Act is required.

◆ Reauthorization of the Ryan White CARE Act

Approved by AIDS Action Executive Board on July 19, 1999

Introduction
In August 1990, the Ryan White Comprehensive AIDS Relief Emergency (CARE) Act was enacted to provide care and treatment for the thousands of Americans living with HIV/AIDS. The rate at which the AIDS epidemic was growing threatened to implode

existing health care and service infrastructures. The CARE Act was reauthorized in 1996 due to the continued growth of the AIDS epidemic. The following paper was developed by the Public Policy Committee of AIDS Action to outline the organization's policy regarding the reauthorization of the CARE Act.

The Ryan White CARE Act, without question, plays the most critical role in ensuring access to appropriate care and services for Americans living with HIV/AIDS. CARE Act funds are used to provide primary medical care, AIDS drugs, viral load testing, treatment information, adherence support, case management, and other essential support services for tens of thousands of individuals living with HIV/AIDS. While each of the CARE Act's components addresses a specific need, they complement each other and play a critical role in making Ryan White the health care and social service safety net of last resort. The Ryan White CARE Act is needed to ensure that our nation can continue to meet service needs and successfully support access to life saving therapies. The structure of the CARE Act has worked effectively to: dramatically improve the quality of life for people living with HIV disease and their families; reduce use of costly inpatient care; and increase access to care for underserved populations, including people of color.

The intricate, fragile, AIDS care infrastructure, constructed to ensure comprehensive health care and services for people with AIDS who had nowhere else to turn, is struggling to keep pace with new and ongoing demands. The success of the CARE Act is based on a recognition that medications alone are not enough to effectively fight AIDS. This coordinated and comprehensive approach makes the CARE Act a cost-effective and efficient investment -- one which must be continued.

Since its enactment in 1990, this program has directly benefited hundreds of thousands of individual clients who have HIV disease. Over the years, the program has helped build an infrastructure that enables many people with HIV disease to access a comprehensive continuum of care.

In recent years, the development of new treatments has resulted in a reduction of the AIDS death rate. This increased longevity among people with HIV has contributed to an increased demand on the HIV/AIDS care infrastructure. In fact, Ryan White providers have experienced from 30 to 40 percent increases in the number of new patients. This increase is understandable given the success of the new treatments when coupled with support services. In fact, one of the goals of the CARE Act is to help patients receive a

standard of care that is in line with the Public Health Service guidelines for the treatment of HIV disease and opportunistic infections.

If the United States is to continue to meet the challenges presented by this complex epidemic, it is essential that we support innovative and flexible solutions to solve our nation's AIDS epidemic. The Ryan White CARE Act, itself, was created in this spirit. This important piece of legislation is scheduled to expire on September 30, 2000. It is an essential component in our nation's fight against HIV and AIDS and must be reauthorized.

Why Reauthorize the CARE Act?
US Total AIDS Cases:
1990 (First Authorization) 155,619
1996 (Reauthorization) 481,234
1999 670,000

- In 1998, at least 500,000 people received primary care and support services under the Ryan White CARE Act. 60% of those were people of color.

- AIDS is the leading cause of death among African-Americans between the ages of 25 and 44, and the fifth leading cause of death among all Americans in this age group. In fact, the Congressional Black Caucus declared an AIDS State of Emergency in June of 1998.

- Well over 600,000 Americans have been diagnosed with AIDS and more than 400,000 have died of the disease.

- According to the Centers for Disease Control and Prevention, there are between 650,000 and 900,000 Americans infected with HIV, and the number of AIDS cases in the United States has nearly doubled over the past five years.

- More women than ever in the U.S. have AIDS and AIDS cases among women have increased 60% in the first half of this decade. Women now account for 20 percent of the AIDS caseload.

- A 1997 Wall Street Journal/NBC News survey found that young Americans - people in the 18 to 29 year-old age group - identify AIDS as the defining event for their generation. Despite the tragic fact that half of new infections occur in individuals under 25 years of age, a 1997 Yale University/MTV

survey found that 87 percent of young Americans do not believe they are at risk for HIV infection.

- The Centers for Disease Control and Prevention report that HIV infections continue to occur at a rate of over 40,000 new cases a year for the last 5 years.

- Deaths from AIDS have declined significantly each year since 1996. This is a direct result of services made possible by the CARE Act.

Strengths the Ryan White CARE Act

LOCAL CONTROL: Local control under Title I, as currently defined, has allowed individual communities to tailor delivery of services to best meet their needs. In many cases this has resulted in cooperative efforts from various levels of government to develop dynamic and effective responses to the AIDS epidemic.

CONTINUUM OF CARE: The range of medical and supportive services currently in the CARE Act have been a vital piece of providing and improving access to life saving treatments.

LINKAGES WITH OTHER RESOURCES: The resources for combating HIV/AIDS in the US are complex and the CARE Act can serve as a foundation to foster better communication between local, state and federal agencies in order to improve access to care for people living with HIV. Increasing coordination among the following funding sources will also benefit individuals living with HIV disease: Ryan White; HOPWA; CDC; SAMHSA; Medicaid; and the Indian Health Service.

TITLE STRUCTURE: The current structure of the CARE Act has been an effective tool for combating the epidemic. The diversification of funding streams has created an environment that improves access to care (Titles I and II) while providing incentives to develop innovative measures for dealing with HIV disease (Titles III, IV, and Part F).

Title I delivers funding to the U.S. metropolitan areas most severely impacted by the AIDS epidemic in order to improve access to care and treatment without overburdening local health services. Approximately 75% of HIV positive individuals living in the United States reside in EMAs. An increasing number of HIV-positive individuals who receive care from Title I-funded programs are people of color (66%), people who are homeless or marginally-housed, people who are low-income, those who are uninsured or underinsured, and those who are diagnosed with

substance abuse and/or mental illness.

Title II funding has been provided to State and Territorial Health Departments in order to ensure that a comprehensive continuum of care is provided on a state/territory wide level. This Title incorporates both Care Services and the AIDS Drug Assistance Program (ADAP) and provides the vital linkage between support services and treatment for thousands of low-income people living with HIV.

Title III is designed to establish early intervention primary care services or sites in urban and rural areas. Through this Title, health care partnerships and other innovative linkages have been developed. This Title has also helped establish health care in areas that have been traditionally underserved. Often times Title III grants are targeted to communities where the epidemic is growing most rapidly. Currently there are 181 Title III-funded providers who are located in 40 states, the District of Columbia and Puerto Rico.

Title IV focuses on Women, Children, Youth and Families. Programs that have been established through this Title have helped to dramatically reduce the risk of perinatal transmission of HIV -- this demonstrates the success of this Title. Title IV also has an adolescent initiative designed to increase access to HIV care and support services for young people under 25, who account for half of all new HIV infections annually.

Part F is comprised of the AIDS Education and Training Centers (AETCs), Dental Reimbursement Program and the Special Projects of National Significance (SPNS). These diverse programs bridge gaps that are not addressed through the other titles of the CARE Act such as:

AETCs - The AETCs sustain and expand the base of health care providers who are effectively educated and motivated to counsel, diagnose, treat and manage individuals with HIV infection and to assist in the prevention of high-risk behaviors that may lead to infection. The AETC network provides training in the full spectrum of HIV care to urban, rural, high incidence, and low incidence areas. This is extremely important due to the rapid advances and changes that are made in the standards of care for treating HIV.

SPNS - Supports the development of innovative service models for HIV care in order to provide health and social services to communities of color and hard to reach populations.

Dental Reimbursement - Addresses the often overlooked important role of oral health in the early detection and treatment of HIV. This program provides for the uninsured and helps fill the gaps that exist due to many states Medicaid programs not covering dental services.

Modernization of the Ryan White CARE Act
Recommendations

STRUCTURE: AIDS Action supports the multi-Title structure of the CARE Act which features a system of local control and provides a range of services which utilizes the continuum of care. This structure must be used as the blueprint to build-up and stabilize CARE Act infrastructure throughout the nation and changes should not significantly destabilize existing infrastructure and/or service delivery systems.

FLEXIBILITY: Flexibility for local decision making should continue to be built into the RWCA. Service organizations, community-based organizations, and individuals infected and affected by the disease must be involved in defining need and service delivery systems.

Increased local control and accountability for Title II (non-ADAP) should be built into the CARE Act by requiring the establishment of CARE Act consortia for all Title II areas. Title II consortia would emulate the Title I planning councils in both their authority and accountability.

FUNDING DISTRIBUTION: AIDS Action supports a change in the funding formula for both Title I and Title II (non-ADAP) to utilize the actual number of living AIDS cases per the CDC, in conjunction with other relevant data, in calculating the final funding allocations. In addition we support reducing the "hold harmless" provisions of Title I annually to ensure a more need-based and data-driven distribution of funds nationwide. Eventually, the use of HIV surveillance data combined with other relevant data is the desired methodology for the distribution of funding.

AIDS Action supports the current structure of the Title I allocation that includes both 50% formula and 50% supplemental grants. AIDS Action recommends that the severity of need in a given jurisdiction must be considered when developing criteria for supplemental grants. In order to assess severe need a standardized definition, which includes co-morbid factors, should be developed and implemented. This severe need criteria should play a larger role, at least 33%of possible points, in final Title I supplemental award decisions.

DENTAL REIMBURSEMENT PROGRAM: The Dental Reimbursement Program in Part F should be expanded to allow programs in non-university settings the opportunity to participate, and should prioritize funding to those programs with strong linkages to community-based programs.

TARGETED POPULATIONS: The CARE Act should continue to utilize Titles III, IV and Part F in conjunction with local planning bodies for Titles I and II to ensure that currently underserved populations have improved access to care and treatment, while planning for emerging needs. The Council also supports the use of financial incentives and/or technical assistance for programs, in order to ensure their capacity to meet the needs of targeted populations across all Titles.

OUTCOME DATA: Currently the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA) needs the resources to provide needed data collection and dissemination, analysis and evaluation. Resources allocated for data collection, analysis and evaluation need to be delivered to the HAB in order to ensure CARE Act funding is being utilized most effectively. A uniform data collection system should be instituted nationally so that better planning for resource distribution can be done.

INCENTIVES: The current Ryan White CARE Act should do more to encourage localities (cities, counties, states, etc.) to contribute funding to HIV care and treatment. Incentives should be built into the CARE Act to reward localities that have invested resources in response to the needs of the community, and stimulate greater participation from more reluctant localities.

Conclusion

AIDS Action and its members are appreciative of Congress' continued support of the Ryan White CARE Act over the past decade. The result of these efforts is that thousands of people living with HIV/AIDS have been able to lead productive lives due to the care, treatment and services provided by the CARE Act. Throughout the United States, the CARE Act continues to make a tremendous difference in the lives of people living with HIV disease.

The CARE Act is in large part responsible for:

- People with HIV/AIDS living longer, more productive lives.
- Local control that has assisted communities in designing care

and treatment services that meet their specific needs.

- A safety net that helps ensure better access to appropriate care, treatment and services for all people living with HIV/AIDS.

- An effective model of service delivery that can be adapted to meet the needs of other life threatening diseases.

As the AIDS epidemic continues to grow and expand into more disenfranchised communities, the need for CARE Act services is even more critical to the health and well being of individuals who have to deal with multiple barriers in accessing health care.

The success of the Ryan White Care Act depends on funding.
Click here to view the FY 2000 Appropriations Chart.

DEPARTMENT OF HEALTH & HUMAN SERVICES

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CDC Fact Sheet

CDC Draft Guidelines for Improved Data on U.S. HIV Epidemic New Systems Urgently Needed to Guide Prevention Efforts

The Centers for Disease Control and Prevention (CDC) has released draft guidelines calling on all states to track the course of the HIV epidemic as an extension of their AIDS surveillance programs. CDC is advising states that name-based systems of surveillance are the most likely to provide the quality data necessary to direct community prevention and treatment programs. CDC will work with those states that choose to use alternative tracking systems that rely on codes or "unique identifiers" rather than names, and will provide the technical assistance necessary to help them comply with performance standards. To address the urgent need for information to ensure effective targeting of prevention and care services while recognizing legitimate concerns about confidentiality and access to testing and care, CDC has called for all states and territories to conduct HIV surveillance in addition to their AIDS surveillance programs.

The guidelines respond to recent treatment advances that have slowed the progression from HIV to AIDS for many individuals. Data on AIDS cases alone can no longer be reliably used to direct prevention efforts to communities currently at greatest risk. The new guidelines address the urgent need for information to ensure effective targeting of prevention services.

The draft guidelines represent the culmination of a lengthy effort by CDC with communities and public health partners nationwide to address emerging information needs and issues surrounding the effective implementation of HIV reporting. The proposed recommendations are designed to 1) provide accurate and reliable data for communities to effectively direct scarce resources for HIV prevention and treatment; 2) maintain strict confidentiality of HIV data, including controlled access and strong penalties for abuse; and 3) continue support for anonymous testing options so that systems do not deter individuals at risk from accessing HIV testing, treatment, and prevention services.

As of July 1, 1998, thirty-two states had implemented HIV surveillance using the same reporting system for both HIV and AIDS cases; three of these states conduct pediatric surveillance only. Additional states are now working to expand their AIDS surveillance systems to include HIV cases. The draft "Guidelines for National HIV Surveillance, Including Monitoring for HIV Infection and Acquired Immunodeficiency Syndrome" are designed to provide states recommendations on the best practices to ensure both quality and confidentiality of HIV data.

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CDC Recommendations

Given the importance of HIV surveillance data for directing services and care to individuals with HIV infection, the draft CDC guidelines establish specified performance criteria to assure both the quality and confidentiality of that data. All states will be required to establish an HIV surveillance system that meets these quality and confidentiality criteria within a reasonable time period. The decision on the surveillance system used to gather those data – either a name-based or an alternative "unique identifier" system – will be left up to the states.

Based on available evaluations of name-based HIV surveillance systems, CDC believes that such systems are currently the most likely to meet the necessary performance standards and provide the quality data necessary to direct community prevention and treatment programs. However, CDC's draft policy does allow for flexibility for those states that decide to implement alternative systems. CDC will provide financial and technical assistance to states working to design HIV surveillance systems, including unique identifier-based and name-based systems.

During the next several years, CDC will assist states in implementing HIV surveillance systems, evaluating current performance levels, revising systems as necessary and reassessing performance. After this transition period, CDC will evaluate and award proposals for federal funding of state and local surveillance programs based on their capacity to meet the performance standards. At that time, CDC will work with states to adopt surveillance methods that will enable them to achieve the standards.

Criteria for Quality and Confidentiality

The draft guidance document outlines performance criteria to ensure the quality and confidentiality of HIV data. These criteria include strict confidentiality procedures and protections such as using a single registry, eliminating paper reports, using computer encryption techniques, setting up physical security and limited access to data, and penalties for abuse. Additionally, the guidelines set quality standards for data to ensure completeness (over 85% of diagnoses must be reported), timeliness (over 66% of diagnoses of reported within 6 months of diagnosis), no duplication (less than 5% of cases should be duplicate reports of a single case), and the ability to follow-up with providers on cases of public health importance (e.g., unusual modes of transmission or strains).

Efforts to Evaluate and Address Concerns About Name-Based HIV Reporting

CDC recognizes the concerns regarding name-based reporting of HIV infection and the greater sensitivity of HIV case data. CDC has worked for several years to evaluate and address these issues and has consulted with a diverse group of individuals and organizations from the scientific, public health, and AIDS advocacy communities in developing these proposed guidelines. Of course, CDC will continue to work with states to evaluate the impact of HIV case surveillance as implemented following these guidelines.

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The draft guidelines present the results of these assessments in more detail, but several key steps have been taken, including:

Evaluation of Unique Identifier Systems

CDC has assessed the feasibility of using alternatives to name-based methods for HIV surveillance by reviewing a number of existing state systems that use a variety of numeric codes or "unique identifiers" (UI) rather than names.

Most recent evaluations looked at Social Security number-based systems. Several problems were found with these systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. CDC also found difficulties in assessing the level of duplicate case reports or the ability to reliably link to other public health databases (e.g. death registries).

In UI-based systems, providers must maintain logs or other forms of documentation linking the UI to the name-based medical records. This process may pose additional confidentiality risks if physician-held surveillance registries are not protected by state confidentiality statutes or are located in non-secure areas.

Support for Anonymous Testing

While studies suggest that name-based HIV reporting does not serve as a major deterrent to testing, CDC continues to strongly support anonymous HIV testing and recommends that all states provide anonymous testing options. CDC studies indicate that the lack of anonymous testing serves as a deterrent to testing in some high-risk populations. Unless prohibited by law, CDC requires that states receiving prevention funds to make anonymous testing available. Maintaining anonymous test sites is important for prevention efforts and will not seriously inhibit efforts to track the epidemic. Most people are diagnosed with HIV infection in confidential care settings. Moreover, the time between HIV diagnosis and the point at which individuals enter the care system has become shorter, given new treatment advances. Maintaining an anonymous testing option may help ensure that more individuals learn their status, and if infected, seek early treatment and care. HIV home test kits now offer another anonymous testing option in the United states. And anonymous testing is available in publicly funded counseling and testing sites in all but eleven states. CDC strongly recommends that states not currently offering anonymous testing reevaluate their policies on this issue.

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Strengthening Systems to Protect Confidentiality

Public health departments have maintained an exemplary record in protecting the confidentiality of HIV/AIDS data. Since 1981 there have been few reported breaches of confidentiality in state AIDS reporting systems.

