

Since the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed in 1990, the program has worked diligently to safeguard patient information and counter HIV stigma.



Issues

Confidentiality

Ryan White confidentiality guidelines have helped allay the fears that many people living with HIV have around unwanted disclosure and HIV discrimination.



Ryan White grantees explain to all patients how their information is collected and used.

Building Trust: Confidentiality and the Ryan White HIV/AIDS Program

Every decision you made you thought about confidentiality because people were losing their jobs, their houses, their health care.

— Jane Silver,

first director of AIDS programs for the Department of Health in Washington, DC¹

From the beginning of the Ryan White HIV/AIDS Program, Title I (now Part A) Planning Councils were required to include among their membership a person living with HIV, but finding a member to identify as HIV positive was not always easy. Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Project Officer Sheila McCarthy recalls attending one local Planning Council meeting in the Program's early years in which each person on the council put a "+" or "-" on a blank piece of paper to indicate whether they were HIV positive or negative and then put the paper in a bowl. With at least one + in the bowl, the council could document that it had a member who was living with HIV, but no one knew who that person was.²

Disclosure of one's status as a person living with AIDS and, later, HIV has been an issue from the earliest days of the epidemic, and the desire to protect the confidentiality of HIV status has had a profound impact on the Nation's response to HIV/AIDS, including the Ryan White HIV/AIDS Program. For the Ryan White HIV/AIDS Program, confidentiality concerns have affected the types of testing programs supported; shaped the data that HAB collects about who is accessing funded services and how; and affected how HIV/AIDS cases are reported to the U.S. Centers for Disease Control and Prevention (CDC), which in turn drives Ryan White HIV/AIDS Program funding formulas.

The privacy of all medical information is deeply rooted in history and tradition, going back to the Hippocratic Oath: "Whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private."³ Such privacy has been extremely important for people living with HIV/AIDS (PLWHA), many of whom have faced stigma, discrimination, and hostility from the earliest days of the epidemic. Fears of disclosure remain today.

Overcoming Stigma

“At a holiday dinner with my family there was real china and silverware for everyone but me,” recalls Mildred Wallace, an HIV-positive woman and the Brooklyn Program for AIDS Treatment and Health (PATH) Center’s first peer advocate. “Mine was plastic, and while everyone else was seated according to their age—adults at their tables, children at others—I was relegated to the kitchen counter. The message was loud and clear,” says Wallace. “They knew I had HIV. And I knew I was no longer welcome.”

It is a message that Wallace has been fighting against for more than 15 years, as she works with peers and her community to discuss HIV and counter stigma and misinformation. “We forget how meaningful it is when someone finally remembers your name or talks to you about your problems. . . . We are not our disease,” she says.

Wallace recalls coming to the PATH Center (a Ryan White grantee) for the first time and the fear she had walking through those doors. But she also remembers the poignancy when staff used gloves only for internal exams, not for shaking her hand. There was no HIV stigma; her secrets would be kept confidential rather than shared, like what had happened with her family. She breathed a sigh of relief and, with that, asked how she could help, too.

Given many of the reactions that PLWHA have faced since the beginning of the epidemic, such fears are of no surprise. As noted in the Institute of Medicine’s (IOM’s) landmark 1986 report *Confronting AIDS*, “the stigma associated with AIDS has led to instances of discrimination in employment, housing, and access to social services.”⁴ The 1988 update of the report stated that “numerous anecdotal accounts portray the difficulties faced by persons with AIDS or even by persons who are members of a risk group. A number of court cases have been filed involving victims of AIDS-related discrimination in a variety of settings . . . and complaints have been docketed with State and local human rights commissions.”⁵

Since the beginning of the epidemic in the United States, HIV/AIDS has disproportionately affected populations that already experience discrimination, including gay men; members of racial and ethnic minority groups; and those who engage in certain illegal behaviors, such as illicit drug use and sex work. The stigma faced by PLWHA is rooted in the stigma faced by these populations as well as reactions to the disease itself. As an incurable, progressive illness, AIDS forced people to confront issues of death, and because it is transmissible, people with the disease are sometimes perceived as putting others at risk and even blamed for becoming infected as result of their own behaviors. As an early research team noted,

