IMPLEMENTING IDEALISM:
HIV TESTING AND CONFIDENTIALITY IN NEW YORK STATE

By J. ERIC SMITH

EXECUTIVE SUMMARY

Acquired Immunodeficiency Syndrome (AIDS) is a disease of the immune system caused by the human immunodeficiency virus (HIV), which renders people vulnerable to life-threatening infections and cancers. In the early 1980s, during the nascent days of the AIDS epidemic, there was significant social stigma and fear associated with AIDS infection, as the disease first manifested itself through outbreaks of rare cancers among young gay men in California and New York. HIV was discovered and identified as the AIDS-causing virus in 1984, and prevention education efforts thereafter have focused on HIV testing as a key tool for enabling individuals to best protect themselves and others from infection or transmission. Given the ongoing social stigma associated with AIDS, however, privacy and confidentiality provisions associated with HIV testing remained paramount, and had to be addressed before testing could become widely useful among populations who were fearful that they could be harmed, persecuted, institutionalized or otherwise discriminated against as a result of a positive HIV test.

New York State enacted a seminal piece of legislation in 1989 as Public Health Law Article 27-F (Pub. Health L. §§ 2780-2787): "HIV Testing and Confidentiality Law." The initial Article 27-F provisions have been amended since their passage, and were significantly supplemented in 1998 with the passage of New York State Public Health Law Article 21, Title III, (Pub. Health L. §§ 2130-2139): "HIV Reporting and Partner Notification Law," the provisions of which went into effect in 2000. These laws specifically applied to, and had to be implemented by: physicians and others authorized to order lab tests or make medical diagnoses; persons who receive HIV-related information in the course of providing health or social services; persons who receive HIV-related information pursuant to a release; or health care providers or other medical services plans.

The seemingly simple concepts behind these laws were subject to a great deal of interpretation and ambiguity. While both Article 27-F and Article 21, Title III have been successfully implemented, the machinery required to support their provisions is far more complicated and loophole-ridden than that originally envisioned by the pioneering legal and social activists who first advocated for the confidentiality provisions now embodied in the New York State's health laws. Complicating factors in the implementation process have included:

- Ambiguous language in the original statutes;
- The need for extensive legal counsel and support of providers in making judgment calls associated with protection or legal release of confidential HIV/AIDS information;
- Relatively infrequent enforcement of violations and an associated lack of rigor in compliance;
- Lack of training or supplemental direction after the laws were passed;

- Lack of targeted funding to create compliance mechanisms, especially among small community service providers who could not simply pass such overhead costs back to their customers through insurance reimbursement or other fee-based mechanisms; and
- The overlay of subsequent Federal legislation, most notably the Health Insurance Portability and Accountability Act of 1999, better known as HIPAA.

Conclusions drawn from analyzing this implementation process include:

- After policies are successfully implemented, there may be calls for their elimination as their very success leads the general public or lawmakers to believe that the guiding provisions are no longer necessary;
- If people have a personal interest or belief in the policies they are expected to implement, the implementation is more likely to succeed;
- Mandates are difficult to implement because their machinery is more procedural and less tangible than inducements, capacity building, etc.;
- Privacy is a difficult commodity to administer, especially from a quality control standpoint; and
- Implementation is an iterative process, both in terms of the way the initial policy is framed, and in the way that nascent systems respond to changes or additions to the initial policy.

HIV TESTING AND CONFIDENTIALITY: GOALS AND THEORY

The underlying theories behind the original 1989 New York State Health Law Article 27-F provisions on HIV Testing and Confidentiality were as follows:

- HIV is the communicable virus that causes AIDS, a syndrome of auto-immune diseases with high morbidity when left undiagnosed and untreated;
- Transmission of HIV between people can be prevented by relatively simple protections and precautions, “safe sex” practices being the most widely known among them;
- If people are unaware of their own HIV status, they are less likely to take these precautions than people who are actively aware of their own HIV status;
- The only way to positively know one’s HIV status is by being tested for the presence of HIV antibodies, antigens or RNA in blood serum, urine or saliva;
- Given the stigma associated with AIDS, people are less willing to be tested if they are concerned that their test results could become public information or could be used to discriminate, isolate, institutionalize or otherwise harm them;
- The best way to encourage testing and mitigate the spread of HIV, therefore, is to strictly guarantee the privacy of HIV test results.