Over the past few years, CDC has been working to evaluate additional measures at the state level that could improve confidentiality even further. CDC has recently reviewed state reporting programs and has developed enhanced standards to be used in developing local confidentiality plans. Local programs will be required to meet these performance standards and must ensure confidentiality as a condition of funding. One important security measure CDC is now making available to states is the option of using a double-keyed encryption program. With this system, names and other identifying information may only be accessed with both the key (password) held by the state and the key held by CDC.

To assess the strength of local confidentiality laws that protect HIV data, CDC requested that Georgetown/Johns Hopkins Public Health Law Project review local laws and regulations. All states and many localities have legal safeguards of confidentiality for government-held data, and these laws were found to provide greater protection than laws protecting health information held by private health care providers. Additionally, most states have specific statutory protections for public health data related to HIV. However, state legal protections vary widely.

CDC is therefore promoting efforts to enhance and standardize local confidentiality laws. CDC, in partnership with other public health agencies, the National Conference of state Legislatures, and the Georgetown/Johns Hopkins Public Health Law Project, is working to develop model legislative language to protect confidential, identifiable information held by state and local public health departments against unauthorized and inappropriate use, while still allowing the use of surveillance information to accomplish legitimate public health objectives.

Request for Public Comment

The draft Guidelines represent the combined efforts of CDC and numerous agencies and individuals nationwide. CDC is seeking public comment to ensure the final recommendations promote the best possible approaches to HIV surveillance, as a critical component of future HIV prevention efforts. After the public comment period, which runs from x date to y date, the comments will be carefully reviewed and considered. The Guidelines will be modified as needed before being published in the Morbidity and Mortality Weekly Report. For copies of the draft Guidelines and information on how to submit comments, call the CDC National Prevention Information Network at 1-800-458-5231 or send a written request to P.O. Box 6003, Rockville, MD 20849-6003.

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Chief of Staff

Washington, D.C. 20201

FACSIMILE

DATE: 2/8/98

TO: Chris Jennings

FAX#: 456-6557

FROM: Mary Beth Donahue
Chief of Staff

Phone: 202/690-7431 Fax: 202/401-5783

COMMENTS:

5 **Pages [including this cover]**

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DETERMINED TO BE AN
ADMINISTRATIVE MARKING
INITIALS: RLCR DATE: 04/06/12
2012-0463-S

December 1998

CDC Fact Sheet

CDC Draft Guidelines for Improved Data on U.S. HIV Epidemic
New Systems Urgently Needed to Guide Prevention Efforts

The Centers for Disease Control and Prevention (CDC) has released draft guidelines calling on all states to track the course of the HIV epidemic as an extension of their AIDS surveillance programs. CDC is advising states that name-based systems of surveillance are the most likely to provide the quality data necessary to direct community prevention and treatment programs. CDC will work with those states that choose to use alternative tracking systems that rely on codes or "unique identifiers" rather than names, and will provide the technical assistance necessary to help them comply with performance standards. To address the urgent need for information to ensure effective targeting of prevention and care services while recognizing legitimate concerns about confidentiality and access to testing and care, CDC has called for all states and territories to conduct HIV surveillance in addition to their AIDS surveillance programs.

The guidelines respond to recent treatment advances that have slowed the progression from HIV to AIDS for many individuals. Data on AIDS cases alone can no longer be reliably used to direct prevention efforts to communities currently at greatest risk. The new guidelines address the urgent need for information to ensure effective targeting of prevention services.

The draft guidelines represent the culmination of a lengthy effort by CDC with communities and public health partners nationwide to address emerging information needs and issues surrounding the effective implementation of HIV reporting. The proposed recommendations are designed to 1) provide accurate and reliable data for communities to effectively direct scarce resources for HIV prevention and treatment; 2) maintain strict confidentiality of HIV data, including controlled access and strong penalties for abuse; and 3) continue support for anonymous testing options so that systems do not deter individuals at risk from accessing HIV testing, treatment, and prevention services.

As of July 1, 1998, thirty-two states had implemented HIV surveillance using the same reporting system for both HIV and AIDS cases; three of these states conduct pediatric surveillance only. Additional states are now working to expand their AIDS surveillance systems to include HIV cases. The draft "Guidelines for National HIV Surveillance, Including Monitoring for HIV Infection and Acquired Immunodeficiency Syndrome" are designed to provide states recommendations on the best practices to ensure both quality and confidentiality of HIV data.

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CDC Recommendations

Given the importance of HIV surveillance data for directing services and care to individuals with HIV infection, the draft CDC guidelines establish specified performance criteria to assure both the quality and confidentiality of that data. All states will be required to establish an HIV surveillance system that meets these quality and confidentiality criteria within a reasonable time period. The decision on the surveillance system used to gather those data – either a name-based or an alternative "unique identifier" system – will be left up to the states.

Based on available evaluations of name-based HIV surveillance systems, CDC believes that such systems are currently the most likely to meet the necessary performance standards and provide the quality data necessary to direct community prevention and treatment programs. However, CDC's draft policy does allow for flexibility for those states that decide to implement alternative systems. CDC will provide financial and technical assistance to states working to design HIV surveillance systems, including unique identifier-based and name-based systems.

During the next several years, CDC will assist states in implementing HIV surveillance systems, evaluating current performance levels, revising systems as necessary and reassessing performance. After this transition period, CDC will evaluate and award proposals for federal funding of state and local surveillance programs based on their capacity to meet the performance standards. At that time, CDC will work with states to adopt surveillance methods that will enable them to achieve the standards.

Criteria for Quality and Confidentiality

The draft guidance document outlines performance criteria to ensure the quality and confidentiality of HIV data. These criteria include strict confidentiality procedures and protections such as using a single registry, eliminating paper reports, using computer encryption techniques, setting up physical security and limited access to data, and penalties for abuse. Additionally, the guidelines set quality standards for data to ensure completeness (over 85% of diagnoses must be reported), timeliness (over 66% of diagnoses of reported within 6 months of diagnosis), no duplication (less than 5% of cases should be duplicate reports of a single case), and the ability to follow-up with providers on cases of public health importance (e.g., unusual modes of transmission or strains).

Efforts to Evaluate and Address Concerns About Name-Based HIV Reporting

CDC recognizes the concerns regarding name-based reporting of HIV infection and the greater sensitivity of HIV case data. CDC has worked for several years to evaluate and address these issues and has consulted with a diverse group of individuals and organizations from the scientific, public health, and AIDS advocacy communities in developing these proposed guidelines. Of course, CDC will continue to work with states to evaluate the impact of HIV case surveillance as implemented following these guidelines.

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The draft guidelines present the results of these assessments in more detail, but several key steps have been taken, including:

Evaluation of Unique Identifier Systems

CDC has assessed the feasibility of using alternatives to name-based methods for HIV surveillance by reviewing a number of existing state systems that use a variety of numeric codes or "unique identifiers" (UI) rather than names.

Most recent evaluations looked at Social Security number-based systems. Several problems were found with these systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. CDC also found difficulties in assessing the level of duplicate case reports or the ability to reliably link to other public health databases (e.g. death registries).

In UI-based systems, providers must maintain logs or other forms of documentation linking the UI to the name-based medical records. This process may pose additional confidentiality risks if physician-held surveillance registries are not protected by state confidentiality statutes or are located in non-secure areas.

Support for Anonymous Testing

While studies suggest that name-based HIV reporting does not serve as a major deterrent to testing, CDC continues to strongly support anonymous HIV testing and recommends that all states provide anonymous testing options. CDC studies indicate that the lack of anonymous testing serves as a deterrent to testing in some high-risk populations. Unless prohibited by law, CDC requires that states receiving prevention funds to make anonymous testing available. Maintaining anonymous test sites is important for prevention efforts and will not seriously inhibit efforts to track the epidemic. Most people are diagnosed with HIV infection in confidential care settings. Moreover, the time between HIV diagnosis and the point at which individuals enter the care system has become shorter, given new treatment advances. Maintaining an anonymous testing option may help ensure that more individuals learn their status, and if infected, seek early treatment and care. HIV home test kits now offer another anonymous testing option in the United states. And anonymous testing is available in publicly funded counseling and testing sites in all but eleven states. CDC strongly recommends that states not currently offering anonymous testing reevaluate their policies on this issue.

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Strengthening Systems to Protect Confidentiality

Public health departments have maintained an exemplary record in protecting the confidentiality of HIV/AIDS data. Since 1981 there have been few reported breaches of confidentiality in state AIDS reporting systems.

Over the past few years, CDC has been working to evaluate additional measures at the state level that could improve confidentiality even further. CDC has recently reviewed state reporting programs and has developed enhanced standards to be used in developing local confidentiality plans. Local programs will be required to meet these performance standards and must ensure confidentiality as a condition of funding. One important security measure CDC is now making available to states is the option of using a double-keyed encryption program. With this system, names and other identifying information may only be accessed with both the key (password) held by the state and the key held by CDC.

To assess the strength of local confidentiality laws that protect HIV data, CDC requested that Georgetown/Johns Hopkins Public Health Law Project review local laws and regulations. All states and many localities have legal safeguards of confidentiality for government-held data, and these laws were found to provide greater protection than laws protecting health information held by private health care providers. Additionally, most states have specific statutory protections for public health data related to HIV. However, state legal protections vary widely.

CDC is therefore promoting efforts to enhance and standardize local confidentiality laws. CDC, in partnership with other public health agencies, the National Conference of state Legislatures, and the Georgetown/Johns Hopkins Public Health Law Project, is working to develop model legislative language to protect confidential, identifiable information held by state and local public health departments against unauthorized and inappropriate use, while still allowing the use of surveillance information to accomplish legitimate public health objectives.

Request for Public Comment

The draft Guidelines represent the combined efforts of CDC and numerous agencies and individuals nationwide. CDC is seeking public comment to ensure the final recommendations promote the best possible approaches to HIV surveillance, as a critical component of future HIV prevention efforts. After the public comment period, which runs from x date to y date, the comments will be carefully reviewed and considered. The Guidelines will be modified as needed before being published in the Morbidity and Mortality Weekly Report. For copies of the draft Guidelines and information on how to submit comments, call the CDC National Prevention Information Network at 1-800-458-5231 or send a written request to P.O. Box 6003, Rockville, MD 20849-6003.

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Chief of Staff

Washington, D.C. 20201

FACSIMILE

DATE: Sandy Thurman | L. Jennings

TO: ~~2439~~

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FROM: Mary Beth Donahue
Chief of Staff

Phone: 202/690-7431 Fax: 202/401-5783

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CDC UPDATE
CENTERS FOR DISEASE CONTROL AND PREVENTION
NCHSTP National Center for HIV, STD & TB Prevention
December 1998

CDC Draft Guidelines for Improved Data on U.S. HIV Epidemic

New Systems Urgently Needed to Guide Prevention Efforts

The Centers for Disease Control and Prevention (CDC) has released draft guidelines to assist States in the design and implementation of effective systems to track the course of the HIV epidemic. In the wake of recent treatment advances, which have slowed the progression from HIV to AIDS for many individuals, data on AIDS cases alone can no longer be reliably used to direct prevention efforts to communities currently at greatest risk. To address the urgent need for information to ensure effective targeting of prevention services, CDC has called for all States and territories to conduct HIV case surveillance as an extension of their AIDS surveillance programs.

As of July 1, 1998, thirty-two States had implemented HIV surveillance using the same reporting system for both HIV and AIDS cases; three of these conduct pediatric surveillance only. Additional State are now working to expand their AIDS surveillance systems to include HIV cases. The draft "*Guidelines for National HIV Surveillance, Including Monitoring for HIV Infection and Acquired Immunodeficiency Syndrome*" are designed to provide States recommendations on the best practices to ensure both quality and confidentiality of HIV data.

The draft Guidelines represent the culmination of a lengthy effort by CDC with communities and public health partners nationwide to address emerging information needs and issues surrounding the effective implementation of HIV reporting. The proposed recommendations were designed to ensure that systems address several goals including: 1) the provision of accurate and reliable data for communities to effectively direct scarce resources for HIV prevention and treatment; 2) the protection of confidentiality of HIV data, including controlled access and strong penalties for misuse; and 3) continued support for anonymous testing options so that surveillance does not deter individuals at risk from accessing HIV testing, treatment and prevention services.

Criteria for Quality and Confidentiality

The draft guidance document outlines performance criteria to ensure the quality and confidentiality of HIV data. These criteria are described in detail in the recommendations, and include strict confidentiality procedures and protections (e.g. single registry, elimination of personal identifiers, computer encryption, physical security, limited access, and penalties for abuse) and quality standards for data to ensure completeness (over 85% of diagnoses must be reported), timeliness (over 66% of diagnoses of reported within 6 months of diagnosis), unduplicated reports (less than 5% of cases should be duplicate reports of a single case), and the ability to follow-up with providers on cases of public health importance (e.g., unusual modes of transmission or strains).

CDC Recommendations

Based on published evaluations to date, CDC has concluded that name-based HIV surveillance systems are currently the most likely to meet the necessary performance standards and provide the quality data necessary to direct community prevention and treatment programs. CDC therefore advises that State and local surveillance programs use the same name-based approach for HIV surveillance as is currently used for AIDS surveillance nationwide.

CDC's draft policy does allow for flexibility, if states wish to implement alternative systems. CDC has and will continue to provide financial and technical assistance to states working to design systems that rely on codes or "unique identifiers" (UIs) rather than names. Given the importance of these data for directing services and care to individuals with HIV infection, all states will be required to meet the specified performance criteria to ensure both the quality and confidentiality of the data.

During the next few years, CDC will assist states in implementing HIV surveillance systems, evaluating current performance levels, revising systems as necessary, and monitoring performance. After this transition period, CDC will evaluate and award proposals for Federal funding of state and local surveillance programs based on their capacity to meet the performance standards. At that time, CDC will work with states to adopt surveillance methods that will enable them to achieve the standards.

Efforts to Evaluate and Address Concerns Regarding Name-Based HIV Reporting

While there is widespread support for expanded HIV reporting, many people who support name-based AIDS reporting still have concerns regarding name-based reporting of HIV infection. Concerns about name-based HIV reporting have focused largely on confidentiality, potential non-public health uses of data, the impact of reporting on test-seeking behavior, access to anonymous testing, and possible alternatives to name-based reporting.

CDC recognizes these concerns and the greater sensitivity of HIV case data. CDC has worked for several years to evaluate and address these issues. The agency has conducted several scientific assessments and has consulted with a diverse group of individuals and organizations from the scientific, public health, and AIDS advocacy communities. The guidelines present the results of these assessments in more detail. Four several key steps have been taken, including:

- *Evaluation of Unique Identifier Systems*

Beginning in 1993 to assess the feasibility of using alternatives to name-based reporting for HIV surveillance, several States implemented reporting of HIV cases or CD4+ T-lymphocyte results using a variety of numeric codes. Other States tried to conduct case surveillance using codes that were intended for use in case management systems. In 1995, CDC convened a meeting of these States that identified operational, technical and scientific challenges in conducting surveillance using codes.

Additionally, CDC has conducted a three-year evaluation of social security number-based, non-named, unique identifier (UI) reporting systems in Maryland and Texas.

The evaluation, published in the January 9, 1997, *Morbidity and Mortality Weekly Reports*, revealed several problems with these UI systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. Neither State was able to assess the level of duplicate case reports or the ability to reliably link to other public health databases (e.g. death registries).

Moreover, for the follow-up of UI-based cases, providers must maintain logs or other forms of documentation linking the UI to the name-based medical records. This process may pose additional confidentiality risks if physician-held surveillance registries are not protected by State confidentiality statutes or are located in non-secure areas. Since this evaluation, Maryland is continuing to review and evaluate the performance of its UI system; Texas is seeking to amend its regulations to begin name-based HIV reporting.

- *Evaluation of impact on test-seeking behavior*

CDC studies conducted to date suggest that name-based HIV reporting has not served as a major deterrent to testing. For example, CDC has worked with six health departments to evaluate HIV testing patterns in the twelve months before and the twelve months after the implementation of HIV reporting. In these areas, the number of HIV tests increased in four States and declined in five. The declines were not statistically significant and followed a decreasing trend in testing that began before the implementation of reporting. Although some variability in testing trends was observed among some racial and ethnic subgroups and HIV risk exposure categories.

However, CDC recognizes that for some people reporting may serve as a deterrent. The agency therefore supports that anonymous testing be made available. As additional data on implementation of reporting, CDC will conduct ongoing evaluations to monitor the impact of policy changes on testing behaviors.

- *Support for anonymous testing*

CDC continues to strongly support anonymous HIV testing and recommends that all States provide anonymous testing options. CDC studies indicate that the lack of anonymous testing serves as a deterrent to testing in some high-risk populations. Unless prohibited by law, CDC requires that States receiving prevention funds make anonymous testing available in order to make testing as accessible as possible. Maintaining anonymous test sites is critical for prevention efforts and will not seriously inhibit our ability to track the epidemic. Most persons are diagnosed with HIV infection in confidential care settings. Moreover, the time between HIV diagnosis and the point at which individuals enter the care system has become shorter, given new treatment advances. Maintaining an anonymous testing option may help ensure that more individuals learn their status, and if infected, seek early treatment and care. HIV home test kits now offer another anonymous testing option in the United States. And anonymous testing is available in publicly funded counseling and testing

sites in all but eleven States. CDC strongly recommends that States not currently offering anonymous testing reevaluate their policies on this issue.