The stigma attached to AIDS as an illness is layered upon preexisting stigma. The result is that as public perceptions of AIDS become inextricably tied to perceptions of the groups among which it is most prevalent, the stigma of disease and death become attached to the groups themselves. AIDS has become a symbol: Reactions to AIDS are reactions to gay men, drug users, racial minorities, or outsiders in general.⁶

The early experiences of Frank Oldham bear out these conclusions. Now president and CEO of the National Association of People With AIDS, Oldham lived in New York City’s Chelsea neighborhood and worked at the New York City Department of Health and Mental Hygiene in the 1980s. He recalls an atmosphere during that period akin to a witch hunt in which any gay man who was thin was suspected of being ill. “The general public did not understand HIV transmission; there was a huge fear of people living with AIDS and a fear of gay men.” As one example of these fears and their impact, Oldham remembers a sick colleague in the health department who tried to hide his physical wasting as long as possible by doubling up on his clothes. Other employees went to their supervisors saying that they did not want to sit next to him and, later, that they did not want him working in the office at all.⁷

Many people who lived through the early days recall similar stories; PLWHA were losing their jobs; their homes; custody of their children; and relationships with family, friends, and faith communities. Many PLWHA felt like pariahs. Some were even shunned by health care professionals who were supposed to care for them, often left sitting in darkened hospital rooms with food trays placed just inside the door by workers who refused to enter. For many of those falling ill, it was not just fears of society’s reaction but also the reactions of family and friends that were of great concern and that led people to keep their illness private for as long as possible.

For many gay men, telling their families they had AIDS required that they simultaneously reveal their homosexuality. For others, disclosure meant acknowledging drug use or facing perceptions of sexual promiscuity. After the discovery of HIV as the cause of AIDS and the development of the test for HIV antibodies, a few journalists in prominent publications were even calling for massive testing campaigns and tattooing or quarantining PLWHA. In 1987 alone, the National Gay and Lesbian Task Force received more than 1,000 reports of harassment of gay people that involved references to AIDS.⁸

Some of the most visible cases of discrimination and violence in the first decade were among those who were hemophiliacs, not members of highly stigmatized communities.

Although not blamed for their illness, hemophiliacs still suffered the brutal effects of stigma. The family home of the young Ray brothers in Florida was burned after a judge ordered the local school to welcome them back and, of course, [Ryan White](#) himself fought his own court battle to attend school because of the misguided fears of school administrators and parents. Ryan White's courageous public battle against AIDS-discrimination was nothing short of inspiring; it's because of this he is the namesake of the Ryan White HIV/AIDS Program itself. Although these stories were perhaps the most visible, there were countless others.



[Providers at the Brooklyn Hospital Center's Program for AIDS Treatment and Health \(PATH\) discuss a patient's file confidentially.](#)

Given the enduring nature of these prejudices and the fundamentally intimate nature of the information often related to an AIDS or HIV diagnosis, it is not surprising that many people did not want their HIV status disclosed publicly without their consent, especially in the earliest days of the disease. In the midst of all these fears and emotions, it is easy to understand why confidentiality of information and disclosure of AIDS and, later, HIV status were such pressing concerns.

As PLWHA organized with a collective voice early in the epidemic, they declared their right to “ensure privacy and confidentiality of medical records” in the Denver Principles, which were drafted in 1983 as the foundation of the PLWHA empowerment movement. Despite privacy concerns, moves to make AIDS notifiable to public health authorities rarely produced sustained protest. The CDC, however, was unsuccessful in its efforts to create a national list of reported names. With the development of the HIV antibody test, the landscape changed as AIDS advocates, civil liberties groups, and gay rights organizations fought efforts to create name-based HIV-reporting systems and sought to strengthen protections for HIV-related information.

Efforts to prevent name-based reporting were driven by concerns, often shared by public health officials, that such programs and the fears of breaches of confidentiality and the repercussions of being on a list of PLWHA would prevent people at risk of infection from being tested. Fear of discrimination was compounded by fears related to being on a list that might be associated with criminal behavior, including drug use and sodomy. At the time, sodomy laws in many States still criminalized the sexual behavior of gay men.



To adhere to HIPAA regulations, only registered staff are allowed in areas with medical records.