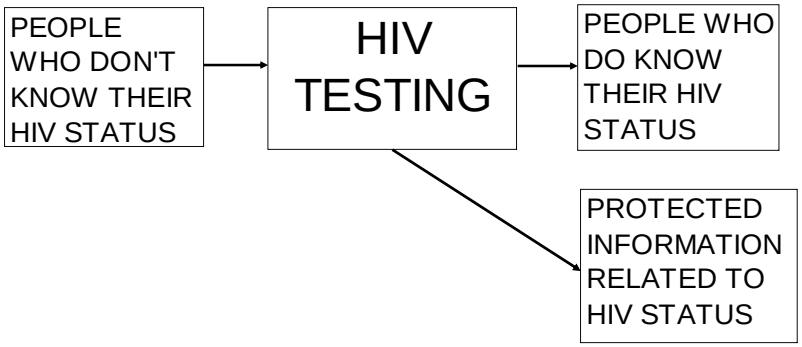
It is important to note at this point that Article 27-F was (and is) not intended to provide a universal panacea regarding the dissemination of confidential HIV or AIDS-related information, since it applies only to information formally collected by physicians, social workers, health care providers or other medical professionals—and not to the casual release of information among friends or colleagues. For example, if a person receives a positive HIV test result, and the testing

agent releases this information without their consent, this is a violation of the law. However, if the HIV-positive individual tells a neighbor of his HIV status, and that neighbor shares that information further, the neighbor is not in violation of Article 27-F or Article 20, Title III. The discussion that follows in this paper, then, is specific to the healthcare and social service and other medical parties charged with policy implementation by the provisions in question, and not to the broader public at large who may or may not chose to protect such medically sensitive information.

THE IDEALIZED MACHINERY AND EARLY IMPLEMENTATION DIFFICULTIES

At its most simple and idealized, the machinery needed to implement the initial concept of HIV Testing and Confidentiality as envisioned in New York State's Article 27-F could best be shown graphically by the following diagram:

WHAT WAS ENVISIONED: THE IDEALIZED MACHINERY



The input to the machinery would have been the population of New York State residents (particularly those from high risk communities) who were ignorant of their HIV status. The machine itself would have tested these people and produced two outputs: people who were aware of their HIV status (and ostensibly could then better protect against inadvertent transmission), and a corpus of information related to their test results—which would be fully and scrupulously protected from release.

Michele McClave has been working in the HIV/AIDS field since shortly after the original Article 27-F provisions went into effect. From 1990-1993, she was the HIV CARE Network Coordinator at Health Systems Agency of Northeastern New York, where she participated in the original implementation of the HIV Testing and Confidentiality provisions. Since 1993, she has worked at the AIDS Council of Northeastern New York, as Director of Consumer Services, Program Director, Deputy Executive Director, and (since 2000) Executive Director. She was actively involved in commenting on the provisions of Article 20, Title III during the policymaking phase, and was responsible for implementing the final approved statutes. In an April 16, 2007 interview, she remembered the initial implementation of the idealized machinery as something far less simple than its framers would have expected.

"When new policies like these are issued, there's often mass confusion among the players responsible for implementation," McClave noted. "We have to figure out all what to do, who to do it with or for, and how to do it, and then develop the policies and procedures needed to document what we come up with. Different providers sometimes end up doing things differently

with the same policies. For example, the State provided forms for us to use, but different agencies used them differently. The clearer the State's policies and directions can be, the easier they are to implement consistently. When the confidentiality policy was first implemented, the State didn't provide any specific training for implementation. We received the paperwork and the forms from them, and then we were just expected to immediately abide by the new policy."

Marcia Brom Smith, Esq., is a partner in a private law firm in Albany, New York. She practices predominately in the healthcare regulatory field representing hospitals, physicians, healthcare plans and other providers. She has advised her clients extensively in healthcare confidentiality implementation issues, including those related to confidential HIV and AIDS related information. In an April 29, 2007 interview, she explained why some of the initial implementation difficulties experienced by both community service providers (such as the one McClave heads) and physicians alike could have been predicted by the underlying ambiguity of the original statutory provisions.