- *Strengthening systems to protect confidentiality*

To date, public health departments have maintained an exemplary record in protecting the confidentiality of HIV/AIDS data. Since 1981 there have been few reported breaches of confidentiality in State AIDS reporting systems. A breach occurred in Florida that involved a health department employee who, without authorization, revealed names from a registry. The staff member was prosecuted under State law, and CDC has worked closely with the State of Florida to further strengthen its security protections.

Over the past few years, CDC has been working to evaluate additional measures at the State level that could improve confidentiality even further. CDC has reviewed State reporting programs and has developed enhanced standards to be used in developing local confidentiality plans. Local programs will be required to meet these performance standards and must ensure confidentiality as a condition of funding. One important security measure CDC is now making available to States is the option of using a double-keyed encryption program. With this system, names and other identifying information may only be accessed through both the key (password) held by the State and the key held by CDC. The encrypted data held by CDC will be protected by an Assurance of Confidentiality under section 308(d) of the Public Health Service Act.

To assess the strength of local confidentiality laws to protect HIV data, CDC requested that Georgetown/Johns Hopkins Public Health Law Project review local laws and regulations. All States and many localities have legal safeguards of confidentiality for government-held data, and these laws were found to provide greater protection than laws protecting the confidentiality of information held by private health care providers. Additionally, most States have specific statutory protections for public health data related to HIV. However, State legal protections vary widely.

CDC is therefore promoting efforts to enhance and standardize local confidentiality laws. CDC is working with other public health agencies, the National Conference of State Legislatures, and the Georgetown/Johns Hopkins Public Health Law Project, is working to develop model legislative language to protect confidential, identifiable information held by State and local public health departments against unauthorized and inappropriate use, while still allowing the use of surveillance information to accomplish legitimate public health objectives.

Request for Public Comment

These Guidelines represent the combined efforts of CDC and numerous agencies and individuals nationwide. CDC is seeking public comment to ensure the final recommendations promote the best possible approaches to HIV surveillance, as a critical component of future HIV prevention efforts. After the public comment period, which runs from x date to y date, the comments will be carefully reviewed and considered. The Guidelines will be modified as needed before being published in the

Morbidity and Mortality Weekly Report. For copies of the draft Guidelines and information on how to submit comments, call the CDC National Prevention Information Network at 1-800-458-5231 or send a written request to P.O. Box 6003, Rockville, MD 20849-6003.

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CDC UPDATE

Embargoed for Release:
4 p.m. EST, October 27, 1998

Contact: NCHSTP Office of Communications
(404) 639-8895

MEDIA CLARIFICATION
JAMA Articles on HIV Testing and Reporting

The *Journal of the American Medical Association* will publish a CDC article entitled, *"Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs"* in their October 28 issue. CDC would like to correct an inaccuracy in the JAMA press release on this article and clarify our strong support for anonymous HIV testing.

The *JAMA* press release begins with the premise that the CDC study contradicts the findings of another article by Andrew Bindman, M.D., from the University of California, San Francisco (UCSF). In fact, while the studies addressed different issues, both articles support the need for access to anonymous HIV testing.

The UCSF study, by Bindman and colleagues, evaluated whether anonymous HIV testing was associated with earlier HIV testing and HIV-related medical care than confidential HIV testing among people diagnosed with AIDS. The study found that HIV-infected individuals who used anonymous testing services got tested and entered care earlier than those who used confidential services. Many people tested in confidential settings did not seek testing prior to becoming ill. The findings underscore the critical need to educate individuals at-risk about the need to learn their HIV status, and if infected, to seek early care.

The CDC study, by Allyn Nakashima, M.D. and colleagues, looked at the impact of the implementation of HIV reporting in six states on test-seeking behavior. The data indicate that HIV reporting by name did not significantly affect the level of HIV testing in publicly funded anonymous and confidential test sites.

As an increasing number of states have either implemented, or begun considering implementation of, HIV surveillance, there has been some concern that HIV reporting might deter people from seeking care. This study should help allay these concerns, as these data show no significant declines in testing following the implementation of HIV reporting. The article concludes that as additional states implement confidential HIV reporting policies, the impact of surveillance on those seeking HIV testing will likely be small and should not hinder HIV prevention efforts. CDC will conduct ongoing evaluations to monitor the impact of policy changes on testing behaviors.

To help ensure that reporting policies do not deter even a small number of people from seeking testing, CDC recommends that states make anonymous testing available. Previous CDC studies indicate that the lack of anonymous testing options may serve as a deterrent to testing in some high-risk populations. Maintaining anonymous test sites is important for prevention efforts and may help ensure that more individuals learn their status and receive the maximum benefit from HIV treatment.

Anonymous testing is currently available in all but eleven states. CDC has strongly recommended that these states reevaluate their policies on this issue. Unless prohibited by state law, CDC requires that states offer anonymous HIV testing as a condition of funding.

###

DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30333

October 27, 1998

Dear Colleague:

Today's issue of the *Journal of the American Medical Association (JAMA)* contains an article by a Centers for Disease Control and Prevention (CDC) author and is entitled "Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs." Data from this study describes trends in HIV testing in publicly funded counseling and testing sites before and after implementation of name-based HIV reporting in six states (Louisiana, Michigan, Nebraska, Nevada, New Jersey, Tennessee).

Overall, there were no significant decreases in the number of HIV tests provided at the counseling and testing sites in the months immediately after HIV reporting was implemented in any state, other than those expected from trends present before HIV reporting. The article concludes that as additional states implement confidential HIV reporting policies, the impact of these policies on those seeking HIV testing will likely be small and should not hinder HIV prevention efforts. (The full text of this article can be found on the *JAMA* Web site at http://www.ama-assn.org/special/hiv/library/readroom/jama98/joc80227.htm.)

There is another article in this issue of *JAMA* entitled "A Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care." This article, by Andrew Bindman, M.D., from the University of California, San Francisco (UCSF), is about a study that clearly demonstrates that individuals tested anonymously sought HIV testing and medical care earlier in the course of HIV disease than did persons tested confidentially.

The researchers used data collected as a part of a cooperative project between the University of California, Berkeley; CDC; and eight state health departments (Arizona, Colorado, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas). This project, called the AIDS Patient Survey (APS), found that anonymous testers spent over a year more (an average of 387 days) in medical care prior to an AIDS diagnosis than did confidential testers. The findings underscore the critical need to educate individuals at risk about the need to learn their HIV status and, if infected, to seek early care. (The full text of this article can be found on the *JAMA* Web site at http://www.ama-assn.org/special/hiv/library/readroom/jama98/joc80107.htm.)

Unfortunately, the original *JAMA* press release about these two articles began with the premise that their findings contradict each other. In fact, the studies simply address different issues. Attached are both studies.

CDC believes that both anonymous testing and comprehensive HIV reporting are vitally important to HIV prevention efforts. Anonymous testing is currently available in all but eleven states. CDC has strongly recommended that states not offering anonymous HIV testing reevaluate their policies on this issue. Unless prohibited by state law, CDC requires that states

offer anonymous HIV testing as a condition of funding. We strongly believe, and have seen demonstrated in states that have both anonymous testing and HIV reporting, that these critical elements of prevention can coexist and provide information that greatly enhances HIV prevention and treatment efforts.

Should you have any questions or need additional information, please call our Office of Communications at (404) 639-8063.

Sincerely,

Helene D. Gayle

Helene D. Gayle, M.D., M.P.H.
Director
National Center for HIV, STD, and TB Prevention
Centers for Disease Control and Prevention

Corneal Decompensation — Continued

of Health. H Edelhauser, PhD, N Anderson, MD, Dept of Ophthalmology, Emory Univ, Atlanta, Georgia. Hospital Infections Program, National Center for Infectious Diseases; Div of Surveillance, Hazard Evaluations, and Field Studies, National Institute for Occupational Safety and Health; Div of Environmental Health Laboratory Sciences, National Center for Environmental Health; and EIS officers, CDC.

Editorial Note: Corneal endothelial decompensation is manifested by opacity of the cornea; it can be a nonspecific response to mechanical or chemical injury (*3*). Mechanical trauma can result from incidental corneal contact by intraocular instruments during surgery; chemical injury can result from the improper use of intraocular drugs, drugs containing preservatives, or from residues from inadequate rinsing of detergents or other residues from surgical instruments (*3,4*). When severe, corneal endothelial decompensation requires corneal transplantation. Of the estimated 1.4 million cataract surgeries performed in the United States each year (*5*), <0.05% are complicated by corneal endothelial decompensation (A. Lubniewski, Veterans Affairs Medical Center, St. Louis, Missouri; and H. Edelhauser, Emory University, Atlanta, Georgia, personal communication, 1998).

Steam autoclaving is the preferred method for sterilizing surgical instruments. Ethylene oxide sterilization can be used for heat-sensitive items. However, because of the environmentally harmful effects of ethylene oxide, the Environmental Protection Agency encourages health-care providers to reduce the use of this form of sterilization. CDC's National Institute for Occupational Safety and Health considers ethylene oxide to be an occupational carcinogen and reproductive toxin (*6,7*). Since the early 1990s, new types of sterilization using plasma gas technology, such as the Abtox Plazlyte system, have been introduced (*1,2*). The inductively coupled plasma atomic emission data obtained from the CDC laboratory analyses, in part, prompted the FDA to issue a safety alert about the use of the Abtox Plazlyte Sterilization system to sterilize ophthalmic instruments (*8*).

To ascertain the extent of this problem, all episodes of corneal decompensation following ophthalmic surgery and information about type of sterilization method used should be reported through state health departments to CDC's Hospital Infections Program, National Center for Infectious Diseases, telephone (404) 639-6413, and to FDA's MedWatch, telephone (800) 332-1088.

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Corneal Decompensation — Continued

Diagnosis and Reporting of HIV and AIDS in States with Integrated HIV and AIDS Surveillance — United States, January 1994–June 1997

Recent reports based on acquired immunodeficiency syndrome (AIDS) surveillance data have highlighted substantial declines in AIDS incidence and deaths. As a result of improvements in treatment and care of persons infected with human immunodeficiency virus (HIV), surveillance of AIDS alone no longer accurately reflects the magnitude or direction of the epidemic (*1*). Current public health and clinical recommendations promote early diagnosis and treatment of HIV disease (*2*). Data on persons in whom HIV infection is diagnosed before AIDS is diagnosed are needed to determine populations in need of prevention and treatment services. This report examines data for persons aged ≥13 years in whom HIV infection was diagnosed in 25 states that conducted name-based HIV surveillance in addition to AIDS surveillance during January 1994–June 1997*. Provisional data indicate that declines in AIDS incidence in these states were not accompanied by comparable declines in the number of newly diagnosed HIV cases.†

In late 1993, the states included in this analysis merged data from the name-based HIV and AIDS case reporting systems into an integrated HIV/AIDS surveillance system. Patient and provider names were deleted before states forwarded data to CDC and replaced by codes. Cases were divided into two mutually exclusive categories: persons in whom HIV infection was diagnosed (without an AIDS diagnosis) and persons in whom HIV infection was diagnosed only when they first had AIDS diagnosed. Data for persons aged ≥13 years were analyzed by the earliest date of diagnosis of HIV or AIDS for January 1994–June 1997. Quarterly trends in the number of persons whose initial diagnosis was HIV infection were compared with quarterly trends in the number of persons whose initial diagnosis was AIDS. HIV and AIDS data were adjusted for delays in reporting of cases and deaths (*3*).

From January 1994 through June 1997, HIV or AIDS was diagnosed in 72,905 persons aged ≥13 years in the 25 states. Of these, HIV infection was the initial diagnosis in 52,690 (72%) and AIDS was the initial diagnosis in 20,215 (28%) (Table 1). From 1995 to 1996, the number of persons in whom HIV infection was the initial diagnosis de-

*Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

†Single copies of this report will be available until April 24, 1999, from the CDC Prevention Information Network, P.O. Box 6003, Rockville, MD 20849-6003; telephone (800) 458-5231 or (301) 519-0459.

Diagnosis and Reporting of HIV and AIDS — Continued

TABLE 1. Estimated number* of persons aged ≥13 years in whom HIV was diagnosed, by quarter of diagnosis and disease status at initial diagnosis† — 25 states§, January 1994–June 1997

	Disease status at initial HIV diagnosis				
	HIV		AIDS		
Quarter of diagnosis	No.	(%)	No.	(%)	Total
1994					
1	4,038	(70)	1,723	(30)	**5,761**
2	4,073	(71)	1,691	(29)	**5,764**
3	3,809	(73)	1,430	(27)	**5,239**
4	3,558	(71)	1,434	(29)	**4,992**
Total¶	**15,571**	**(71)**	**6,337**	**(29)**	**21,908**
1995					
1	3,904	(71)	1,568	(29)	**5,472**
2	3,780	(72)	1,470	(28)	**5,250**
3	3,711	(72)	1,421	(28)	**5,132**
4	3,438	(72)	1,370	(28)	**4,808**
Total¶	**14,895**	**(72)**	**5,863**	**(28)**	**20,758**
1996					
1	3,889	(74)	1,366	(26)	**5,255**
2	3,635	(72)	1,382	(28)	**5,017**
3	3,619	(73)	1,310	(27)	**4,929**
4	3,476	(74)	1,236	(26)	**4,712**
Total¶	**14,652**	**(74)**	**5,313**	**(26)**	**19,965**
1997					
1	3,762	(73)	1,376	(27)	**5,138**
2	3,809	(74)	1,325	(26)	**5,134**
Total	**52,690**	**(72)**	**20,215**	**(28)**	**72,905**

*Numbers are estimates after adjustments for reporting delays. Point estimates are presented for reproducibility of the data.
†For persons who had not had an HIV diagnosis before being diagnosed with AIDS, their AIDS diagnosis date is considered their earliest HIV diagnosis date; for persons initially reported with HIV who subsequently had AIDS diagnosed and reported, they are presented by the earliest diagnosis date, which is their HIV diagnosis.
§Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.
¶Total estimates include cases with missing quarter for HIV diagnoses and AIDS diagnoses.

clined 2%, and the number of persons in whom AIDS was the initial diagnosis declined 9%.

Of 52,690 persons in whom HIV infection was the initial diagnosis, 28% were women, 57% were non-Hispanic blacks, and 18% were infected through heterosexual contact (Table 2). Among selected demographic groups, the number of persons in whom HIV infection was the initial diagnosis during 1995 compared with 1996 declined 3% among men (from 10,762 to 10,395) but increased 3% among women (from 4126 to 4253). The number of persons in whom HIV infection was the initial diagnosis increased 10% among Hispanics (from 971 to 1070) and decreased 3% among non-

Diagnosis and Reporting of HIV and AIDS — Continued

TABLE 2. Characteristics of persons aged ≥13 years with HIV, by disease status at initial diagnosis* — 25 states†, January 1994–June 1997

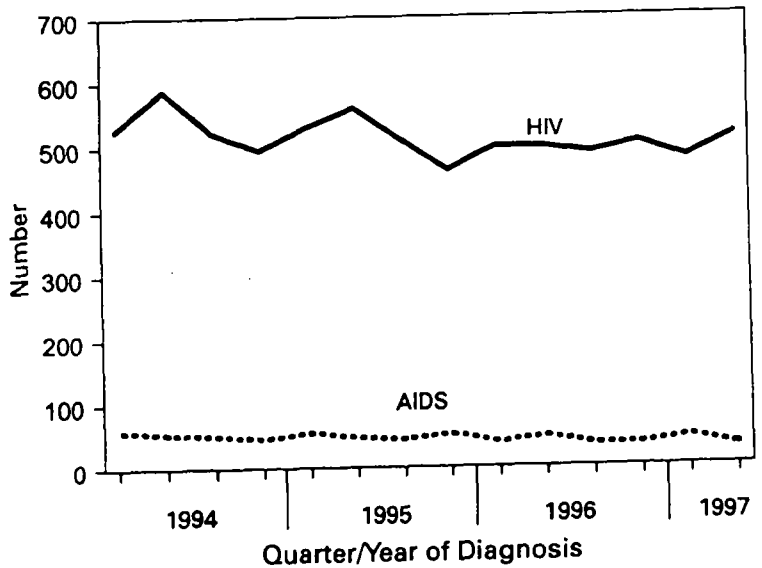
	Disease status at initial HIV diagnosis				
	HIV		AIDS		
Characteristic	No.§	(%¶)	No.§	(%¶)	Total
Sex					
Male	37,996	(72)	16,866	(83)	**54,862**
Female	14,689	(28)	3,348	(17)	**18,037**
Race/Ethnicity**					
White, non-Hispanic	17,929	(34)	9,171	(45)	**27,100**
Black, non-Hispanic	30,229	(57)	9,127	(45)	**39,356**
Hispanic	3,581	(7)	1,660	(8)	**5,241**
Other/Unknown	949	(2)	256	(1)	**1,205**
Risk/Exposure category					
Men having sex with men	17,098	(32)	8,866	(44)	**25,964**
Injecting-drug user	9,671	(18)	3,959	(20)	**13,630**
Men having sex with men/ Injecting-drug user	2,088	(4)	843	(4)	**2,931**
Heterosexual contact	9,279	(18)	2,428	(12)	**11,707**
Other/Unreported	14,552	(28)	4,116	(20)	**18,668**
Age group (yrs)					
13–24	7,200	(14)	653	(3)	**7,853**
25–29	9,384	(18)	2,239	(11)	**11,623**
30–34	11,916	(23)	4,503	(22)	**16,419**
35–39	10,030	(19)	4,608	(23)	**14,638**
≥40	14,159	(27)	8,210	(41)	**22,369**
Total††	**52,690**		**20,215**		**72,905**

*For persons who had not had an HIV diagnosis before being diagnosed with AIDS, their AIDS diagnosis date is considered their earliest HIV diagnosis date; for persons initially reported with HIV who subsequently had AIDS diagnosed and reported, they are presented by the earliest diagnosis date, which is their HIV diagnosis.
†Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.
§Numbers are estimates after adjustments for reporting delays. Point estimates are presented for reproducibility of the data.
¶Percentages may not total 100 because of rounding.
**Persons of races other than black and white were included under "other/unknown" because estimates were too small for meaningful analysis.
††Column totals include missing/other for some categories (e.g., missing sex). Persons infected through receipt of blood or blood products are included under other/unreported risk.