The opposition to name-based HIV reporting was in no way outside the mainstream. In its 2000 report *The Role of Name-Based Notification in Public Health and HIV Surveillance*, the World Health Organization wrote: “HIV [name reporting] is a more sensitive issue owing to the potentially harmful social and economic consequences that may arise from breaches of confidentiality. Thus, wherever possible, reports to public health authorities should be made without any personal identifiers.”⁹

People feared not just their names being reported to the health department but also the potential impact of the inclusion—and release—of their HIV status in their medical records. “People were afraid to get tested because they were afraid they would lose their life and their livelihood, that they would be treated differently,” notes Jane Silver, first director of AIDS programs for the Department of Health in Washington, DC. Noting the potential positive impact of more widespread acceptance of testing, the IOM noted that “fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures.”¹⁰

One broadly embraced public health strategy was anonymous HIV testing: allowing people to get tested by simply providing an easy-to-remember pseudonym to use for accessing their results when they were available. Some evidence shows that the availability of anonymous testing (and, presumably, release from the fear of any possible disclosure of identity) can increase the number of people who seek testing and can encourage testing of more people who are at high risk of infection.

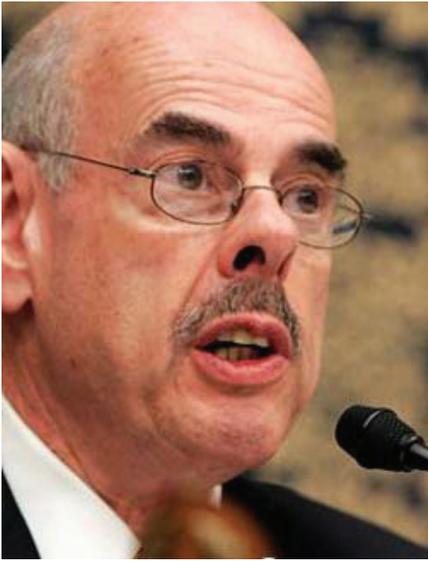
Confidentiality in the Ryan White Legislation

The original Ryan White Comprehensive AIDS Resources Emergency (CARE) Act passed by Congress in 1990 (Public Law 101–381, 104 Stat. 576) reflected the debates about HIV testing and names reporting. The confidentiality provisions it included were applicable almost solely to the section of the bill related to early intervention services. They focused on protecting information about people who accessed services while making sure those who were tested for HIV knew if and how their test results would be reported and ensuring that providers had the option of providing the test anonymously (see box, [Confidentiality Provisions in the Ryan White HIV/AIDS Program Legislation.](#))

At the time the legislation was drafted, AZT (zidovudine) had been approved to treat HIV, and treatments were also available for HIV-related opportunistic infections. The treatments were affirmative reasons for people to be tested for HIV; if positive, they could monitor their health and get treatment when appropriate. At the same time, health care systems were already buckling under the weight of those who had full-blown AIDS. Given the widespread fears about the confidentiality of HIV test results, the push for HIV testing was not a priority among AIDS advocates or most service providers.

Representative Henry Waxman, a leader on HIV issues in the U.S. House of Representatives, believed firmly in the need for early intervention and had previously pursued legislation to support counseling and testing, confidentiality, and nondiscrimination protections. Waxman understood that to encourage people to get tested, they would have to be assured that nothing bad would happen as a result of the test. The public health community had advised that successful early intervention would require taking away barriers by ensuring confidentiality of medical records and protection from discrimination.

Waxman’s original efforts to include an early intervention program in the Health Omnibus Programs Extension (HOPE) Act of 1988 (Public Law 100–607) were unsuccessful because not enough of his colleagues were willing to support the antidiscrimination protections; without those protections, Waxman would not proceed.¹¹ Waxman resurrected his efforts for early intervention programs as part of the legislation that would become the Ryan White CARE Act, and ultimately, early intervention services became Title III (now Part C). It was within this context that debates over HIV testing played out on the Hill.



Representative Henry Waxman (D-CA) champions for legislation to protect the identities of people living with HIV/AIDS.

Representative William Dannemeyer put forward a number of amendments counter to the advice of AIDS advocates and many public health professionals, including provisions mandating reporting of HIV-positive test results by name to State health authorities. In speaking against those provisions, Waxman clearly laid out the arguments against mandatory name-based HIV reporting in the Ryan White HIV/AIDS Program:

Who are the people that have AIDS? For the most part, they are gay men and drug users, people who have in many States in this country [been] regarded as having committed crimes. If their names are going to be on a list and they are afraid their name is going to be on that list for the purpose of prosecuting them and putting them in jail or putting them in camps, they are not going to come in. This would undermine exactly the public health purpose.