"There are different types of legal requirements," Smith explained. "One type would be self-executing policies where there is no interpretation required and it is obvious what the subjects of the requirement are supposed to do. An example would be stop signs or stop lights along a road: they apply to a specific population (in this case, drivers), who know exactly what they are supposed to do when they encounter them. More complex regulatory requirements require interpretation by the target population, and usually that interpretation must ultimately come from a lawyer. Providers who are subject to these laws have to make judgment calls on a daily basis. Most of the judgment calls that providers have to make relate to who can obtain information protected by the statutes. There are a number of exceptions in the statutes themselves, and the providers need to apply the facts and circumstances to the language of the exceptions. This is where the complexity of interpretation presents itself and where the services of an attorney who is trained to apply law to particular facts and circumstance can be most helpful."

"If providers make the wrong judgment call, they can be subject to lawsuits by individuals who are harmed by the release of the information or by the failure to comply with a request to provide the information when someone is authorized to access it," Smith continued. "The system is always biased to inaction, or nondisclosure, and given the goals of the statutes, this is probably preferable. If the providers wish to seek legal counsel in making these judgment calls, then the costs of implementation and compliance increase, particularly if the provider does not have in-house counsel at their disposal."

As McClave noted, her organization and other community-based providers encountered similar issues of interpretation. However, as lightly-funded nonprofit or regional agencies under State contracts, they were unable to afford the extensive legal expertise that most hospitals, physicians and healthcare networks could access. Fortunately, the New York State AIDS Institute (the Department of Health's contracted clearinghouse organization for AIDS funding and policy throughout the State) recognized the need for such support, and created a central legal resource to help all the small social service organizations working in the AIDS field with their initial implementation difficulties.

"In the early days of the confidentiality policy, the State's AIDS Institute provided funding to the Legal Action Center in New York City to be a legal consultant for all of the Community Based Organizations in the State to help them comply with the new law," McClave explained. "The Legal Action Center tends to be policy oriented, so they can help when you encounter some unusual or grey areas in protecting confidential HIV information. We've had

cases where information has been requested by subpoena or court order, and if we're not sure exactly what to do, we can go to the Legal Action Center and get specific advice and direction. They're still a key player in HIV confidentiality in New York State. Without them, there would be a lot more confidentiality mistakes made around the State."