Hispanic blacks (from 8569 to 8300) and 2% among non-Hispanic whites (from 5093 to 4966). Men who have sex with men (MSM) accounted for the largest proportion of the HIV diagnoses (32%). Analysis of trends by risk/exposure category is complicated by the high proportion of HIV cases with unreported risk (28%).

Of 52,690 persons in whom HIV infection was the initial diagnosis, 7200 (14%) were aged 13–24 years. The number of HIV diagnoses per quarter-year was approximately

FIGURE 1. Estimated number of persons aged 13–24 years with HIV infection, by disease status at the time of initial diagnosis with HIV — 25 states*, January 1994–June 1997†



*Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.
†Adjusted for reporting delays.

constant in this age group, declining 4% from 1995 to 1996 (from 2066 to 1991) (Figure 1). Of persons in this age group, 3203 (44%) were female, 4566 (63%) were non-Hispanic black, and 394 (5%) were Hispanic; by risk category, 2270 (31%) were MSM, 1886 (26%) acquired HIV through heterosexual contact, and 449 (6%) were injecting-drug users; 1074 (15%) had AIDS subsequently diagnosed. An additional 653 persons aged 13–24 years had AIDS initially diagnosed.

Reported by: State and local health departments; Div of HIV/AIDS Prevention—Surveillance, and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

Editorial Note: The data from these 25 states indicate that from 1994 through mid-1997, the number of persons in whom HIV infection was the initial diagnosis was stable and declines over the entire period were slight. Compared with reported declines in AIDS incidence nationally (*1*), these data suggest that HIV incidence was relatively stable in these states. In particular, the number of new HIV diagnoses among persons aged 13–24 years probably more closely indicate HIV incidence trends because young persons have more recently initiated high-risk behaviors.

HIV surveillance data include persons who were infected more recently than were persons reported with AIDS, and their characteristics indicate more recent trends in

HIV transmission. Many of the new HIV diagnoses in these states occurred among blacks, women, young MSM, and persons infected through heterosexual contact with substantial increases observed among Hispanics. The HIV case data from these states reflect the changing demographic and risk profile of an epidemic that disproportionately affects racial/ethnic minorities (*1,3*). Race/ethnicity is not a risk factor for HIV infection but is likely a marker for other factors that may be predictive of increased risk for HIV infection (e.g., low income, lack of education, and higher rates of injecting and non-injecting drug use) (*4*). Black and Hispanic persons who engage in high-risk sex or drug-using behaviors should be a major focus of HIV-prevention efforts, including strategies to promote knowledge of HIV status through voluntary test seeking and to facilitate entry to care and treatment.

Of persons in whom HIV infection was the initial diagnosis, 14% were adolescents and young adults aged 13–24 years, compared with 3% of persons in whom AIDS was the initial diagnosis. This age group is an important target for HIV prevention efforts because a large proportion of all new HIV infections occur among persons in this age group (*5*). In particular, reduction of high-risk sexual behaviors among adolescent and young adult women and MSM is needed to reduce HIV transmission in this age group.

In the 25 states, declines in the number of cases were larger among persons in whom AIDS was the initial diagnosis than among those in whom HIV infection was the initial diagnosis. Most persons with HIV had been tested in a medical facility or other clinical-care setting and had had an opportunity for early treatment interventions to delay HIV-related morbidity and mortality, contributing to declines in AIDS incidence (*6*). In the future, AIDS surveillance data will increasingly reflect access to testing and response to therapy in the population. Approximately one fourth of all new diagnoses in these states occurred among persons who had already developed AIDS when HIV infection was first diagnosed. AIDS surveillance data should be used to target underserved populations for early testing and prompt referrals for treatment.

HIV and AIDS surveillance data mostly reflect the characteristics of persons tested in medical care and other confidential settings. These data may not represent the characteristics of all persons with HIV infection because persons tested anonymously are not reported to the surveillance system, and some persons with HIV infection have not been tested. However, approximately 140,000 persons living with HIV have already been reported and characterized, representing most prevalent infections in these states (*7*). The degree to which integrated HIV and AIDS surveillance data are representative of all infected persons is expected to increase over time as the proportion of untested persons decreases.

The public health usefulness of the HIV surveillance data is affected by the performance of the system of case reporting and follow up (*8*). In these 25 states, most of which require laboratory-based reporting of HIV-positive test results, HIV reporting was very complete. Only 12% of persons in whom HIV infection was the initial diagnosis had not been reported to CDC as an HIV case before being reported as an AIDS case. CDC estimates that <2% of HIV cases are duplicates based on matching of the national coded surveillance database. CDC has developed methods for estimating the risk distribution for AIDS cases with unreported risk (*3*); however, similar methods for HIV cases are not yet available. In this report, the proportion of HIV cases by risk/exposure categories is an underestimate until follow up is completed for cases reported without risks (*3*). Name-based HIV reporting should facilitate epidemiologic

Diagnosis and Reporting of HIV and AIDS — Continued

follow up to increase the completeness of risk/exposure, clinical, treatment, and other data relevant to effective HIV-prevention community planning.

This report highlights the continued need for effective HIV and AIDS prevention programs to reduce rates of HIV transmission and demonstrates the usefulness of integrated HIV and AIDS surveillance data to direct these efforts. State and local areas without such surveillance have limited ability to monitor local changes in HIV infection and disease trends. In these areas, approximately 200,000 persons have had HIV diagnosed (without AIDS) (7), but data are not available to describe trends in new HIV diagnoses. Implementing integrated HIV and AIDS surveillance in these states and local areas is necessary to provide accurate information for targeting resources to populations most affected (e.g., adolescents, women, racial/ethnic minorities, and young MSM) and for evaluating program effectiveness.

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Notice to Readers

Availability of Report on Health Promotion

"Health Promotion in the City," a report prepared for CDC, is a review of current practice and recommendations for new directions to improve the health of urban populations. The report describes social and economic factors that have influenced the health of urban populations during the previous 40 years, assesses the extent to which existing interventions address major causes of ill health, and explores new sources for theory and practice for urban health promotion. The report suggests specific actions that community leaders and organizations, local and state health departments, public health officials, federal agencies, foundations, and universities can take to strengthen health promotion practices in urban communities in the United States.

Copies of this report are available from CDC's Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, 4770 Buford Highway, N.E., Mailstop K-45, Atlanta, GA 30341-3724; telephone (770) 488-5269.

Notice to Readers

Epidemiology in Action Course

CDC and Emory University will cosponsor an applied epidemiology course designed for practicing state and local health department professionals. This course, "Epidemiology in Action," will be held at CDC during November 2–13, 1998. The course emphasizes the practical application of epidemiology to public health problems and comprises lectures, workshops, classroom exercises (including actual epidemiologic problems), roundtable discussions, and computer labs. Topics covered include descriptive epidemiology and biostatistics, analytic epidemiology, epidemic investigations, public health surveillance, surveys and sampling, computers and Epi Info software, and discussions of selected prevalent diseases. There is a tuition charge.

Applications must be received by September 11, 1998. Additional information and applications are available from Department PSB, Rollins School of Public Health, Emory University, 7th floor, 1518 Clifton Road, N.E., Atlanta GA 30322; telephone (404) 727-3485; fax (404) 727-4590; or email ogostan@sph.emory.edu.

Addendum: Vol. 47, No. RR-2

In the *MMWR Recommendations and Reports*, "Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States," the following names should be added as persons who presented data at the Public Health Service Task Force meeting on May 9, 1997: Robert Coombs, MD, PhD; Rhoda Sperling, MD; David Shapiro, PhD; Miriam Poirer, PhD; Kenneth Ayers, DVM; and David Morse, PhD.

Erratum: Vol. 47, No. RR-4

In the *MMWR Recommendations and Reports*, "Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection," on page 8 in Table 2 a typesetting error occurred in the third bulleted item under Category B: Moderately Symptomatic. Following is the corrected table.

rubella, and up to 85% of susceptible pregnant women who are infected during their first trimester may give birth to an infant with CRS.[2]

Reported by: H Heshmati, MD, J Moini, MD, C Krugg, Brevard County Health Dept, Merritt Island; M McMillan, C Castro, J Griffiths, Broward County Health Dept, Fort Lauderdale; HT Janowski, MPH, Florida Dept of Health. Vessel Sanitation Program, Special Programs Group, National Center for Environmental Health; Child Vaccine Preventable Disease Br, Epidemiology and Surveillance Div, National Immunization Program; Miami Quarantine Station, Program Operations Br and Surveillance and Epidemiology Br, Div of Quarantine, National Center for Infectious Diseases, CDC.

CDC Editorial Note: Although rubella is typically a mild, self-limited disease in adults, infection in pregnant women can result in serious adverse health outcomes for the fetus, including CRS, a group of birth defects including deafness, cataracts, heart defects, and mental retardation. In the United States, approximately 10% of young adults are susceptible to rubella; in other countries, some without routine vaccination policies for rubella, susceptibility rates for rubella range from 4% to 68%.[3] During 1994-1996, 12 laboratory-confirmed cases of CRS were reported in the United States.[4]

Although a definitive quantitation of the risk for transmission of rubella among crew members and passengers on the cruise ships could not be ascertained, risk for infection among those crew members of cruise ship B could be estimated. Results of the serosurvey among crew members indicate that at least 41 (11%) of 366 were acutely infected with or susceptible to rubella at the time of the serosurvey. This serosurvey was conducted after recognition of an ongoing outbreak of rash illnesses among crew members, and it is likely that rubella susceptibility rates at the outset of the outbreak would have been higher.

The risk for transmission of infection and an outcome of CRS in pregnant passengers in their first trimester of pregnancy on cruise ship B was difficult to determine because (1) the rubella immune status of these pregnant passengers was unknown and (2) the consequences of rubella infection in susceptible pregnant women (i.e., CRS) may not be evident for several months after the exposure. If pregnant passengers were exposed, and assuming that approximately 10% of these women were susceptible to rubella and 85% of susceptible pregnant women who are infected during their first trimester will give birth to an infant with CRS, one case of CRS could potentially occur each week among passengers sailing during the outbreak.

Minimizing or eliminating the risk for rubella exposure among susceptible pregnant women is important because of the potential for serious adverse health outcomes for the fetus. To interrupt transmission of rubella among crew members and to prevent transmission of infection and CRS among susceptible pregnant women, CDC recommended administration of MMR to all crew members lacking documented immunity to rubella; serologic testing to determine susceptibility to rubella for all crew members ineligible for vaccination, including pregnant women; active surveillance aboard the ship to detect new rubella infections; prospective notification of the potential risk for rubella exposure to all embarking passengers until 30 days after the last confirmed rubella infection; and retrospective notification to all passengers sailing during the period of potential rubella transmission. These recommendations were effective in interrupting rubella transmission among crew members on cruise ship B: no additional rash illnesses were identified after their implementation.

This report of two clusters of rubella infections on commercial cruise ships demonstrates that crew members—many from countries without routine rubella vaccination programs—are potential groups of susceptible persons at risk for rubella infection. To prevent future rubella outbreaks among such persons, CDC recommends that cruise lines administer MMR to all crew members without documented immunity to rubella. Although reported rubella cases in these two outbreaks were limited to crew members, cruise ship travel provides a semiclosed environment for crew and passenger interactions, conducive to the potential spread of rubella and many other infectious diseases among crew and passengers. To prevent transmission of rubella infection and subsequent CRS, women of childbearing age, particularly pregnant women, should be immune to rubella before cruise ship excursions or international travel.

The outbreaks described in this report illustrate the potential for transmission of infectious disease among persons traveling across international borders, including aboard commercial cruise ships. Previous infectious disease outbreaks reported among crew members and passengers have included diarrheal diseases and other vaccine-preventable diseases such as influenza.[5] Approximately 4 million persons travel aboard North American cruise ships each year (CDC, unpublished data, 1998). Ensuring routinely recommended adult vaccinations for all crew members will substantially decrease the potential for future outbreaks of vaccine-preventable illnesses aboard cruise ships. All suspected cases of rubella and other notifiable vaccine-preventable diseases should be reported to the nearest state and local health department. State health departments should report all suspected cases of rubella to CDC's Child Vaccine-Preventable Disease Branch, Epidemiology and Surveillance Division, National Immunization Program, telephone (404) 639-8230.

References 5 available.

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers—Maryland and Texas, 1994-1996

MMWR 1998;48:1254-1271.
2 tables omitted

NOTIFIABLE DISEASE reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 81 states were conducting name-based human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However, because of concerns about name-based HIV surveillance, Maryland and Texas implemented HIV surveillance using non-name unique identifiers (UI).* This report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infection; the findings indicate some limitations to the use of a Social Security number-based UI for HIV surveillance.

In both Maryland and Texas, UI surveillance for HIV was implemented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social

AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data.[8] Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland and Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems.[1] In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

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*Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors; and participants of certain research projects. No exemptions to reporting exist in Texas.

†HIV-infected persons with a CD4+ T-lymphocyte count of <200 cells/μL meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

Approval of Installation of Air Bag On-Off Switches for Certain Motor-Vehicle Owners

MMWR 1997;46:1098-1099

ON NOVEMBER 18, 1997, the U.S. Department of Transportation (DOT) announced a final rule that allows vehicle owners who meet certain qualifying criteria to have air bag on-off switches installed in their vehicles beginning January 19, 1998.* The on-off switch can be installed for the driver, passenger, or both. Owners who certify that they or another occupant of their vehicle are in one of four identified risk groups can request and receive authorization from the National Highway Traffic Safety Administration (NHTSA) to have a switch installed. Additional information is available from NHTSA's World-Wide Web site (http://www.nhtsa.dot.gov) or from the DOT Auto Safety Hotline ([800] 424-9393), where copies are available of the brochure *Air Bags & On-Off Switches: Information for an Informed Decision* and the form *Request for Air Bag On-Off Switch*. These materials also will be available at state motor-vehicle offices, automobile clubs, and some new car dealerships.

Reported by: National Highway Traffic Safety Administration. Div of Unintentional Injury Prevention, National Center for Injury Prevention and Control, CDC.

CDC Editorial Note: Air bags are effective in reducing many deaths and injuries in moderately severe frontal impact crashes.[1] However, air bags also have posed special risks for children and short-stature persons who may be sitting too close to either the steering wheel or the dash board at the time of deployment.[2,3]

Because air bags are designed to supplement the use of lap and shoulder belts and not to replace them, air bags alone do not protect occupants in every type of crash (e.g., rollover crashes). Combination lap and shoulder belts and child safety seats remain the most effective occupant-protection devices available. Therefore, all occupants of a motor vehicle should use combination lap and shoulder belts consistently, and all children aged ≤12 years should be transported in the back seat in age- and size-appropriate restraints. Regardless of whether the vehicle has an air bag and whether a vehicle owner or operator decides to install an on-off switch, the rear seat is the safest seating position.

The decision to have an on-off switch installed must be in accordance with the DOT ruling. If a switch is installed, however, drivers must exercise discretion when deciding to turn it on or off and must understand both the circumstances in which the air bag poses unusual injury risks and when the air bag can provide additional protective benefits. Because the occurrence of crashes with air bag deployment cannot be predicted, drivers and front-seat passengers should always position themselves as far back from the air bag as possible, and all occupants should be properly restrained at all times.

References 3 available.

*49 CFR Parts 571 and 596.

From the CDC

Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence data, diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained separately from name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases. In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994-December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

Maryland

In 1993, the Maryland legislature mandated UI reporting of both positive HIV tests and patients with CD4+ T-lymphocyte counts of <200 cells/μL (CD4+).† Health-care providers requesting HIV or CD4+ tests are required to construct the UI code for each patient, include the code on the laboratory slip, and record it in a surveillance log that matches the UI to patient identifiers (e.g., medical record number, patient name, or other patient code) for purposes of case investigation and follow up. Laboratories licensed by Maryland are required to submit the UI-based reports to the state health department through the local health departments.

Of 9971 HIV-infection reports entered during July 1994-December 1996, all UI elements were present for 7119 (71%). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994-June 1996, and declined slightly during July-December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1-847 days). During October-November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIV-infection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

Completeness of HIV-infection reporting was estimated by comparison to cases of AIDS reported in the AIDS surveillance registry. Of AIDS cases with dates of HIV diagnosis from July 1995 through June 1996, data elements to construct UI were available for 633 (85%) cases. Of these, 319 (50%) matched to HIV-infection reports with full UI in the UI database.

Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from clients and record the UI on the HIV C&T record. During 1995-1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

Texas

In 1994, the Texas Board of Health amended regulations to require named reporting of HIV-infected children aged <13 years and UI reporting of HIV-infected adolescents and adults. Both health-care providers ordering an HIV test and laboratories performing the test report confirmed HIV infections to the Texas Department of Health (TDH) through the local health departments. Neither providers nor laboratories are required to maintain registries linking UI to patient identifiers.