We talk about gay men and drug users. There is another group that is likely to have AIDS, and they have pleaded with us and said, "Don't adopt this Dannemeyer amendment." That is the Hemophiliac Foundation.

Well, wait a minute. Hemophilia is not a kind of thing where society has the same perspective as about gay men and drug users. But, they tell us, remember Ryan White, a kid, a hemophiliac who had a blood transfusion and got AIDS and was forced out of school and his family thrown out of the city in which they lived.

Tell these people not to worry, come in and trust the gentleman from California [Dannemeyer] and others who would like to have their names down on a list. If we want people to come in, we need to encourage them to come in. We need to give them the medications that will keep them from getting AIDS, and we need to show them that we are trying to control and treat the disease, not to punish them for possibly having the infection. The way we have handled every contagious disease in this country is to let the States decide how to handle the matter.

. . . .

Mr. Chairman, some States will decide they want to have the names down on a list so they can do contact tracing. Other States may decide they do not need to have a name on a list. They can do contact tracing by talking to the individual who has been tested. I ask, 'How are you going to know about the sexual partners of people who are infected without them telling them to you?'¹²

Ultimately, Title III (now Part C) included provisions that required States or independent entities to provide early intervention services to protect the confidentiality of those receiving care in accordance with State or local law, to counsel those being tested about how test results would be reported in their jurisdiction, and to offer the option of anonymous testing. The bill did not address issues of discrimination because the Americans With Disabilities Act of 1990 (42 U.S.C. § 126) was making its way through Congress at the same time and would be the vehicle for those protections. The provisions did not directly affect Titles I and II (now Parts A and B), the largest components of the Ryan White HIV/AIDS Program, but concerns about confidentiality had a profound impact on how those components were funded.

Part A and Part B grantees are funded in significant part by formula-based grants that use disease data from the CDC to determine how funds will be allocated. Those data were based on reported AIDS cases because nationwide HIV data were not available, although the Ryan White Program served people living with HIV from the beginning. The funding formulas have evolved with each reauthorization of the Ryan White HIV/AIDS Program in an effort to more accurately reflect the disease burden and now include HIV cases, a result of more and more States adopting name-based HIV reporting. As of 2008, all States had confidential name-based HIV reporting, although most



As a community health center, La Clínica del Pueblo, a Ryan White-funded grantee in Washington, DC, offers a safe place for those living with and without HIV disease.

States still offer the option of anonymous testing. By Fiscal Year (FY) 2013, all Ryan White HIV/AIDS Program formula funding will be based on living cases of HIV/AIDS.¹³

As early as 1991, HRSA wanted to collect client-level data to determine exactly how many people were being served and what services each person was receiving, but confidentiality concerns also affected how it was able to collect those data. A client-level data collection system does not require reporting names, only a unique identifier assigned to each client by the service provider. According to McCarthy, there was too much opposition from grantees to implement the system: “Nobody trusted us in terms of being the Federal Government and concerns about what we would do with the data. People were absolutely convinced that if there was client-level data that we would be able to identify people because they did not think a unique identifier would protect people.”

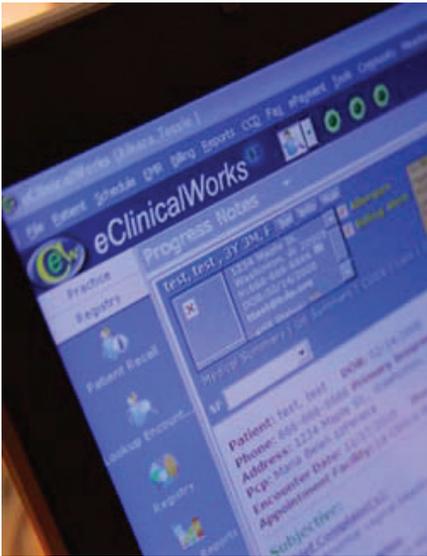
As a result of these limitations, for most of the duration of the Ryan White HIV/AIDS Program, HRSA has been able to collect only duplicated data, meaning that one person might be counted several times in service data if he or she was seen at more than one agency. The duplicated data limited the agency’s ability to determine and report on the Program’s full impact because it could not determine exactly how many people were served or how they used the full range of Ryan White services within a community.