"PILING ON" MAKES IMPLEMENTATION MORE COMPLICATED

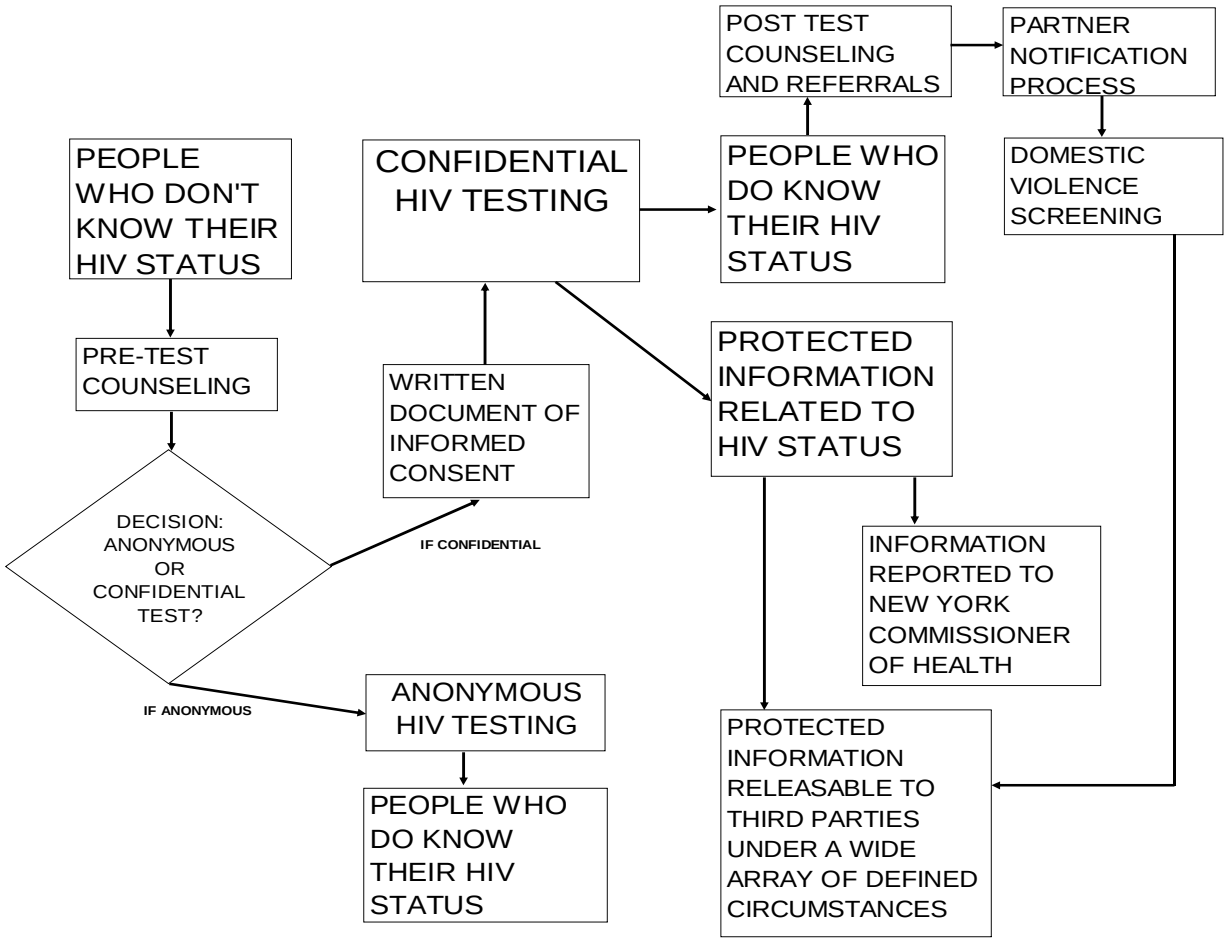
As the initial HIV Testing and Confidentiality provisions evolved through the early days of implementation, and as administrative and prevention successes began to accumulate, the confidentiality realm began to fall prey to the implementation game that Eugene Bardach defined as "piling on" in his book *Implementation Games*. (MIT Press, 1978). Bardach described "piling on" as follows: "Ironically, the initial successes of a new program contain the potential for its longer-run debilitation. As onlookers see the new program begin to move in it intended direction, some see it as a new political resource, an opportunity to throw their own goals and objectives onto the heap. The net effect of a large number of additional objectives added to the heap may topple it." In the case of HIV Testing and Confidentiality, policy and practice slowly evolved through the 1990s as legal decisions made by private firms (on behalf of physicians, etc.) or the Legal Action Center (on behalf of the State's Community Based Organizations) fed back into the system, with additional related requirements often integrated into them.

Changes that were "piled on" and integrated into the machinery that ultimately complicated the idealized model discussed above included:

- Formal provisions and procedures for pre-test and post-test counseling;
- Provisions to allow anonymous testing (in which no name is associated with the test results, and no notification of results are provided to anyone except the individual being tested) vs. confidential testing (in which a name is associated with the test results);
- Provisions to track epidemiological information related to the spread of HIV, including reporting confidential test result information to the State;
- Provisions to formally notify the partners of infected individuals who might themselves also be infected due to sexual, drug-related or other high risk contacts, in order to allow them to be tested as well, and receive similar services;
- Provisions to ensure domestic violence screens are conducted in the partner notification process, to ensure that infected individuals are not battered or killed by domestic partners who learn of their own potential infection via this program.

With all of these additional provisions added into the equation through the "piling on" process, the actual implementation machinery now looks less like the simple model originally intended, and more like the piece of complicated machinery documented on the following page:

WHAT ACTUALLY HAPPENED: THE IMPLEMENTED MACHINERY



UNINTENDED CONSEQUENCES: EXCEPTIONS DEFINE THE RULES

Ironically, a machine that was originally intended to ensure that confidential HIV and AIDS related information was never released has now become a machine that dedicates a large amount of time and energy to figuring out when it is acceptable to release such information. The rules are often defined more by the exceptions than by the norms.