Approximately 23,000 HIV-infection reports were received at TDH during the evaluation period. Since 1995, TDH excluded approximately 7000 paper HIV reports with three or more missing UI data elements. Of 16,119 HIV-infection reports entered into the UI database, all UI elements were present for 9923 (62%). Element-specific presence ranged from 66% (SSN) to 97% (sex). Overall, 60% of reports were submitted in periodic batches, which had a longer time from date of HIV test to receipt by TDH (median: 173 days; range: 26-974 days) than the 40% of reports submitted individually (median: 59 days; range: 2-906 days).

Completeness of HIV-infection reporting was estimated by comparison to AIDS surveillance data using the same methodology as in Maryland. Data elements to construct UI were available for 1762 (79%) of AIDS cases with dates of HIV diagnosis in the specified period. Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995-June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data element (n=208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

Reported by: L Solomon, DrPH, L Eldred, DrPH, J Markowitz, PhD, P Ryan, MS, G Benjamin, MD, Maryland Dept of Health and Mental Hygiene. AS Robbins, PhD, DW Hamaker, SA King, MA, SK Melville, MD, MC Thomas, MS, DM Simpson, MD, State Epidemiologist, Texas Dept of Health. Div of HIV/AIDS Prevention-Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

CDC Editorial Note: HIV and AIDS surveillance data are needed to provide reliable population-based data to guide public health programs. During 1995-1996, the first declines in the incidence of AIDS-opportunistic infections and AIDS deaths were reported in the United States (6% and 23%, respectively), in part, as a result of increasingly effective HIV therapy.[1] On the basis of revised HIV treatment guidelines,[2] the impact of treatment advances on AIDS trends is expected to continue and will reduce the usefulness of AIDS data alone to monitor HIV-infection trends and morbidity. CDC and other public health and advocacy organizations have recognized the need for national HIV case surveillance while continuing to discuss the relative merits of HIV surveillance methods based on numeric codes compared to the name-based approach employed for AIDS surveillance.[1,3]

CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs.[4] States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (>85%)[5] and documentation of risk exposures (≥93% of cases).[6] Evaluation of name-based HIV surveillance has shown 74%-97% completeness of reporting[7] (CDC, unpublished data, 1997), and documentation of risk exposures (≥76% of cases).[6] Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and

Barawan Somali Refugees — Continued

Because some Barawan Somali refugees were infected with both helminthic and protozoan pathogens, the interim recommendation for mass pre-embarkation therapy with 3-day mebendazole was changed to single-dose albendazole (400 mg per kg of body weight) for all persons except pregnant women.† This approach was considered preferable because of the high prevalence of mixed intestinal parasites, the low cost of albendazole, and the ease of single-dose therapy before departure (*4–6*). The optimal choices of agent(s) and duration of therapy for mass treatment of intestinal parasites among refugee populations remain to be determined.

The program of enhanced screening for and management of infectious diseases among this vulnerable refugee population enabled the implementation of population-based interventions before members of this group dispersed to multiple locations in ≥20 states. CDC is notifying health officials in the states in which refugees are being resettled of the results of the pre-embarkation medical screening and treatment. CDC also is working with IOM and state refugee health programs to develop a shared database of refugee medical screening results.

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†Albendazole is currently approved by the Food and Drug Administration for treatment of neurocysticercosis and hydatid disease.

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers — Maryland and Texas, 1994–1996

Notifiable disease reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 31 states were conducting name-based human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However, because of concerns about name-based HIV surveillance, Maryland and Texas implemented HIV surveillance using non-name unique identifiers (UI)*. This report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infection; the findings indicate some limitations to the use of a Social Security number-based UI for HIV surveillance.

*Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors; and participants of certain research projects. No exemptions to reporting exist in Texas.

HIV Case Surveillance — Continued

In both Maryland and Texas, UI surveillance for HIV was implemented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence data, diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained separately from name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases. In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994–December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

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Of 9971 HIV-infection reports entered during July 1994–December 1996, all UI elements were present for 7119 (71%) (Table 1). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994–June 1996, and declined slightly during July–December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1–847 days). During October–November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIV-infection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

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Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records

†HIV-infected persons with a CD4+ T-lymphocyte count of <200 cells/µL meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

HIV Case Surveillance — Continued

TABLE 1. Number of reports of HIV infection and percentage of reports that included data elements for unique identifiers (UIs), by reporting period — Maryland (MD) and Texas (TX), July 1994–December 1996

Reports/Data element	State	July–Dec. 1994	Jan.–June 1995	July–Dec. 1995	Jan.–June 1996	July–Dec. 1996	Overall
Total no. reports	MD	2,238	1,691	1,866	1,881	2,295	**9,971**
	TX*	3,932	3,399	3,597	2,852	2,339	**16,119**
Data element†							
Social Security number	MD	69.6	73.1	81.2	83.5	84.5	**78.4**
	TX	56.7	68.6	65.0	69.5	75.2	**66.0**
Date of birth	MD	95.2	96.3	98.7	99.3	98.8	**97.6**
	TX	88.4	89.8	93.1	96.8	97.6	**92.6**
Sex	MD	96.8	97.2	98.7	99.2	99.4	**98.3**
	TX	91.5	97.5	98.4	99.1	97.9	**96.6**
Race/Ethnicity	MD	85.8	88.5	91.6	94.0	89.9	**89.8**
	TX	80.8	91.6	94.4	97.1	95.4	**91.1**
% Reports with full UI	MD	61.3	65.9	74.9	78.5	76.5	**71.4**
	TX	51.8	61.9	61.6	66.5	71.3	**61.6**

*Excludes approximately 7000 records that had three or more missing UI data elements.
† Proportion of all reports containing specific UI data elements.

with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from clients and record the UI on the HIV C&T record. During 1995–1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

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HIV Case Surveillance — Continued

TABLE 2. Percentage completeness of HIV-infection reporting, availability of unique identifier (UI) data elements in alternate databases, and sources of report — Maryland and Texas, July 1994–December 1996

Characteristic	Maryland (n=9,971)	Texas (n=16,119)
Completeness of reporting		
HIV*	50.4	26.0
CD4+ T-lymphocyte count*	44.4	NA†
HIV§	52.3	NA
Availability of UI data elements in alternate databases		
Birth¶	No	No
Death	Yes	Yes
Sexually transmitted disease	No	No
Tuberculosis	No	No
Drug assistance**	Yes	Yes
Medical assistance††	Yes	No
Hospital discharge	No	No
Source of HIV report		
Public	30%§§	77%§§
Private	70%¶¶	23%***

*AIDS cases reported through July 1997 compared with the UI database.
† Not available.
§ HIV cases diagnosed from July 1995 through June 1996 in HIV counseling and testing sites compared with the UI database.
¶ Used for pediatric AIDS surveillance only.
** Federal- and state-funded medication program.
†† Federal- and state-funded medical-assistance program.
§§ Includes local health departments and state laboratory.
¶¶ Includes community-based organizations and private clinics and laboratories.
*** Includes community-based organizations, hospitals, private physicians, clinics, and laboratories.

specified period (Table 2). Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995–June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data element (n=208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

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HIV Case Surveillance — Continued

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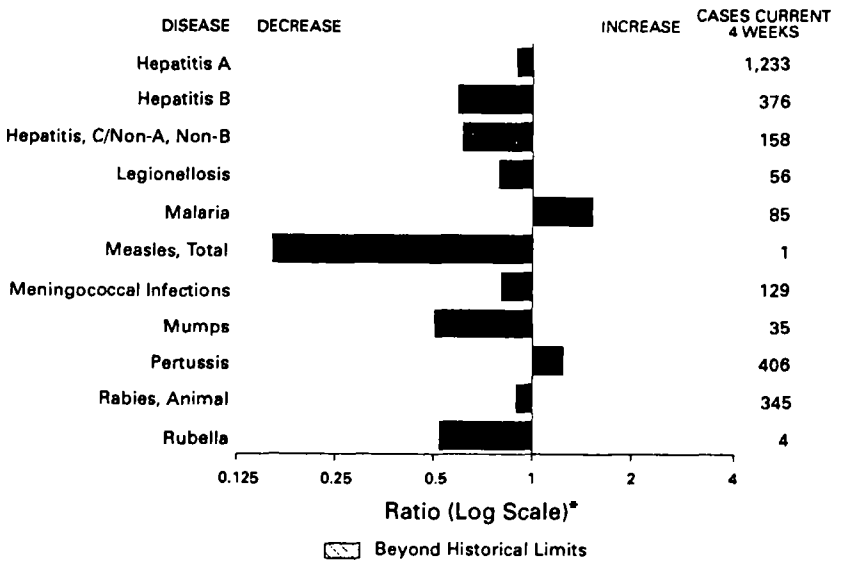
CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs (*4*). States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (>85%) (*5*) and documentation of risk exposures (≥93% of cases) (*6*). Evaluation of name-based HIV surveillance has shown 74%–97% completeness of reporting (*7*; CDC, unpublished data, 1997), and documentation of risk exposures (≥76% of cases) (*6*). Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data (*8*). Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland and Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

(Continued on page 1271)

FIGURE I. Selected notifiable disease reports, comparison of provisional 4-week totals ending December 27, 1997, with historical data — United States



*Ratio of current 4-week total to mean of 15 4-week totals (from previous, comparable, and subsequent 4-week periods for the past 5 years). The point where the hatched area begins is based on the mean and two standard deviations of these 4-week totals.

TABLE I. Summary — provisional cases of selected notifiable diseases, United States, cumulative, week ending December 27, 1997 (52nd Week)

	Cum. 1997		Cum. 1997
Anthrax	0	Plague	4
Brucellosis	75	Poliomyelitis, paralytic†	1
Cholera	10	Psittacosis	37
Congenital rubella syndrome	4	Rabies, human	2
Cryptosporidiosis*	1,950	Rocky Mountain spotted fever (RMSF)	396
Diphtheria	5	Streptococcal disease, invasive Group A	1,404
Encephalitis: California*	118	Streptococcal toxic-shock syndrome*	31
eastern equine*	10	Syphilis, congenital**	525
St. Louis*	12	Tetanus	42
western equine*	-	Toxic-shock syndrome	133
Hansen Disease	109	Trichinosis	9
Hantavirus pulmonary syndrome*†	18	Typhoid fever	344
Hemolytic uremic syndrome, post-diarrheal*	60	Yellow fever	-
HIV infection, pediatric*§	214		

-:no reported cases
*Not notifiable in all states.
†Updated weekly from reports to the Division of Viral and Rickettsial Diseases, National Center for Infectious Diseases (NCID).
§Updated monthly to the Division of HIV/AIDS Prevention–Surveillance, and Epidemiology, National Center for HIV, STD, and TB Prevention (NCHSTP), last update November 25, 1997.
¶One suspected case of polio with onset in 1997 has also been reported to date.
**Updated from reports to the Division of STD Prevention, NCHSTP.

TABLE IV. Deaths in 122 U.S. cities,* week ending January 3, 1998 (53rd Week)

Reporting Area	All Causes, By Age (Years)						P&I† Total
	All Ages	>65	45-64	25-44	1-24	<1	
NEW ENGLAND	619	452	96	44	11	16	47
Boston, Mass.	169	112	26	20	1	10	14
Bridgeport, Conn.	U	U	U	U	U	U	U
Cambridge, Mass.	16	14	1	1	-	-	1
Fall River, Mass.	25	20	3	1	1	-	-
Hartford, Conn.	57	36	11	7	2	1	2
Lowell, Mass.	31	26	5	-	-	-	4
Lynn, Mass.	20	12	4	3	1	-	-
New Bedford, Mass.	24	18	4	2	-	-	1
New Haven, Conn.	34	22	6	3	2	1	1
Providence, R.I.	68	53	9	2	2	2	-
Somerville, Mass.	9	7	2	-	-	-	-
Springfield, Mass.	44	35	4	3	1	1	4
Waterbury, Conn.	41	35	6	-	-	-	5
Worcester, Mass.	81	62	15	2	1	1	15
MID. ATLANTIC	2,582	1,815	449	216	60	38	133
Albany, N.Y.	60	45	8	2	2	3	3
Allentown, Pa.	25	20	3	-	2	-	1
Buffalo, N.Y.	79	61	10	5	1	2	8
Camden, N.J.	35	13	11	6	4	1	8
Elizabeth, N.J.	34	20	5	6	-	3	-
Erie, Pa.	29	21	6	1	1	-	2
Jersey City, N.J.	54	37	8	5	-	4	3
New York City, N.Y.	1,408	995	246	121	31	15	61
Newark, N.J.	64	28	17	13	5	1	3
Paterson, N.J.	23	10	3	4	1	1	-
Philadelphia, Pa.	400	282	70	35	8	5	19
Pittsburgh, Pa.§	45	33	6	2	3	1	2
Reading, Pa.	38	30	3	5	-	-	4
Rochester, N.Y.	124	94	23	6	1	-	11
Schenectady, N.Y.	35	26	7	2	-	-	1
Scranton, Pa.	24	21	3	-	-	-	1
Syracuse, N.Y.	60	46	10	1	1	2	2
Trenton, N.J.	32	23	7	2	-	-	4
Utica, N.Y.	13	10	3	-	-	-	-
Yonkers, N.Y.	U	U	U	U	U	U	U
E.N. CENTRAL	1,939	1,394	361	110	37	37	111
Akron, Ohio	60	44	12	3	1	-	1
Canton, Ohio	48	41	5	1	-	1	1
Chicago, Ill.	418	276	94	31	9	8	26
Cincinnati, Ohio	63	49	9	5	-	-	8
Cleveland, Ohio	119	86	21	5	2	5	1
Columbus, Ohio	133	94	26	8	1	4	10
Dayton, Ohio	88	68	14	4	2	-	11
Detroit, Mich.	230	149	49	19	8	5	12
Evansville, Ind.	48	42	2	2	-	-	3
Fort Wayne, Ind.	49	38	8	1	2	-	2
Gary, Ind.	5	2	2	1	-	-	-
Grand Rapids, Mich.	55	43	5	4	2	1	5
Indianapolis, Ind.	151	104	32	6	5	4	-
Lansing, Mich.	37	25	10	1	1	-	2
Milwaukee, Wis.	107	81	19	4	1	2	7
Peoria, Ill.	44	34	10	-	-	-	3
Rockford, Ill.	67	53	10	3	1	-	4
South Bend, Ind.	62	45	10	4	-	3	5
Toledo, Ohio	83	60	12	7	2	2	7
Youngstown, Ohio	74	60	11	1	-	2	3
W.N. CENTRAL	764	573	108	38	20	14	61
Des Moines, Iowa	136	103	19	6	6	2	12
Duluth, Minn.	27	18	8	-	-	1	4
Kansas City, Kans.	39	26	8	4	1	-	2
Kansas City, Mo.	74	47	10	3	2	1	8
Lincoln, Nebr.	32	26	3	2	1	-	4
Minneapolis, Minn.	101	81	14	5	-	1	3
Omaha, Nebr.	65	51	6	4	2	2	2
St. Louis, Mo.	137	102	15	9	6	5	4
St. Paul, Minn.	64	53	10	1	-	-	10
Wichita, Kans.	90	66	15	4	3	2	2
S. ATLANTIC	817	525	141	99	30	22	49
Atlanta, Ga.	U	U	U	U	U	U	U
Baltimore, Md.	154	92	33	19	6	4	15
Charlotte, N.C.	99	67	21	5	2	4	9
Jacksonville, Fla.	134	96	17	12	5	4	9
Miami, Fla.	96	52	21	17	5	1	1
Norfolk, Va.	U	U	U	U	U	U	U
Richmond, Va.	86	53	13	10	6	4	6
Savannah, Ga.	42	31	6	4	1	-	3
St. Petersburg, Fla.	59	46	8	5	-	-	3
Tampa, Fla.	U	U	U	U	U	U	U
Washington, D.C.	120	75	22	13	5	5	3
Wilmington, Del.	27	13	-	14	-	-	-
E.S. CENTRAL	600	410	120	40	18	10	52
Birmingham, Ala.	118	71	24	14	6	1	13
Chattanooga, Tenn.	28	16	10	-	1	1	2
Knoxville, Tenn.	67	51	14	-	2	-	8
Lexington, Ky.	58	38	12	5	-	3	5
Memphis, Tenn.	106	72	25	5	1	3	11
Mobile, Ala.	93	66	11	8	7	1	1
Montgomery, Ala.	1	1	-	-	-	-	-
Nashville, Tenn.	129	95	24	8	1	1	12
W.S. CENTRAL	1,260	828	252	113	42	24	67
Austin, Tex.	65	44	9	7	-	5	2
Baton Rouge, La.	26	15	7	4	-	-	1
Corpus Christi, Tex.	27	22	3	1	1	-	3
Dallas, Tex.	163	105	36	11	6	5	7
El Paso, Tex.	61	38	10	10	2	-	7
Ft. Worth, Tex.	79	51	11	7	4	6	2
Houston, Tex.	293	192	63	29	6	3	20
Little Rock, Ark.	71	49	16	3	1	2	3
New Orleans, La.	121	60	30	16	14	1	-
San Antonio, Tex.	184	127	40	13	3	1	13
Shreveport, La.	46	30	10	2	3	1	2
Tulsa, Okla.	124	95	17	10	2	-	7
MOUNTAIN	664	479	110	44	12	19	58
Albuquerque, N.M.	76	59	10	6	1	-	3
Boise, Idaho	35	25	6	3	1	-	1
Colo. Springs, Colo.	U	U	U	U	U	U	U
Denver, Colo.	80	63	9	4	-	4	10
Las Vegas, Nev.	122	73	38	8	3	-	5
Ogden, Utah	14	10	1	1	1	1	2
Phoenix, Ariz.	89	61	11	4	3	10	6
Pueblo, Colo.	25	20	4	1	-	-	1
Salt Lake City, Utah	95	73	7	10	2	3	15
Tucson, Ariz.	128	95	24	7	1	1	15
PACIFIC	1,151	826	205	77	23	20	108
Berkeley, Calif.	25	19	4	-	-	2	2
Fresno, Calif.	U	U	U	U	U	U	U
Glendale, Calif.	4	4	-	-	-	-	1
Honolulu, Hawaii	71	48	17	3	3	-	2
Long Beach, Calif.	83	66	10	4	1	2	15
Los Angeles, Calif.	214	160	41	6	4	3	11
Pasadena, Calif.	29	15	10	4	-	-	7
Portland, Oreg.	83	52	18	10	3	-	2
Sacramento, Calif.	U	U	U	U	U	U	U
San Diego, Calif.	128	84	26	8	6	5	16
San Francisco, Calif.	140	102	20	14	2	2	19
San Jose, Calif.	135	113	9	7	1	5	13
Santa Cruz, Calif.	29	19	3	5	2	-	4
Seattle, Wash.	130	85	30	12	2	1	6
Spokane, Wash.	71	59	8	4	-	-	10
Tacoma, Wash.	U	U	U	U	U	U	U
TOTAL	10,396¶	7,302	1,842	781	253	200	676

U: Unavailable -: no reported cases

*Mortality data in this table are voluntarily reported from 122 cities in the United States, most of which have populations of 100,000 or more. A death is reported by the place of its occurrence and by the week that the death certificate was filed. Fetal deaths are not included.