Confidentiality concerns also had a profound impact on how services were delivered at the community level. Clinics avoided using the word “AIDS” in their name, because many people feared being seen walking into a clinic that obviously served PLWHA. Denver General Hospital, for instance, had an AIDS clinic that was called an “oncology clinic.”¹⁴ It was not (and still is not) unusual for PLWHA to travel long distances to go to clinics outside their neighborhoods.

At other times, agencies with clients’ best interests at heart created opportunities for unintended disclosures of HIV status. McCarthy recalls one local health department that took appropriate pride in its home visits program, which brought services directly to clients; the department initially failed to recognize the impact of using health department vehicles with the word “AIDS” on the side. In a similar anecdote, McCarthy remembers going to a low-incidence State and seeing the list of clients on the AIDS Drug Assistance Program written on a piece of paper and hanging on the side of the case manager’s file cabinet. She also recalls AIDS directors who knew every person in the State getting care.



A finger-prick HIV test being administered.



Ryan White grantees can track patient health outcomes using unique client identifiers.

Such anecdotes point to the critical role that individual providers and information holders have in preserving HIV confidentiality. The HIV/AIDS Bureau (HAB) has provided its funded agencies with guidance and assistance in this area. The personal health information held by many Ryan White grantees has long been covered by a diversity of State confidentiality laws and, in many cases, is now covered by the privacy protections of the Health Insurance Portability and Accountability Act of 1996 (HIPAA; Public Law 104-191). In 2004, HAB produced a resource guide on HIPAA, *Protecting Health Information Privacy and Complying With Federal Regulations*, for HIV service providers and HAB staff.¹⁵

Implementing and Evolving Confidentiality Protections

In the 2006 reauthorization of the Ryan White HIV/AIDS Program, Congress included several provisions to encourage and require grantee submission of client-level data, including funding for the development of a new data system to support the submission of client-level data across the Program. At the same time, Congress included language requiring that “any information submitted to, or collected by, the Secretary [of the U.S. Department of Health and Human Services] under this title excludes any personally identifiable information.”

HAB worked with grantees to develop a client-level data system that would provide the data needed while protecting the identity and health information of Ryan White clients. Although grantees had concerns about the transition to client-level data, acceptance was much greater than in the early days of the Program as a result of the Congressional mandates and the recognition that the Ryan White Program would be well served if HAB, grantees, and advocates could point to concrete data about the Program’s impact.

To incorporate client-level data in its data reporting system, HAB embarked on a process to develop and incorporate a unique client identifier (UCI) that would allow grantees to report client-level data without breaching the confidentiality of those served. In this way, HAB would be able to comply with other congressional mandates that no personally identifiable information be submitted by grantees.

The UCI is a unique, 11-character, alphanumeric code that distinguishes one Ryan White client from all others and is the same for the client across all provider settings. The UCI is derived from the first and third letters of a client’s first and last name, his or her date of birth (MM/DD/YY), and a code for gender (1 = *male*, 2 = *female*, 3 = *transgender*, 9 = *unknown*). A 12th character, A to Z, is added if a provider needs to distinguish between two clients with the same UCI.¹⁶

Funded agencies provide detailed information on the demographics, services received, and health status of each client over time. The data have a number of built-in protections, including encryption at the source and transmission to HAB across secure lines. The data allow HAB to monitor a person’s service utilization and health status over time as well as track that person’s care across multiple agencies. The system enables the following activities:

- HAB can report accurate, unduplicated counts of clients and improve measurement and reporting of Ryan White HIV/AIDS Program performance goals.
- HAB and funded agencies can identify gaps between accepted standards of care and services received.
- Funded agencies can identify service delivery needs and evaluate progress in meeting core clinical performance goals.¹⁷

Positive Outcomes of Client-Level Data Collection

Grantees began collecting client-level data in January 2009 as part of the requirements for the new Ryan White Services Report, an evolution of the previous Ryan White Data Report (see the HRSA publication *Using Data to Measure Public Health Performance* to

HRSA Publications on Data and Confidentiality

The Power of Technology

[Download PDF](#)

Scaling the Mountain: Managing Data in the Age of Accountability

[Download PDF](#)

Building IT Capacity: Using Client-Level Data to Meet Consumer Needs

[Download PDF](#)

learn more).¹⁸ HAB provided technical assistance and support to grantees to help them build capacity in this area, including projects funded by the Special Projects of National Significance (SPNS) Program. The Louisiana Public Health Information Exchange (LaPHIE), one of the SPNS-funded projects, demonstrates the positive effects of using personal health data to improve linkage and access to care while protecting patient confidentiality.