A March 16, 2001 training seminar sponsored and documented by Lorman Educational Services on "Confidentiality of Medical Records in New York State" explained the general provisions of how confidential HIV and AIDS related information was to be protected, then described the exceptions for cases in which it is acceptable for parties to release such information. There were 21 specific exceptions for health and social service providers, four specific exceptions for county, State or local health officers, four specific exceptions for physicians or their agents, plus four mandatory reporting requirements for information to be transmitted to the New York State Commissioner of Health. Needless to say, this complexity often makes it difficult for implementers to adhere to the letter and intent of the laws. Conversely, as professionals working with confidential HIV information grow more accustomed to acceptable and somewhat routine releases of such information, they are more apt to err on the side of releasing information that was not, in fact, covered by one of the many exceptions.

"Quality control is very difficult at all levels when it comes to confidentiality," explained Michele McClave of the AIDS Council during our interview. "People just slipping and saying something they shouldn't is one of our biggest risks. There are lots of subtle things that you have to think about when it comes to quality control, and lots of things that aren't listed in any policy, but could result in an inappropriate release of information. For example, we have to have an anonymous outgoing telephone line, so the caller ID doesn't say 'AIDS Council' at the other end, since we don't know who is answering the phone. We have to be careful about what we talk about in public: if you discuss someone's T cell counts, protease inhibitors or other drugs that only people with HIV take, then you have given away their status without every explicitly doing so. This is an issue in walk-in testing situations. You don't want to give away information through subtle diagnostics. There are also many issues associated with 'need to know.' In the beginning, we interpreted the law to mean that all of our employees could have a need to know regarding clients' HIV protected information. Over the years, we have narrowed that significantly, and now information is not shared outside of the line of communication and supervision for each case manager. If two case managers working near each other feel they need to share information, it has to be approved or adjudicated by their common supervisor."

Attorney Marcia Brom Smith reinforced the importance of need to know provisions when assessing how and when to implement HIV Confidentiality provisions, as well as the ways in which providers seek to mitigate or minimize the impacts of accidental disclosure: "One concept that has been applied in the medical community regarding disclosure is the need for healthcare professionals to know the HIV status of a particular patients," she explained. "Common sense would indicate that anyone who may come in contact with the bodily fluids of a patient should know whether that patient is HIV positive or not. The healthcare community has addressed this issue not by mandating disclosure of HIV status by all patients in all circumstances, but rather by treating HIV like any other infectious disease and requiring that all providers have infection control practices that will protect healthcare professionals from exposure to any infectious disease. Effective infection control practices are mandated by State and Federal regulations and the Joint Commission on Accreditation of Healthcare Organizations, which surveys providers to ensure they are meeting these requirements. This way, doctors don't have to ask or find out patients' HIV status before treating the patient. In the early '80s, before the HIV confidentially law was in effect, this was not the case: some doctors and dentists were requiring patients to disclose their status before treating them."

WHERE THE RUBBER MET THE ROAD: WHO DID WHAT?

The New York State Department of Health's AIDS Institute serves as a central clearinghouse for managing policy, financial, and procedural matters related to HIV and AIDS care and prevention throughout New York. The AIDS Institute issues contracts to a variety of providers throughout the State to provide services at regional and local levels, and to meet specific demographic needs within the HIV-positive community. The AIDS Institute's contracts serve as key conduits for promulgating and enforcing HIV Testing and Confidentiality and Partner Notification provisions, as contractors are required to adhere to State requirements as part of the terms and conditions of their contracts.

The primary focal point for the HIV Confidentiality provisions is on health and social professionals working specifically with information directly gleaned from HIV testing, and the

treatment and management of patient care after HIV positive test results have been returned. Specifically, the original HIV Testing and Confidentiality provisions apply to:

- Physicians and others authorized to order lab tests or make medical diagnoses;
- Persons who receive HIV-related information in the course of providing health or social services;
- Persons who receive HIV-related information pursuant to a release;
- Health care providers or other medical service plans.

In order to implement the provisions of the both the original Article 27-F Testing and Confidentiality provisions, as well as the later Article 20, Title III requirements for Partner Notification, the AIDS Institute, its contractors, and the other medical and social professionals listed above had to create a significant body of procedures and documentation. Important elements of the HIV Testing and Confidentiality implementation process are discussed in the following paragraphs.