†Pneumonia and influenza.

§Because of changes in reporting methods in this Pennsylvania city, these numbers are partial counts for the current week. Complete counts will be available in 4 to 6 weeks.

¶Total includes unknown ages.

HIV Case Surveillance — Continued

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems (*1*). In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

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Weekly Notifiable Disease Morbidity Data and 122 Cities Mortality Data

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Debbie Bou

brief Secretary
brief members of Congress 11/98
letter → state & local health
Dept
Notice november (mid→end)
blurb in MMWR
month after comment—
reciere & review comment
guidelines → 3/99
effective 4/99

Deborah—

- MARYLAND has improved sys a lot.

differential costs for different states

12/2/98

Time Line and Roll-out Plan for HIV Reporting Guidelines

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- HIV surveillance guidelines package to CDC OD.
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- Meeting with OS Staff Divisions (including but not restricted to ASPE, ASL, ASPA, CDC, IGA, OPHS) to coordinate congressional and other communication related to the guidelines.
- Briefing with Secretary Shalala **(November 19)**.

December (depending on when Secretary briefing occurs, and CDC is able to publish)

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1999
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Staff of Appropriations Subcommittee: Labor/HHS Education and Related Agencies:
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Congressional Hispanic Caucus:
Chair: Rep. Xavier Becerra (D-CA)

Congressional Native American Caucus:
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Rep. Dale Kildee (D-MI)

Committee on Indian Affairs
Chair: Senator Ben Nighthorse Campbell (R-CO)

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Revised 11/27/98

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12/18 President mtg w/ Council for AIDS.

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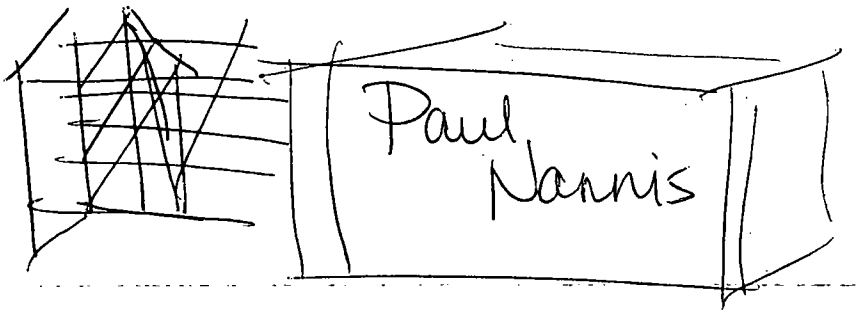
Revised 11/27/98

required follow-up



Questions to Answer

① what's in CDC reg re: performance standards - (Golmer, Church)

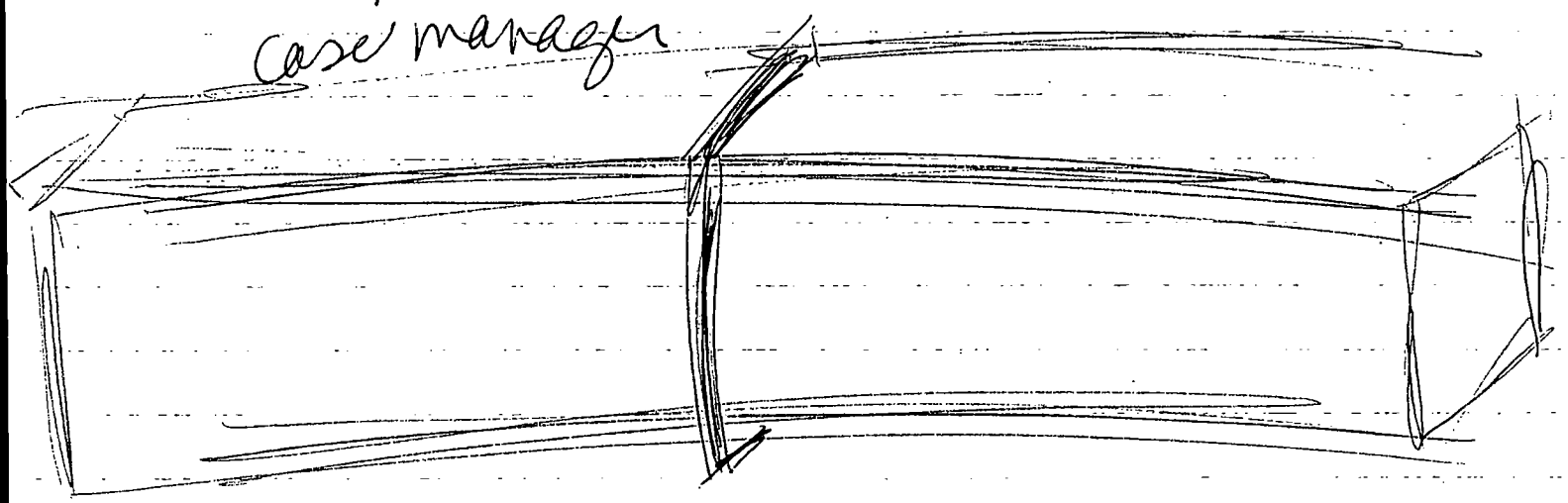
② report on MD, etc - MA, TX

③ study re: linking surveillance to outreach (can we link w/o names?)

④ ~~Navigator~~

④ help on eval → control/comparison groups

→ ① SW fn based out of original provider site case manager



IMPROVING HIV SURVEILLANCE SYSTEMS

The President has proposed a demonstration project providing States with funds to develop HIV surveillance systems that utilize privacy protection codes rather than names based reporting. These States would be required to apply their disease surveillance strategies in ways that link infected individuals with critical health care and social support services. As a condition of recieving funds, States would also be required to evaluate their new surveillance systems.

BACKGROUND

Current Surveillance Systems Are No Longer Adequate

Presently, all people diagnosed with AIDS are reported by name to State and local health departments. State officials then delete ~~patient~~ identifying information from the reports and forward them to the Centers for Disease Control (CDC) for compilation of national data on the AIDS epidemic. At the beginning of the epidemic, this was a reliable way to determine the extent of infection nationwide, because people with HIV routinely developed AIDS within a very short time period. However, because of the success of ~~protease inhibitors together with antiretroviral therapies,~~ AIDS deaths have declined and people are living longer with asymptomatic HIV disease. ~~This means that~~ the current method of tracking the AIDS epidemic is no longer reliable, because it is based solely on the end stages of disease progression. Health care organizations, AIDS advocates, and Federal, State, and local public health officials ~~are~~ all ~~in~~ agree~~ment~~ that generating better data on the scope of the HIV epidemic is essential.

States Work Independently to Track Levels of HIV Infection

State and local public health officials are working together ~~in order~~ to develop HIV surveillance systems, ~~that will work~~. Presently, twenty-eight States have chosen to implement name-based HIV surveillance systems that build off their current surveillance systems. Because of privacy concerns, three States have chosen to implement non-name based systems, where HIV infected individuals would be reported to public health officials by a unique code that cannot be traced rather than by name. Although there is a high level of interest in developing non-names based surveillance systems, there is a significant cost associated with the development of these systems because there is no existing public health infrastructure to support them.

Movement Towards a National HIV Surveillance System

The CDC has developed draft regulations that would require States to implement HIV surveillance systems by April of 1999. As presently drafted, these regulations emphasize the importance of State flexibility when developing a reporting system. They do not require any particular method of surveillance and establish performance measures for both names based and non-names based systems.

POLICY DESCRIPTION

The President has proposed a three part demonstration project to explore the issues surrounding HIV surveillance.

1. Developing New Surveillance Systems

would need to meet standards set forth in CDC draft regulation.

use of encryption, development of codes, etc. population based surveys would not be acceptable.

2. Linking Infected Individuals with Critical Health Care and Social Support Services
importance of early treatment, opportunities for education leading to possibility of increased prevention, name studies

3. Evaluating the New Surveillance Systems
reports based on technical evaluation of system (number of duplications, cases of lost or missing data) and success of system in promoting early treatment and patient education (numbers of infected individuals entering treatment or recieveing social support services). States would be required to identify sentinel events (such as confidentiality breaches) and would be required to take immediate action to rectify the situation. or lose funding (?) no

Reaction of AIDS Advocates
generally in favor, name groups

Privacy Concerns
the use of non-name based reporting generally protects privacy more than names based; different than unique medical identifiers; it's on State level, and it's for a disease;
good test case for national level, because if it works for these people it works for anyone.

BUDGET EFFECTS

Unknown.

Date: 10/26/98

FAX

Health Division

Office of Management and Budget
Executive Office of the President
Washington, D.C. 20503

To: Sarah Bianchi
Fax:
Phone:

From: Barb

Number of Pages (not including cover):

Subject:
Per your request - Already sent to Lorell Weiss.

Please call if there are any problems with this transmission:

Health Division (Front Office)	202/395-4922
Health & Human Services Unit	202/395-4925
Health Programs & Services Branch	202/395-4926
Health Financing Branch	202/395-4930

Fax Numbers:

Health Division (Front Office)	202/395-3910
Health Division (Room 7001)	202/395-7840
Health Division (Room 7002)	202/395-5048

CDC UPDATE NCHSTP

September 1998

Dangerous Intersection of Drug Use and Sexual HIV Transmission Points to Critical Need for Comprehensive HIV Prevention Among Drug Users

Sharing syringes and other equipment for drug injection is a well known route of HIV transmission, yet injection drug use contributes to the epidemic's spread far beyond the circle of those who inject. People who have sex with an injection drug user (IDU) also are at risk for infection through sexual HIV transmission. And, children born to mothers who contracted HIV through injecting drugs or having sex with an IDU may become infected as well.

Since the epidemic began, injection drug use has directly and indirectly accounted for more than one-third (36%) of AIDS cases in the United States. This disturbing trend appears to be continuing. Of the 60,634 new cases of AIDS reported in 1997, 19,463 (32%) were IDU-associated.

- 76% of these cases were among people whose only or most likely risk factor was injection drug use.
- 12% were among male IDUs who also reported having sex with other men.
- 11% were among men and women whose sex partners were IDUs.
- 1% were among children born to mothers who were either IDUs or the sex partners of IDUs.

Racial and ethnic minority populations in the United States bear the heaviest burden of HIV disease related to drug injection. In 1997, IDU-associated AIDS cases made up 38% of all cases among African Americans and 37% of all cases among Hispanics, compared with 22% of all cases among whites.

Likewise, IDU-associated AIDS has a greater impact on women than on men. Since 1981, at least 61% of all AIDS cases among women have been attributed to injection drug use or sex with partners who inject drugs, compared with 31% of cases among men.

Noninjection drugs (such as "crack" cocaine) also contribute to the spread of the epidemic when users trade sex for drugs or money, or when they engage in risky sexual behaviors that they might not engage in when sober. One study of over 1,000 young adults in three inner-city neighborhoods found that crack smokers were three times more likely to be infected with HIV than non-smokers.

What Is Needed to Prevent HIV Transmission Among Drug Users?

Comprehensive HIV prevention interventions for substance abusers must provide education on how to prevent transmission through sex.

Numerous studies have documented that drug users are at risk for HIV through both drug-related and sexual behaviors, which places their partners at risk as well. Comprehensive programs must provide the information, skills, and support necessary to reduce both risks. Researchers have found that many interventions aimed at reducing sexual risk behaviors among drug users have significantly increased the practice of safer sex (e.g., using condoms, avoiding unprotected sex) among participants.

Substance abuse treatment *is* HIV prevention, but lack of drug treatment slots complicates prevention efforts.

In the United States, about half a million drug treatment slots are available at any given time. However,

the nation has an estimated 1.5 million active IDUs and many others who use noninjection drugs or abuse alcohol. Clearly, the need for substance abuse treatment vastly outstrips our capacity to provide it. Effective substance abuse treatment that helps people stop using drugs not only eliminates the risk of HIV transmission from sharing contaminated syringes, but, for many, reduces the risk of engaging in risky behaviors that might result in sexual transmission.

For injection drug users who cannot or will not stop injecting drugs, the once-only use of sterile needles and syringes remains the safest, most effective approach for limiting HIV transmission.

To minimize the risk of HIV transmission, IDUs must have access to interventions that can help them protect their health. They must be advised to always use sterile injection equipment; warned never to reuse needles, syringes, and other injection equipment; and told that using syringes that have been cleaned with bleach or other disinfectants is not as safe as using new, sterile syringes.

The availability of new, sterile syringes varies across the country. HIV prevention strategies for IDUs who continue to inject have included various approaches to increasing the availability of sterile syringes, reducing the risk of HIV transmission through needle sharing, and increasing access to drug treatment.

- In some communities, drug paraphernalia laws have been modified to exclude syringes, syringe prescription laws have been repealed, and pharmacy regulations and practice guidelines restricting the sale of sterile syringes have been changed. Efforts to reduce HIV risk through these types of policy changes have been evaluated and found to be effective. For example, Connecticut reported significant reductions in the sharing of drug injection equipment after implementing policies that increased access to such equipment through pharmacies or syringe exchange programs.

- In other communities, syringe exchange programs have been established to increase the availability of sterile syringes. A review of extensive scientific evidence has shown that syringe exchange programs can be an effective part of a comprehensive strategy to reduce HIV transmission. The evidence also demonstrates that these programs do not encourage the use of illegal drugs. Many syringe exchange programs also provide drug users with referrals to drug counseling, drug treatment, and medical services and risk-reduction education. The most effective syringe exchange programs have had the strong support of their communities, including appropriate state and local public health officials. In addition to offering linkages to appropriate treatment and medical services, effective syringe exchange programs make needles available on a replacement basis only. In 1997, an estimated 113 syringe exchange programs were operating in the United States.

Having access to sterile injection equipment is important, but it is not enough. Preventing the spread of HIV through injection drug use requires a wide range of approaches, including:

- preventing initiation of drug injection,
- using community outreach programs,
- improving access to high quality substance abuse treatment programs,
- instituting HIV prevention programs in jails and prisons,
- providing health care for HIV-infected IDUs, and
- making available HIV risk-reduction counseling and testing for IDUs and their sex partners.

Better integration of all prevention and treatment services is critically needed.

HIV prevention and treatment, substance abuse prevention, and sexually transmitted disease treatment and prevention services must be better integrated to take advantage of the multiple opportunities for intervention – first, to help the uninfected stay that way; second, to help infected people stay healthy; and third, to help infected individuals initiate and sustain behaviors that will keep themselves safe and prevent transmission to others.

CDC's Role in HIV Prevention for IDUs

CDC is the lead federal agency responsible for monitoring the epidemic and preventing HIV/AIDS. In cooperation with other federal agencies and offices responsible for addressing drug use - for example, the Center for Substance Abuse Prevention (CSAP) and the Center for Substance Abuse Treatment (CSAT) of the Substance Abuse and Mental Health Services Administration, the National Institute for Drug Abuse (NIDA) of the National Institutes of Health, and the White House's Office of National Drug Control Policy (ONDCP) - CDC works to address the HIV/AIDS risks presented by illicit drug use.

CDC's role is to provide communities with the best available science to guide comprehensive HIV prevention programs. As part of this process, CDC conducts an ongoing research synthesis process that seeks to identify the most recent and relevant scientific findings from around the world, both published and unpublished, and make them available to prevention program planners. CDC constantly combs the scientific literature, reviews domestic and international scientific databases, and speaks with colleagues around the world to identify effective interventions for all populations at risk, including IDUs.

CDC also provides financial and technical assistance to communities to help them address the unique prevention needs of IDUs, their sex partners, and their children. For example, CDC directly funds 94 community-based HIV prevention programs that provide prevention services in minority communities and other populations at high risk, many of whom are IDUs. Through the HIV Prevention Cooperative Agreements, CDC awards funds to health departments in 50 states, 6 cities, 7 territories, and the District of Columbia. These funds support the provision of services at state and local levels to high-risk populations (including IDUs). Services include health education and risk-reduction activities, such as street outreach programs, as well as HIV counseling, testing, referral, and partner counseling. Prevention needs are prioritized through the HIV Prevention Community Planning process. CDC also funds many national and regional organizations to provide technical assistance to local programs across the country.