LaPHIE is a partnership of the Louisiana State University (LSU) Health Care Services Division, which runs several public hospitals, and the Louisiana Office of Public Health (OPH). LaPHIE established an electronic link between OPH clinics and LSU's electronic medical records system to link into care PLWHA who are not in care. OPH maintains the list of PLWHA in the State and also receives and tracks their CD4 and viral load test reports.

PLWHA who do not have results for either CD4 or viral load reported for a year or more are determined to be out of care and are listed in LaPHIE. If that patient then enters care at any of the LSU hospitals, a message goes to the electronic records system. In addition, the doctor or nurse gets an instant message that the person tested HIV positive but is not currently receiving care, providing an opportunity to reengage that patient. The program was developed after extensive research on legal and ethical issues as well as consumer input through a variety of mechanisms, and technological and systematic protections are in place.¹⁹ In the program's first 14 months, 199 patients were identified as out of care, and of those, 89 have returned to care.²⁰

The understanding that personalized data and information can profoundly affect individual and community health is having a powerful impact on improving quality of care. Nevertheless, many of the fears that existed at the beginning of the epidemic still exist today, and programs must move forward with that in mind. According to Phill Wilson of the [Black AIDS Institute](#), the biggest fear of the newly diagnosed people with whom he speaks today "is that they will be rejected, that they will lose friends and family, that people won't love them. The issue of their own mortality is a distant second. They are more afraid of the stigma than the disease, at least initially, although that changes over time. The good news is that that fear is, in fact, increasingly unfounded, but people don't know that, and the perceived risk is too great."

Wilson said he receives calls from many people who are entering care for the first time with full-blown AIDS, a significant proportion of whom knew they were positive but had not entered care for fear that others would learn of their status. He notes that these fears are still found in big cities and small towns all over the country, even in the HIV epicenters that have been dealing with large-scale HIV epidemics for decades. Wilson observes: "No matter how big of a city we live in, most of us live in neighborhoods, and while the larger city may be available to you, that's not where you live. It doesn't matter if you live in Southeast Washington, DC, or Brookhaven, Mississippi. . . . From the calls I get, especially from young people, they are afraid of the stigma."²¹

Conclusion: The Need for Confidentiality Continues

Much has changed for the better in the three decades of AIDS—better understanding of HIV transmission, effective treatments, and protections in the Americans with Disabilities Act for people living with HIV/AIDS—but the stigma, discrimination, and related fears that drive the need for strong confidentiality protections remain disturbingly prevalent:

- From FY 2000 through FY 2009, the U.S. Equal Employment Opportunity Commission received 2,175 complaints of HIV discrimination. More people claimed discrimination in FY 2009 than in any year since FY 2002.²²
- A 2009 survey of barriers to health care found that nearly 63 percent of respondents with HIV reported one or more of the following experiences: being refused needed care; being blamed for their health status; or experiencing a health care professional refusing to touch them, using excessive precautions, using harsh or abusive language, or being physically rough or abusive.²³



A case manager goes over a client's record.

- A man living with HIV was ejected from an assisted-living facility in Little Rock, Arkansas, in 2009, and in 2007 a campground in Alabama banned a toddler living with HIV from using its common areas, including the swimming pool.²⁴
- Until early 2010, the United States maintained a travel and immigration ban on people living with HIV that was “rooted in fear rather than fact,” according to President Barack Obama.²⁵

People living with HIV, like those with any medical condition, will always have a right to confidentiality. The lingering stigma and discrimination associated with the disease continue to heighten the importance of strong protections for HIV-related information. The Ryan White HIV/AIDS Program has produced many publications and initiatives to increase education and understanding of HIV and confidentiality of patient data and to counter stigma and misinformation. The Program will continue to work with grantees to make sure measures are in place to protect personal health information while harnessing the power of information to improve the health and wellbeing of PLWHA.