Detailed organizational regulations: The original laws have been interpreted and implemented with assistance from the Legal Action Center (for New York State Community Based Organizations) and various attorneys, judges and law firms (for private healthcare practitioners). Each organization must create its own internal policies and regulations that tailor the spirit and letter of the governing laws to the organizations' specific needs and skills. "In order to continue providing services, sometimes you have to look at the policies and find the loopholes that that allow you to meet the intent of the law while still doing what you need to do efficiently," said McClave. "The partner notification system [see below] is designed to inform people if they might have been exposed. But if a client tells us or their physician that they have or will perform partner notification, then we don't necessarily have to go through the whole formal notification process."

Standard consent, release and report forms: The State created standard forms so that the myriad number of organizations working in HIV/AIDS care and management throughout the State would be able to communicate clearly and consistently about whether individuals had provided informed consent before releasing confidential information, and even then only to organizations or individuals with specific requirements to receive it.

Counseling standards: There are prescribed counseling standards both before and after HIV tests are conducted. These were considered onerous in the early days of the implementation process, though this has improved in recent years. "The AIDS Institute has streamlined the pre-test counseling requirements to make it simpler and quicker," noted McClave. "What's left now is essentially just what's needed. The number of tests since then has increased, so it's been successful in that way."

HIV Confidentiality Hotlines/Public Information: Healthcare providers, physicians and social service organizations have organized legal means for acquiring information about rules and rights associated with HIV Testing, Confidentiality and Partner Notification. In order for individual citizens of the State to have similar information access, and to receive such information confidentially, the State implemented Confidentiality Hotlines and created both print and electronic based literature explaining the requirements and services associated with the laws under discussion. The New York State HIV Confidentiality Hotline can be reached toll-free at (800) 962-5065, and is useful to both providers and individuals seeking assistance with confidentiality issues. The Legal Action Center (the AIDS Institute's contracted legal advisors

for confidentiality matters) also publishes a free document called "HIV/AIDS Testing, Confidentiality & Discrimination: What You Need to Know About New York Law," which is available in print and online versions.

Partner Notification Infrastructure (with related domestic violence screening): These provisions, which went into effect in 2000, were the most extensive of those "piled on" to the original Testing and Confidentiality laws. Partner Notification provisions provide methodologies and requirements for informing people who may have had contact with an HIV-positive individual, after that individual learns of the HIV status through confidential testing. Domestic violence screens are conducted to protect HIV positive individuals and their domestic partners. (These services are not available under the anonymous testing model). "The partner notification program is generally working smoothly now," McClave commented. "It comes into play in HIV testing and through physicians who identify HIV positive individuals. It has evolved to meet the needs of different communities. For instance, in rural areas, where the counties don't have the personnel to administer the partner notifications, the State generally handles it. This is actually better: it's not your neighbors or your friends or people everyone knows in a small community knocking on your door to tell you that you have been exposed to HIV."

Data management, analysis and control standards: HIV positive results from confidential testing are reported to the New York State Commissioner of Health. The reports must include the name of the protected individual, names and addresses of contacts, dates that contacts had been notified, and information related to the domestic violence screening under the partner notification program. These data are used to develop epidemiological analysis of the spread of HIV throughout the State. Information reported must be controlled and communicated in ways that ensure it remains protected, just as it must be in the offices of healthcare providers and social service workers. Data analysis must be presented in ways that do not divulge or compromise the protected status of any individual whose confidential HIV information is covered under the provisions of Article 27-F or Article 20, Title III. Providers must not only consider their own use and control of confidential HIV information, but also how it might be used or inadvertently released down the line. "We are only supposed to release HIV information from our own records, once we have proper authorization," observes McClave. "If another provider releases information that we have given them, then we could be held accountable."

Disclaimers and other legal language: Documentation originating from organizations working in the HIV field needs to contain specific disclaimers related to its subsequent use or release. For example, responses to all written electronic correspondence sent to Michele McClave's office at the AIDS Council of Northeastern New York contained the following clause: "STATEMENT PROHIBITING REDISCLOSURE OF CONFIDENTIAL INFORMATION: This information has been disclosed to you from confidential records that are protected by state law. State law prohibits you from making further disclosure of this information without the specific written consent of the person to whom it pertains, or as otherwise permitted by law. Any unauthorized further disclosure in violation of state law may result in a fine or jail sentence or both. A general authorization for the release of medical or other information is NOT sufficient authorization for further disclosure. Disclosure of confidential HIV information that occurs as a result of a general authorization for the release of medical or other information will be in violation of the state law and may result in a fine or jail sentence or both. (NYS PUBLIC HEALTH LAW - ARTICLE 27-F SECTION 2782.5a)."