In addition, CDC conducts research that provides information used to develop effective prevention programs for IDUs. This includes not only surveillance data on populations at greatest risk, but findings from behavioral and evaluation studies to identify the most effective approaches to prevention.

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Last Update: September 24, 1998
Centers for Disease Control & Prevention
National Center for HIV, STD and TB Prevention
Division of HIV/AIDS Prevention
email: hivmail@cdc.gov

Date:_____

FAX

Health Division

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Executive Office of the President
Washington, D.C. 20503

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HRSA

The conference agreement provides $12,000,000 in additional funding to be targeted to addressing treatment outcome disparities in communities of color, and will compliment existing and previously planned targeted HIV/AIDS minority activities. In allocating these funds, consideration should be given to the territories, such as in the Virgin Islands, where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000. The conference agreement designates $5,000,000 in Title I supplemental funding and directs that these funds be allocated to eligible metropolitan areas that have 30% or more African American and Latino HIV/AIDS cases in an effort to improve the quality of care and health outcomes for African Americans living with HIV/AIDS; $3,000,000 in Title III to be used for targeted planning grants designed to build the HIV primary care capacity of indigenous organizations serving African American communities highly impacted by HIV/AIDS; $2,000,000 in Title IV to address the prevalence of HIV and AIDS among African American children; and $2,000,000 for subcontracts awarded through in AIDS Education and Training Centers to the Historically Black Colleges and Universities for the education of health care providers serving African American communities on the Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents as developed by the Department of Health and Human Services.

Sufficient funds are included within breast and cervical cancer screening to provide $200,000 for the Women Reaching for Wellness: Promoting Breast Health for American Indian Women in Montana and Northern Wyoming program at Saint Vincent Hospital in Billings, Montana and $250,000 for screening activities at the Montgomery County, Pennsylvania Health Department.

Sufficient funds are included within the National Institute for Occupational Safety and Health to expand efforts to implement the national occupational research agenda, fully fund the intramural research program at the Morgantown, WV facility, and provide $1,000,000 to augment activities of the Colorado School of Mines.

The conference agreement provides $15,000,000 for prevention research instead of $10,000,000 as proposed by the House. The Senate bill contained no similar provision.

The conference agreement provides $10,000,000 for health disparities demonstrations as proposed by the Senate. The House bill contained no similar provision. The conference agreement also provides additional funding for health disparities activities in existing programs throughout the Department. It is expected that the Secretary will provide the House and Senate Appropriation Committees with a detailed proposal of how these funds will be coordinated and expended to reduce health disparities in minority populations.

The conference agreement provides $10,000,000 for CDC to implement section ~~2626~~ of the Public Health Service Act, CDC Guidelines for Pregnant Women. It is noted that the implementation of voluntary testing and treatment of pregnant women is working exceptionally well and that the vast majority of women agree to be tested on a voluntary

The conference agreement includes $18,000,000 in additional funding to be targeted to addressing urgent HIV prevention needs in the African American community. ← CDC In allocating these funds, consideration should be given to the territories, such as in the Virgin Islands, where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000. These funds will compliment existing and previously planned targeted HIV/AIDS minority activities, and are to be allocated on the following basis:

-- $10,000,000 is included for the Directly Funded Minority Community Based Organizations Program to fund grant applications from indigenous organizations with a history of providing services to the African American community to target the high risk populations of women, youth and men;

-- $4,000,000 is included for the creation of new community development grants to 20 African American communities highly impacted by HIV/AIDS. The funding will support needs assessments and planning processes to integrate HIV, STD, TB, substance abuse prevention, treatment and care;

-- $2,500,000 is for technical assistance to grantees under the Directly Funded Minority Community Based Organizations, to be provided by national, regional, and local minority organizations; and

-- $1,500,000 is included for CDC Faith-Based Initiative program to develop HIV and substance abuse prevention training grants and curriculum at the divinity schools of the Historically Black Colleges and Universities; capacity building grants for Faith centered direct service programs; and provide coordination for community planning, leadership, and program development.

CDC

The CDC is urged to institute program guidance and oversight mechanisms to ensure that the Prevention Community Planning Groups priorities are accurately reflected in the state or local plan submitted for grant award to the CDC, and that the funding awarded corresponds to the demographics of the local epidemic and the identified needs.

basis. In the last three years, the number of newly reported pediatric AIDS cases related to perinatal HIV transmission fell 55 percent. It is believed that priority for funding should be placed on outreach, counseling, and voluntary testing of pregnant women rather than mandatory testing of newborns.

The conference agreement endorses Congress' intent to invest ~~strongly into~~ HIV prevention programs and interventions to stem the tide of new HIV infections. CDC is directed to allocate a significant proportion of the HIV/AIDS program for grants and cooperative agreements for HIV prevention programs.

Knowledge of HIV status is essential because it allows individuals to make informed decisions about treatment and prevention of further transmission. Therefore, CDC is encouraged to undertake activities, in consultation with academic researchers and community groups, that will encourage individuals at risk to be tested. CDC is further encouraged to carefully review any policies that may deter individuals, particularly individuals and groups at highest risk, from knowing their HIV status. Similarly, CDC is urged to undertake activities to improve referral from publicly funded testing sites to primary care.

It is agreed that there is a need for demonstration projects to evaluate the effectiveness of CDC's model death scene protocol for Sudden Infant Death Syndrome.

Between 1985 and 1991, 82 percent of Salmonella outbreaks were traced to contaminated shell eggs. It is understood that a new pasteurization technology has been developed employing heat and water which achieves the established FDA standards for the destruction of all strains of Salmonella commonly found in shell eggs. The technology preserves egg quality during extended refrigerated storage without materially

EMERGENCY

Public Health & Social Service Emerg. Fund.

Public health data indicates that African Americans and other minorities are disproportionately and more severely impacted by HIV/AIDS and experience significantly higher morbidity and mortality rates than do other populations in the United States. The conference agreement includes an additional $50,000,000 to address the HIV/AIDS crisis facing the African American community and other racial and ethnic minority communities due to the changing demographics of the disease. These funds are to be available to address prevention and treatment needs of minority communities that are heavily impacted by HIV/AIDS, and should compliment existing and previously planned targeted HIV/AIDS minority activities. These funds are available for the Secretary of the Department of Health and Human Services to transfer to other agencies to: expand and improve access to state-of-the-art HIV/AIDS therapies; strengthen and expand targeted HIV/AIDS effective prevention and intervention activities; support HIV/AIDS substance abuse activities; provide critical technical assistance in high risk communities; and build and sustain HIV/AIDS infrastructure. In allocating these funds, consideration should be given to the territories, such as in the Virgin Islands, where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000.

NIH

The Director is urged to provide funding to the Office of Research on Minority Health (ORMH) in addition to existing and previously planned activities for the purpose of increasing the number of African American principal investigators funded to conduct HIV behavioral and clinical research targeting the links between substance abuse, sexual behaviors and the extraordinary HIV infection rates in African Americans. Special emphasis should be placed on research into ways of breaking this linkage. Research designed to build a culturally competent community knowledge base in areas hardest hit by HIV/AIDS is also a priority. The ORMH is urged to expand support to non-traditional organizations in the Black Faith community, in particular those which are able to play a critical role in outreach to individuals who live in areas hardest hit by HIV/AIDS would also be a priority. This is an effort to improve the quality of care and health outcomes for African Americans and other minorities that are at risk for and living with HIV/AIDS. In allocating these funds, consideration should be given to the territories, such as in the Virgin Islands, where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000.

The Director is urged to expand and strengthen population based research to more effectively target at-risk persons, address community norms and support the adoption of HIV risk reduction behaviors and sustain behavioral change among high risk populations. Such activities should specifically consider targeting: pregnant and parenting teenagers and their sexually active partners; African American heterosexual men in age specific populations; African American women in age specific populations ranging within the child bearing ages of 15 to 44; and provide for risk reduction for crack cocaine abusing youth who participate in the sex for drugs trade that is associated with such drug use.

The Director is urged to cooperate in completing the Institute of Medicine study on cancer among minorities and the medically undeserved, and to provide timely access to requested data to enable the IOM to complete the study in an expeditious fashion. The Director is expected to report on the study's progress during the hearings on the fiscal year 2000 budget request.

SAMHSA

The conference agreement provides $22,000,000 in additional, targeted funding to compliment existing and previously planned targeted HIV/AIDS minority activities to strengthen abuse treatment and prevention programs that include an HIV component. These funds should also be used to address the HIV epidemic in the territories, such as in the Virgin Islands where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000.

Within the total amount provided, $16,000,000 is for the Center for Substance Abuse Treatment, of which $9,000,000 shall be used for comprehensive residential treatment for women and their children, and $7,000,000 shall be dedicated to treatment programs serving youth and men; and $6,000,000 is for the Center for Substance Abuse Prevention to be targeted to prevention services for African American youth.

GDM

The conference agreement includes $8,000,000 for the Office of Minority Health to strengthen the role of the OMH in HIV health care promotion and prevention at the state and local level. These funds will complement existing and previously planned targeted HIV/AIDS minority activities. These funds will allow OMH to: initiate an educational campaign to improve knowledge and awareness among HIV-infected racial and ethnic minorities, and the health care providers serving these populations, of the importance of state-of-the-art therapy for HIV/AIDS in improving the length and quality of life; fund cooperative agreement grantees to work with states to strengthen and monitor state, local and territorial plans for providing HIV services to minorities; collaborate with SAMHSA to fund programs aimed at coordination of services for HIV, drug treatment and mental health; fund state and territory offices of minority health for demonstration projects to improve minority access to information and services and HIV/AIDS treatment; and collaborate with NIH and CDC to fund prevention research studies on HIV-related behaviors.

The OMH is urged to make community development and coordination grants to indigenous organizations with a history of supporting community development efforts in health promotion and disease prevention that would support the development of leadership coalitions to conduct needs assessments and planning processes for the purpose of integrating HIV, STD, TB, substance abuse prevention, treatment and care services. These funds should also be used to address the HIV epidemic in the territories, such as in the Virgin Islands where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000.

The conference agreement expects HHS to maintain the current level of support for Meharry Medical College to continue a cooperative agreement to support the development of an integrated health delivery system in a historically undeserved community, and that the Office of Minority Health should provide no more than $1,000,000 of the total amount provided for the effort. The remainder shall be provided by other agencies of HHS. The conference agreement includes funds within the Office of Minority Health to continue a study on managed care and historically minority health professions schools.

Lisa 6907800

HIV/AIDS

Greg 6906047

① privatization
states doing IDs, not Fed govt
limited population
test case

② CDC
guidelines haven't been released yet; whether perf. standards should be same for both; state flex; CDC recc name based; states can use non name

③ resources
this is more expensive than names

Jane Horvath — Hill

greg Jones

Leslie Hardy — 260 [illegible] 5956 new mon.
[illegible]
260 73294

HILL

CDC announced that they would be doing case reporting for HIV; interpreted that they would be endorsing name reporting. But it's not as clear cut as that.

AIDS reporting was okay until protease inhibitors started working; CDC can't track epidemic.

need some way to ID cases

Conservatives reporting names — also in favor of criminalizing HIV infection.

name reporting Hepatitis B, gonnorea, syphilis

MA
IL
TX
MD
} using unique IDs

taking effort; no infrastructure to report → need to invent system of coding unless you use something that can be tracked.

Case surveillance system.

better for privacy → although only one bad breach.

names reporting works okay.

Dept pushing for state flexibility... cost for govt.

support

Waxman (CA-D) commerce
Pelosi (CA-D)
Brown (D-OH) ranking member

privacy

Joe 1903

against

Colburn (OK-R) criminal sanctions for folks who are positive but don't tell partners.
Ackerman (D-NY) → reg testing of prison inmates... passed both chambers →

Deborah Von Zinkernagel
senior advisor HIV/AIDS policy.
6905566

Francine DePeister 6908598
Leg wash office CDC

(Bell, Debbie)

Call Sandy
Kevorkian
CDC Director

IMPROVING HIV SURVEILLANCE SYSTEMS

SUMMARY

This proposal would fund a demonstration project providing States with funds to develop HIV surveillance systems that utilize privacy protection codes rather than name-based reporting. These States would be required to apply their disease surveillance strategies in ways that link infected individuals with critical health care and social support services. As a condition of recieving funds, States would also be required to evaluate their new surveillance systems.

BACKGROUND

- **Importance of Accurate HIV Surveillance Systems.** In 1995, AIDS became the leading cause of death for all Americans aged 25-44. Over half a million American men, women and children have been diagnosed with AIDS, and more than 300,000 have already died from this disease. It is vitally important to have an accurate national surveillance system in order to allocate limited resources, target and evaluate prevention efforts, and project the future of the epidemic.

- **Surveillance Systems Are Outdated.** Presently, all people diagnosed with AIDS are reported by name to State and local health departments. State officials then delete identifying information from the reports and forward them to the Centers for Disease Control (CDC) for compilation of national data on the AIDS epidemic. At the beginning of the epidemic, this was a reliable way to determine the extent of infection nationwide, because people with HIV routinely developed AIDS within a very short time period. However, because of the success of new drug therapies, people are living longer with asymptomatic HIV disease. Therefore, because the current method of tracking the AIDS epidemic is based solely on the end stages of disease progression, it is no longer reliable. Health care organizations, AIDS advocates, and Federal, State, and local public health officials are all in agreement that generating better data on the scope of the HIV epidemic is essential.

- **Present State Surveillance Systems Raise Privacy Concerns.** State and local public health officials are currently working together to develop accurate HIV surveillance systems. Thirty-one States have chosen to implement name-based HIV surveillance systems. Although this issue is still being debated, there is concern in both the public health and advocacy communities that name-based surveillance systems would discourage infected individuals from seeking testing and treatment because of the fear of confidentiality breaches. In addition, because people are living longer with asymptomatic HIV disease, public health officials would have the names of people with HIV on record for an extended period of time, increasing the possibility of confidentiality breaches. Although there is a high level of interest in developing non-name based surveillance systems that include essential privacy protections, the significant cost associated with the development of these systems is discouraging for many States.

- **Movement Towards a National HIV Surveillance System.** The CDC has developed

draft regulations, to be released in December of 1998 that would require States to implement HIV surveillance systems by April of 1999. As presently drafted, these regulations emphasize the importance of State flexibility when developing a reporting system. They do not require any particular method of surveillance but establish performance measures for both names based and non-names based systems.

POLICY DESCRIPTION

This proposal would create a three part demonstration project to explore the issues surrounding non-name based HIV surveillance.

- **Developing new surveillance systems.** States would be provided funding to develop and implement HIV surveillance systems that use encryption and other non-name based methodologies to track the level of HIV infection in their State. These systems would utilize "privacy protection codes" rather than the names of individuals when forwarding data to the State Department of Health, ensuring that only patients and health care providers have identifying information on the HIV status of individuals. Recent evaluations of existing non-name based surveillance systems indicate that States have higher rates of missing data and may have difficulty conducting adequate follow-up with infected individuals in order to collect HIV risk information. States would need to adequately address these issues in their grant proposals.

- **Linking infected individuals with critical health care and social support services.** As a condition of recieving Federal funds, States would enhance their current efforts to link infected individuals with critical health care and social support services. Special outreach efforts to educate individuals about the new privacy safeguards and the importance of early diagnosis and treatment should be undertaken. In addition, strategies to improve referral to primary care sources would be implemented for those infected individuals being tested at publicly funded sites.

- **Evaluating the New Surveillance Systems.** States would be required to perform a technical evaluation of their new surveillance systems that focused on rates of record duplication and lost or missing data. They would also be required to evaluate the success of the outreach, education, and patient referral strategies in promoting HIV testing and early entry of infected individuals into primary care.

POLICY RATIONALE

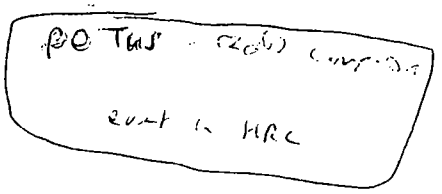
Funding a demonstration project that would assist States in the development and implementation of non-name based HIV surveillance systems would be advantageous for the following reasons:

- **Non-name based surveillance systems provide greater privacy protections.** AIDS advocates have come out strongly in favor of non-name based HIV surveillance systems. Advocates believe that non-name based surveillance systems will reduce the fear of stigma and the loss of confidentiality while enabling the collection of better data on HIV infection.

- **Non-name Based Surveillance Systems Protect the Hispanic Community.** In 1997, the incidence of AIDS among Hispanics was 37.7 per 100,000 individuals, almost 4 times the incidence rate for whites. There is a widespread fear among the Hispanic population that mandatory names reporting for HIV infection will eventually lead to deportation of infected individuals. This provides a strong disincentive to request testing or receive care. The implementation of non-name based surveillance systems will help assure the Hispanic community that their infection status will not be used by State or Federal immigrantion agencies to discriminate against them when they apply for citizenship or naturalization.

- **Provides a Test Case for National Unique Medical Identifiers.** There was a great deal of concern when the Administration proposed to implement a national system of unique medical identifiers. We have since stated that we would not implement such a system until privacy protection legislation has passed. However, implementing a non-names based HIV surveillance system differs significantly from the original Federal proposal. This system would be developed at State option for a limited subset of individuals who would otherwise be identified by name to State public health agencies. It is important to note, however, that if States are able to design non-name based surveillance systems that are able to meet current public health needs and adequately protect the privacy of HIV infected individuals, they may provide a roadmap for designing a portable medical record using unique medical identifiers.