Confidentiality Provisions in the Ryan White HIV/AIDS Program Legislation

Ryan White HIV/AIDS Treatment Extension Act of 2009

<http://www.gpo.gov/fdsys/pkg/PLAW-111publ87/html/PLAW-111publ87.htm>
(Public Law 111–87, October 30, 2009)

Sec. 2695G(c) CONFIDENTIALITY. — This part may not be construed to authorize or require any medical facility, any designated officer of emergency response employees, or any such employee, to disclose identifying information with respect to a victim of an emergency or with respect to an emergency response employee.

Ryan White HIV/AIDS Treatment Modernization Act of 2006

<http://www.gpo.gov/fdsys/pkg/PLAW-109publ415/pdf/PLAW-109publ415.pdf>
(Public Law 109–415, December 19, 2006)

Title II: Care Grants

SEC. 2625. EARLY DIAGNOSIS GRANT PROGRAM. (g)(ii) for those individuals with a positive test result, post-test counseling (including referrals for care) is provided and confidentiality is protected.

Title III: Early Intervention Services

SEC. 2661. CONFIDENTIALITY AND INFORMED CONSENT. (a) CONFIDENTIALITY. The Secretary may not make a grant under this part unless, in the case of any entity applying for a grant under section 2651, the entity agrees to ensure that information regarding the receipt of early intervention services pursuant to the grant is maintained confidentially in a manner not inconsistent with applicable law.

Title V: General Provisions

SEC. 2685 PRIVACY PROTECTIONS (a) In General—The Secretary shall ensure that any information submitted to, or collected by, the Secretary under this title excludes any personally identifiable information. (b) Definition—In this section, the term “personally identifiable information” has the meaning given such term under the regulations promulgated under section 264 (c) of the Health Insurance Portability and Accountability Act of 1996.

Ryan White CARE Act Amendments of 2000

www.gpo.gov/fdsys/pkg/BILLS-106s2311enr/pdf/BILLS-106s2311enr.pdf
(Public Law 101–381, 104 Stat. 576)



Social worker Maria Lopez escorts a patient to La Clínica Tepayac. HIV stigma is particularly high in the Latino community.

Title II: Care Grant Programs, Subtitle C—Certain Partner Notification Programs
SEC. 2631. GRANTS FOR PARTNER NOTIFICATION PROGRAMS. (2)(A) In the case of a health entity that provides for the performance on an individual of a test for HIV disease, or that treats the individual for the disease, the State requires, subject to subparagraph (B), that the entity confidentially report the positive test results to the State public health officer in a manner recommended and approved by the Director of the Centers for Disease Control and Prevention, together with such additional information as may be necessary for carrying out such program.

Title III: Early Intervention Services

SEC. 2661. [300ff-61] CONFIDENTIALITY AND INFORMED CONSENT (a) CONFIDENTIALITY.—The Secretary may not make a grant under this part unless, in the case of any entity applying for a grant under section 2651, the entity agrees to ensure that information regarding the receipt of early intervention services pursuant to the grant is maintained confidentially in a manner not inconsistent with applicable law.

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990

<http://thomas.loc.gov/home/thomas.php>

Title III: Early Intervention Services

SEC. 2661. CONFIDENTIALITY AND INFORMED CONSENT. (a) CONFIDENTIALITY.—The Secretary may not make a grant under this part unless—(1) in the case of any State applying for a grant under section 2641, the State agrees to ensure that information regarding the receipt of early intervention services is maintained confidentially pursuant to law or regulations in a manner not inconsistent with applicable law; and (2) in the case of any entity applying for a grant under section 2651, the entity agrees to ensure that information regarding the receipt of early intervention services pursuant to the grant is maintained confidentially in a manner not inconsistent with applicable law.

Sect. 2662 PROVISION OF CERTAIN COUNSELING SERVICES. (a)

COUNSELING BEFORE TESTING.—The Secretary may not make a grant under this part unless the applicant for the grant agrees that, before testing an individual for HIV disease, the applicant will provide to the individual appropriate counseling regarding the disease based on the most recently available scientific data), including counseling on—(6) provisions of law relating to the confidentiality of the process of receiving such services, including information regarding any disclosures that may be authorized under applicable law and information regarding the availability of anonymous counseling and testing pursuant to section 2664(b)d.