Anonymous Testing Methodologies and Sites: While countless organizations throughout the State offer confidential HIV testing, anonymous testing is a much more restricted resource. When individuals opt for anonymous testing, they are not eligible to participate in the organized post-test counseling, partner notification, or domestic violence screening programs. If they convert their anonymous test results to confidential test results, they may then participate in these programs. "Anonymous testing is all State run now," McClave explained. "They're still doing it in the prisons and a few community locations. But it's not as readily available as confidential testing. Part of the reason for this is that anonymous testing results can hurt funding coming into the state from Federal sources. Anonymous results don't count toward Center for Disease Control totals, since they are not confirmed as single individual cases. That can cause the State and providers to lose funds, since funding is tied to case loads."

Training: Given the large number of people working in AIDS-related services throughout the State and the many case-specific exceptions to the basic provisions of the Confidentiality rules, training has been one of the most crucial elements of the implementation process. "HIV Confidentiality is the first thing we talk about with new staff members," notes McClave. "Our prevention department trains them and has them sign forms saying that they won't release information. Once a year, we all do a more extensive, full-day program to keep people reminded and updated on the confidentiality requirements."

RESOURCES: WHAT DID IT TAKE TO IMPLEMENT AND ENFORCE?

Resources associated with the implementation of the Article 27-F and Article 20, Title III included three elements: human resources, financial resources, and enforcement resources. Each played a crucial role in the successful implementation of the policies and their provisions, though only the in case of enforcement did the policies specifically and extensively address resources, in large part because they were not associated with specific line-item costs or personnel expenditures covered under other State contracts or licensing provisions.

Human resources deployed in this implementation generally included State employees, State-licensed professionals (doctors, lawyers, nurses and social workers), employees of quasi-governmental authorities (The AIDS Institute), and employees of contracted agents of the government (Community Service Providers, Community Based Organizations, Multiple Service Agencies, etc.). In very few cases were employees hired specifically to work on confidentiality issues; generally these requirements were imposed atop the general provisions of extant positions. The fact that most of these providers and individuals already had existing working relationships mitigated the impacts of "complexity of joint action," as defined in Jeffrey L. Pressman and Aaron Wildavsky's *Implementation* (Third Edition, University of California Press, 1984). Very few new working relationships needed to be forged, and Government contracting terms discussed below served to provide effective incentives for recipients of State funding to comply with the terms and provisions of the new policies.

Financial resources associated with implementation of Article 27-F and Article 20, Title III are generally provided under terms of State contracts, fees collected by licensed practitioners, or higher overhead charges passed on to insurance carriers, without specific supplemental State funding—with some relatively small exceptions for notification, counseling and testing provisions. The State also specifically funds the Legal Action Center, allowing that organization to support the State's various Community Based Organizations without each of them having to pursue specific invoicing or payments associated with legal services rendered.

Enforcement resources hinge solely on the power of the State to punish violations, since these policies were clearly mandates as defined by Richard F. Elmore in his "Instruments and Strategy in Public Policy" (*Policy Studies Review*, Autumn 1987): Article 27-F and its successor policies had compliance as their primary goal, their primary hard costs are related to enforcement, and they have specific benefits to individuals, but more diffuse benefits to society as a whole. Article 27-F defines specific penalties imposed by State for violations of its provisions: a $5,000 penalty per occurrence of violation, payable to State Department of Health, with willful violations possibly resulting in misdemeanor charges ($2,000 penalty and/or one year in jail). The policy also offers additional remedies in the form of complaints to AIDS Institute's Special Investigation Unit, or lawsuits for injunctive relief or monetary damages. While these enforcement standards may have some deterrent effect on those who wish to violate them, in general, enforcement actions have grown less common over the years since the policy was first enacted.

"There was probably more enforcement in the early days of the confidentiality policy," observes McClave. "Today, while we still get reviewed for compliance in our contracts with the State, in general there's less attention being paid to the issue of confidentiality, and less education about it too. Many clients don't know their own rights related to this. We're probably stricter in our compliance and adherence with the confidentiality policy that other organizations that don't have HIV and AIDS as their primary mission and do this all the time. We essentially pay strict attention to the policies and requirements voluntarily, and because it's the right thing to do. No one is aggressively enforcing our implementation otherwise."