* HHS - cost estimates
public health departments



John Myers - UP

Date:_____

FAX

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Note that Hispanics 21% of new cases reported in Dec. 1997.

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CDC UPDATE NCHSTP

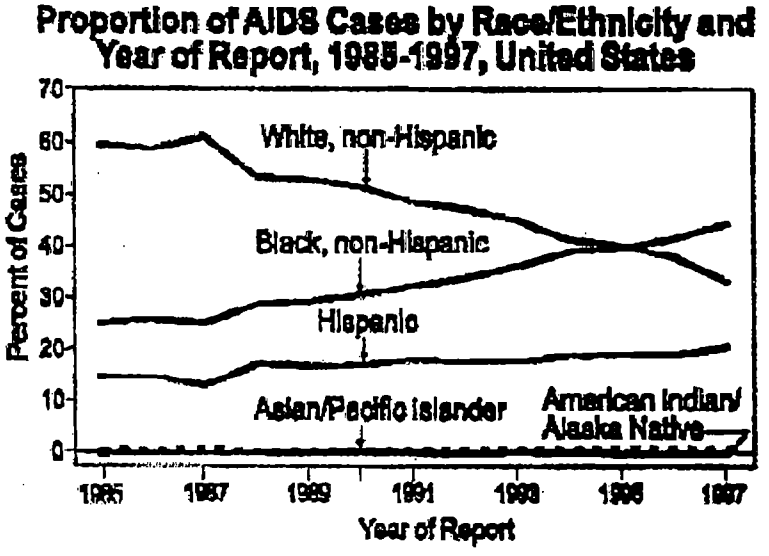
June 1998

Critical Need to Pay Attention to HIV Prevention for African Americans

In the United States, African Americans have been disproportionately affected by HIV and AIDS. Through December 1997, CDC had received reports of 230,029 cases of AIDS among African Americans. Although that is 36% of the 641,086 cases reported, African Americans represent only an estimated 13% of the total U.S. population.

Researchers estimate that 240,000-325,000 African Americans are infected with HIV. Approximately 1 in 50 African-American men and 1 in 160 African-American women are believed to be infected with HIV. Of those infected with HIV, it is estimated that 93,000 African Americans are living with AIDS.

In 1997, more African Americans were reported with AIDS than any other racial/ethnic group. Of the total AIDS cases reported that year, 45% (27,075) were reported among African Americans, 33% (20,197) were reported among whites, and 21% (12,466) were reported among Hispanics. Among women and children with AIDS, African Americans have been especially affected, representing 60% of all women reported with AIDS in 1997 and 62% of reported pediatric AIDS cases for 1997.



HIV Data Show These Trends Are Continuing

HIV data from a recent CDC study comparing HIV and AIDS diagnoses in 25 states with integrated reporting systems provide a much clearer picture of recent shifts in the epidemic, with a larger percentage of HIV than AIDS cases diagnosed among African Americans, especially women. During the period from January 1994 through June 1997, African Americans represented 45% of all AIDS diagnoses, but 57% of all HIV diagnoses. Among young people (ages 13 to 24), 63% of the HIV diagnoses were among African Americans.

CDC's HIV Prevention Efforts Targeting African Americans

The disproportionate impact of HIV/AIDS on African Americans underscores the importance of increasing prevention efforts in this community. HIV prevention efforts must take into account cultural issues, as well as social and economic factors - such as poverty, underemployment, and poor access to the health care system - that impact many U.S. minority communities. For over a decade, CDC has worked closely with national-, regional-, and community-based organizations to design and implement HIV prevention efforts directed to African Americans. Clearly, the most effective programs are those designed and implemented by the African-American community itself.

CDC is currently supporting, directly or indirectly, hundreds of community-based organizations across the United States in implementing programs and providing HIV prevention services to the African-American community. Programs focus on a wide range of activities, including risk-reduction counseling, street and community outreach, prevention case management services, and efforts to help individuals at risk gain access to HIV testing and treatment and related services.

Additionally, to help establish greater capacity within the African-American community to provide HIV prevention services, CDC has instituted a program to assist national and community-based organizations serving these communities in building the infrastructure needed to deliver HIV testing, counseling, health care, and support services. And because of the critical role the faith community plays in mobilizing community leaders and in reaching and serving the community at large, CDC established a collaboration with the faith community in 1987 as part of multi-sectoral program to encourage positive response to, and participation in, HIV prevention. While the effort began modestly, with direct funding to faith organizations of roughly $100,000 the first year, the program had grown to $500,000 annually by 1994 and to the current funding level of $900,000 in 1997. Roughly half of this initiative currently targets the African-American faith community.

CDC has several major initiatives and numerous research projects designed to reach the African-American community including:

- CDC currently provides $253 million in funding to state and local health departments for HIV prevention programs. Since December 1993, CDC has funded a process designed to put more of the decisions about how these prevention funds are directed in the hands of the communities affected. Under this process, HIV Prevention Community Planning, health departments are required to establish priorities in conjunction with a planning group that brings together health department staff, representatives of affected populations, epidemiologists, behavioral scientists, service providers, and other community members to identify prevention needs and interventions to meet these needs.

  This process helps ensure that HIV prevention efforts are locally relevant and address the unique epidemic and prevention needs of each community.

  CDC has conducted several recent assessments to determine what proportion of these funds are used to reach minority populations. While not all programs are targeted by race (some, for example, target high-risk communities such as injection drug users or people being treated in STD clinics, which include individuals from multiple races), it is clear that a significant proportion of funding for major programs, such as counseling and testing and risk reduction programs, are targeted to African Americans. Of programs identified as specifically targeting a racial/ethnic group (representing $143 million), 36% of programs ($52 million) target African Americans. By comparison, 36% target Caucasians, and 22% target Hispanics.

- CDC also directly funds minority and other community-based organizations to design and implement HIV prevention programs that are highly targeted to high-risk individuals within racial and ethnic minority populations. Many serve gay and bisexual men of color or injection drug users as their primary focus. CDC currently provides $18 million to fund 94 community-based organizations through this program. Seventy-one (76%) of these organizations direct their programs to African Americans.

- CDC funds a $9 million program to assist National and Regional Minority Organizations in building capacity to deliver HIV prevention programs and services within these communities. Many of these organizations directly serve the African-American community. Organizations supported through this initiative include the National Organization of Black County Health Officials ($450,000), the National Minority AIDS Council ($455,000), the Association of Black Psychologists ($320,000), the National AIDS Minority Information and Education Program ($291,000), and the National Council of Negro Women ($451,000).

- Last year, to further evaluate the current capacity of community-based organizations serving minority organizations, CDC funded the Harlem AIDS Directors ($400,000) to conduct an assessment to identify unmet needs.

- Additionally, CDC conducts numerous behavioral research projects aimed at reducing HIV infection in the African-American community. For example, the prevention of HIV in Women and Infants Project is a community-level behavioral intervention research project targeting young women ages 15-34. The project is designed to improve the understanding of factors influencing women's behavior changes regarding condom and contraceptive use and to improve the development and delivery of prevention interventions. Another example is the Young African-American Men's Study. This study is a 2-year formative study to prevent HIV/AIDS in young African-American men. Data are being collected in Chicago and Atlanta through interviews, observations, and group discussions with community leaders, health care providers, and young men who have sex with men. In addition to these examples, there are numerous research projects designed to better understand risk behaviors and design effective interventions for African Americans at highest risk for HIV infection, including injection drug users, women who are partners of injection drug users, individuals with high rates of STDs, and young gay and bisexual men of color.

There is no question that as long as the epidemic continues to spread in the African-American community, these programs must continue, and even more must be done. It is also clear that the public sector alone can not successfully combat HIV and AIDS in the African-American community. Overcoming the current barriers to HIV prevention and treatment requires that leaders in the community acknowledge the severity of the continuing epidemic among African Americans and play an even greater role in combating HIV/AIDS in their own communities.

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Last Update: July 24, 1998
Centers for Disease Control & Prevention
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CDC UPDATE

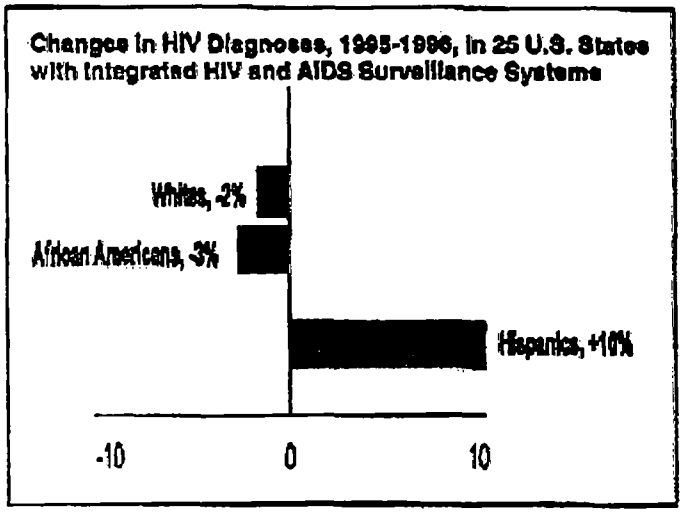
June 1998

Impact of HIV/AIDS on Hispanics in the United States

Hispanics in the United States include a diverse mixture of ethnic groups and cultures. With more than 25 million Hispanics, the United States has the fifth largest Hispanic population in the world, following Mexico, Spain, Argentina, and Colombia. Although Hispanics represent an estimated 10% of the total U.S. population, they account for 18% of the 641,086 AIDS cases reported in the United States through December 1997.

In 1997, 60,634 new AIDS cases were reported to CDC. Of these, 12,466 (21%) occurred among Hispanics. The AIDS incidence rate (the number of new cases of a disease that occurs during a specific time period) among Hispanics was 37.7 per 100,000 population in 1997, almost 4 times the rate for whites (10.4 per 100,000) and almost half the rate of African Americans (83.7 per 100,000 population).

A recent CDC study examined data from the 25 states[1] that had integrated HIV and AIDS surveillance from January 1994 through June 1997. This study showed that HIV diagnoses increased 10% among Hispanics between 1995 and 1996 (the most recent year for which overall trends can be examined). However, the number of cases reported among Hispanics was relatively small, since many states with large Hispanic populations have not implemented integrated HIV and AIDS reporting and were not included in the study. At the same time, HIV diagnoses declined slightly among African Americans (-3%) and among whites (-2%) in these states. Of the 7,200 young people ages 13-24 years who were diagnosed with HIV from January 1994 to June 1997, 5% were Hispanic.



Historical Trends in HIV and AIDS Cases

Most HIV and AIDS cases reported to date among Hispanics have been among men, although the proportion of cases among women is rising. Among Hispanic men, the majority of reported cases have been among gay and bisexual men and injection drug users. Among Hispanic women, most cases have been the result of heterosexual exposures, although drug use also plays a major role in the spread of infection to women. A large proportion of Hispanic women were infected through injection drug use or by having sex with an injection drug user. To reduce the toll of the epidemic among Hispanic men, women, and children, prevention programs must address the intersection of sexual and drug-related risks.

CDC's HIV Prevention Efforts Targeting Hispanic Populations

Since early in the HIV/AIDS epidemic, CDC recognized that Hispanic populations were being disproportionately affected and took a number of steps to better target HIV prevention efforts in these communities. The following is a brief overview of some of those activities.

- CDC currently provides $253 million in funding to state and local health departments for HIV prevention programs. Since December 1993, CDC has funded a process designed to put more of the decisions about how these prevention funds are directed in the hands of the communities affected. Under this process, HIV Prevention Community Planning, health departments are required to establish priorities in conjunction with a planning group that brings together health department staff, representatives of affected populations, epidemiologists, behavioral scientists, service providers, and other community members to identify prevention needs and interventions to meet these needs. This process helps ensure that HIV prevention efforts are locally relevant and address the unique epidemic and prevention needs of each community.

  CDC has conducted several recent assessments to determine what proportion of these funds are used to reach minority populations. While not all programs are targeted by race (some, for example, target high-risk communities such as injection drug users or people being treated in STD clinics, which include individuals from multiple races), it is clear that a significant proportion of funding for major programs, such as counseling and testing and risk-reduction programs, are targeted to Hispanics. Of programs identified as specifically targeting a racial/ethnic group (representing $143 million), 22% of funds ($31.4 million) target Hispanics.

- CDC also directly funds minority and other community-based organizations to design and implement HIV prevention programs that are highly targeted to high-risk individuals within racial and ethnic minority populations. Many serve gay and bisexual men of color or injection drug users as their primary focus. CDC currently provides $18 million to fund 94 community-based organizations through this program. Sixty-four of these organizations

  direct their programs to Hispanics. CDC recently announced the availability of an additional $4 million in fiscal year 1998 for community-based organizations for HIV prevention activities directed to African-American and Hispanic populations.

- CDC funds a $9.5 million program to assist National and Regional Minority Organizations in building capacity to deliver HIV prevention programs and services within minority communities. Of these 22 organizations, 8 exclusively serve Latino/Latina populations and 3 others serve several minority populations including Latino/Latinas.

- Additionally, CDC conducts a number of behavioral research projects aimed at reducing HIV infection in the Hispanic community.

  - The *People of Color Initiative*, designed to reduce the disproportionate spread of HIV/AIDS among minority populations, will develop, strengthen, support, and, as needed, redesign HIV prevention strategies targeting racial and ethnic minority communities.

  - The *Women and Infants Demonstration Project* is a community-level behavioral intervention research project targeting young women ages 15 to 34, most of whom are members of racial/ethnic minority populations. This project is designed to improve understanding of factors influencing women's behavior changes regarding condom and contraceptive use and to improve the development and delivery of interventions.

  - The *Prevention of HIV Infection in Youth at Risk* project focuses primarily on young men of color. This program is developing and evaluating approaches to encourage young African-American and Hispanic men who have sex with men to reduce behaviors that put them at risk for HIV.

Building Better Prevention Programs for Hispanics

While race and ethnicity alone are not risk factors for HIV infection, underlying social and economic conditions (such as language or cultural diversity, higher rates of poverty and substance abuse, or limited access to health care) may increase the risk for infection in some Hispanic-American communities.

In addition to addressing these underlying conditions, improved prevention efforts for Hispanics will require focusing on several key challenges. To reduce the infection risk for Hispanic women, efforts to prevent drug use and HIV must be better integrated. And to adequately address the prevention needs of Hispanic gay and bisexual men, homophobia must be confronted on a national, societal, and community level. Finally, we must apply lessons learned in designing culturally appropriate prevention efforts to developing effective programs for communities not yet effectively reached. Despite successes to date, this epidemic is far from over. As long as we continue to see preventable infections occur each year, we can and must do better.

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1. Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, Wyoming

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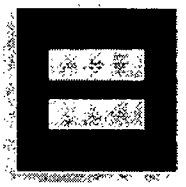

HUMAN RIGHTS CAMPAIGN

HIV Surveillance

Health organizations, AIDS groups, and federal, state and local public health officials are all in agreement that generating better data on the scope of the HIV epidemic is essential. Those data can help allocate limited resources, target and evaluate prevention efforts, and project where the epidemic is going. As AIDS deaths have declined and people are living longer with asymptomatic HIV disease, a national picture of the epidemic based on the end stages of disease progression may be less useful. The central question is how to get better data on early HIV infection.

- Currently, all people who are diagnosed with AIDS are reported by name to state and local health departments. State health departments then delete patient identifying information from the report and send the information to the CDC for compilation into a national picture of the AIDS epidemic.
- The federal government does not require that any particular disease be reported to local, state, or federal public health authorities. That decision is made by each state individually. If the federal government mandates the reporting of HIV disease and the manner in which that reporting should occur, it will be treating HIV differently than every other disease.
- In recognition of the fact that any new system of data collection must be supported by local communities affected by the epidemic, public health officials are working with those communities all across the country to develop HIV surveillance systems that will work. This process should continue without interference or mandates from the federal government.
- While some organizations recommend the reporting of HIV by name, the National Alliance of State and Territorial AIDS Directors and the Association of State and Territorial Health Officials oppose federal mandates.
- The fact that 28 states have implemented reporting of HIV by name does not provide a legitimate rationale for mandating all states to do so. Approximately 75% of individuals living with HIV reside in states that have chosen not to implement a named based system.
- Mandatory reporting of the names of people with HIV disease to state and local health departments may discourage people from getting tested and seeking treatment. While confidentiality laws are in effect, potential for discrimination still exists.
- Because people with HIV disease are living longer without symptoms, public health officials would have records of people with HIV for an extended period of time. Fears of breaches in confidentiality are real and legitimate. No comprehensive legislation exists which protects the privacy and confidentiality of identifiable health information.
- Unique identifier reporting is an alternative to name based reporting. In a unique identifier system, an HIV-infected individual would not be reported by name to public health officials, but rather by some form of a unique code that could not be traced back to the person.
- Non-names based surveillance systems, such as unique identifier reporting and populations based sampling, will enable the collection of better data on HIV disease, while protecting confidentiality

and not discouraging people from seeking HIV testing. Several states are developing such systems and they should be supported in that effort.

- To ensure that no individual is deterred from seeking testing, anonymous testing options should be available in all states. A federal mandate would lead to the elimination of such testing and the newly approved HIV home sample collection kits.

The Human Rights Campaign
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