Sec 2663. APPLICABILITY OF REQUIREMENTS REGARDING CONFIDENTIALITY, INFORMED CONSENT AND COUNSELING. The Secretary may not make a grant under this part unless the applicant for the grant agrees that, with respect to testing for HIV disease, any such testing carried out by the applicant will, without regard to whether such testing is carried out with Federal funds, be carried out in accordance with conditions described in Sections 2661 and 2662.

Sect. 2667 USE OF FUNDS. (c)(5) the State, except as provided in any paragraph (2) through (4), maintains the confidentiality of the results of testing for HIV disease in each prison operated by the State or with amounts provided by the State, and makes disclosures of such results only as medically necessary.

Subtitle B—Emergency Response Employees

SEC. 2688. RULES OF CONSTRUCTION (c) CONFIDENTIALITY—This subpart may not be construed to authorize or require any medical facility, any designated officer of emergency response employees, or any such employee, to disclose identifying information with respect to a victim of an emergency or with respect to an emergency response employee. [Subtitle repealed in 2006.]

Credits and Sources

Sources

1. Conversation with Jane Silver, April 2011.
2. Conversation with Sheila McCarthy, May 2011.
3. Hippocratic Oath. Hippocrates. National Library of Medicine. History of Medicine Division.
4. Institute of Medicine, National Academy of Sciences. *Confronting AIDS, Directions for Public Health, Health Care, and Research*. Washington, DC: National Academy Press; 1986.
5. Institute of Medicine, National Academy of Sciences. *Confronting AIDS, 1988 Update*. Washington, DC: National Academy Press; 1988.
6. Herek G, Glunt E. An epidemic of stigma: public reactions to AIDS. *American Psychologist* 1988;43:886–891.
7. Conversation with Frank Oldham, May 2011.
8. Herek G, Glunt E. An epidemic of stigma: public reactions to AIDS. *American Psychologist* 1988;43:886–891.
9. Joint United Nations Programme on HIV/AIDS. The role of name-based notification in public health and HIV surveillance. 2000. Available at: http://data.unaids.org/Publications/IRC-pub01/jc338-name-based_en.pdf. Accessed August 29, 2011.
10. Institute of Medicine, National Academy of Sciences. *Confronting AIDS, 1988*.
11. Conversation with Timothy Westmoreland, May 2011.
12. *Congressional Record*. June 13, 1990. p. H3550.
13. CDC, HIV Infection Reporting. 2010. Available at: www.cdc.gov/hiv/topics/surveillance/reporting.htm. Accessed August 29, 2011.
14. Conversation with Sheila McCarthy, May 2011.
15. Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). Protecting health information privacy and complying with Federal regulations: a resources guide for HIV services providers and the Health Resources and Services Administration's HIV/AIDS Bureau staff. April 2004. Available at: <ftp://ftp.hrsa.gov/hab/hipaa04.pdf>. Accessed August 29, 2011.
16. HRSA. 2010 Ryan White HIV/AIDS Program Services Report Instruction Manual. January 2010. [Available here](#).
17. Mills R. Presentation: Ryan White HIV/AIDS Program Services Reporting System, FY 2009 Data Collection Plan: Operations Details. [Available here](#). Accessed August 29, 2011.
18. HRSA, HAB. Using data to measure public health performance: a guide for Ryan White HIV/AIDS Program grantees. 2010. [Available here](#). Accessed August 29, 2011.
19. Conversation with Jane Herwehe, LSU Health Care Services Division, and DeAnne Gruber, Louisiana OPH, May 2011.
20. Cole J. Using HIV Surveillance Data to Prompt Clinical Action. [Conference presentation.] Ryan White HIV/AIDS Program All-Grantee Meeting, August 2010. [Available here](#). Accessed August 29, 2011.
21. Conversation with Phill Wilson, May 2011.
22. Lambda Legal. HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report. November 2010. [Available here](#). Accessed August 29, 2011.
23. Lambda Legal. HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report. November 2010. [Available here](#). Accessed August 29, 2011.
24. Lambda Legal. HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report. November 2010. [Available here](#). Accessed August 29, 2011.
25. Obama, B. Remarks by the President at Signing of the Ryan White HIV/AIDS Treatment Extension Act of 2009. October 30, 2009. [Available here](#). Accessed August 29, 2011.

Photography

Photographs © See Change