CONCLUSION: TOO SUCCESSFUL FOR ITS OWN GOOD?

In general terms, the implementation of Article 27-F and Article 20, Title III have been successful. The original goals and aspirations of the statutes and the legal and medical advocates who framed them were largely met, though their infrastructure ended up being much more complicated than originally anticipated. One interesting and unforeseen complication to the State's HIV confidentiality policies was the enactment of the Federal Healthcare Insurance Portability and Accountability Act of 1996 (HIPAA), which contained medical record confidentiality provisions of its own for all healthcare cases, not only for those associated with HIV and AIDS. While HIPAA demonstrates that core concepts embedded in the original goals have become far more widely accepted for other health care conditions, it has added confusion and complexity for those working in the HIV and AIDS fields in New York State.

"HIPAA is even stricter that the confidentiality law in some ways, and we have to figure out which provisions apply or take priority over the other," notes McClave. "It's very confusing. There are similar issues in the laws governing release of mental health information."

"HIPAA does not pre-empt state laws that are more protective of individual rights, either the right to privacy or the right to access of their medical information," explains Smith, who has worked on similar issues with her healthcare clients. "In practice, that means that if the HIV statute that New York passed is more protective than HIPAA, whether in part or in whole, then whatever parts or the entire statute is not over-ruled by HIPAA. For example, if a provider could disclose HIV confidential information under HIPAA, but not disclose it under the New York law, then the New York law would trump HIPAA. A common example of that in New York is that consent to provide confidential information is not required by HIPAA when the provider is conducting healthcare treatment, payment or operations—but New York still does require that

the providers get their patients' consent to release information for those purposes, such as releasing information to third party payers. In that case, New York's law still takes precedence."

On some plane, the most telling indicator of a program's successful implementation may be the call for its elimination, as its premises and practices become so commonplace that they no longer seem to require special protocols, policies or practices. As the general concept of treating medical records as confidential, private information has become more widespread and accepted, there have been proposals made to eliminate New York's HIV Testing, Confidentiality and Partner Notification laws, essentially treating AIDS as a disease of no greater or lesser exclusivity than any other, and deserving no more or less special protection for people living with it. McClave does not believe that such proposals would be wise.

"There are movements in the State now to try to do away with the HIV confidentiality requirements," she notes. "Some change is possible, but it's not likely any time soon that they will be completely eliminated. But people keep whittling away at the protection. First it was the mandatory testing of pregnant woman, then mandatory testing of accused rapists. No one can easily argue in public with any of those changes on their own merit, but they set precedents for imposing other, less benevolent mandatory testing requirements later. I don't think we're ready to get rid of the HIV/AIDS provisions and just treat it as we treat any other diseases. I still hear from clients that they are treated differently in medical situations when their HIV status is known. There is still a level of fear and stigma out there."

While the elimination of Article 27-F and Article 20, Title III would certainly make her work easier, McClave concluded by explaining why she and so many of her colleagues have been willing to work so hard to implement—and now preserve and protect—the programs required by those statutes. "Overall, the confidentiality system is cumbersome, but we believe in what it is designed to accomplish, so that makes it much easier to implement," she said.

Policymakers should consider her words as they seek to craft new laws and regulations, and recognize that if the implementers support and embrace the goals and ideals embodies in the new statutes, they will almost certainly be more effective at bringing them through a complete and successful implementation process.

Acknowledgment: This article was originally prepared for Professor Robert T. Nakamura's Implementation seminar at the University at Albany's Rockefeller College.

REFERENCES AND WORKS FOR FURTHER CONSIDERATION

STATUTES AND REGULATORY LANGUAGE

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- New York State Public Health Law Article 21, Title III, (specifically portions implemented under Pub. Health L. §§ 2130-2139): "HIV Reporting and Partner Notification Law."
- Public Law 104-191, (specifically portions implemented under 42 USC § 1320d.): "Health Insurance Portability and Accountability Act of 1996."

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- "Health Care Provider Responsibilities Regarding HIV Reporting and Partner Notification: A Question and Answer Sheet." Public Health Forum (Internet Resource), New York State Department of Health.
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