

Call to Action:

Assisting People with Undiagnosed HIV Infection

David Ernesto Munar
AIDS Foundation of Chicago

June 2007



Call to Action

- CDC recommendations and current Illinois law
- Community perspectives on the CDC recommendations
- Assisting the undiagnosed—a critical analysis
- Changes to Illinois law
- Key questions and considerations

Overview of CDC recommendations and current Illinois law

CDC's 2006 HIV testing recommendations

- **Routine testing:** healthcare providers should offer testing to all patients ages 13-64 regardless of identified risk
- **Pre-test counseling optional:** To streamline testing, healthcare works need only give patients nominal "pre-test information"
- **No separate consent form:** General consent for healthcare should be sufficient for HIV testing
- **Opt-out testing in all settings:** Patients should be informed testing will be performed unless they refuse
- **Verbal consent sufficient:** Patients should be allowed to accept or refuse testing verbally (no patient signature)

CDC's 2006 HIV testing recommendations *continued*

- **Informed consent** : patients **should** be tested only with their informed consent
- **Voluntary, non-coercive**: Testing should remain voluntary and non-coercive
- **Giving HIV+ results:**
 - Provide results in person
 - Provide counseling and referrals for follow-up care
 - Provide professional translation (not a family member) if needed

Illinois requires healthcare providers obtain written, informed consent before administering voluntary HIV testing:

- The patient must document that informed consent has been granted with his/her signature.
- The consent form must address HIV testing *specifically*.
- Specific consent for HIV testing may be included on the same form as general consent for healthcare.
- Examples of specific consent language:
 - “I am informed of and accept voluntary HIV testing.”
 - “Unless I have declined HIV testing in the option provided above, I understand that I will receive voluntary HIV testing.”

IL: Required Pre-Test Information

- Meaning of test results include its purpose, potential uses, and limitations Voluntary nature of the test and the right to withdraw consent at any time
- Right to anonymous testing and confidentiality
- If appropriate, availability of additional or confirmatory testing
- If appropriate, availability of referrals for further information or counseling

Note: The law requires healthcare providers to counsel their pregnant patients about HIV and recommend voluntary HIV testing. Additional pre-test information is required.

For more information, see:

www.aidschicago.org/pdf/2006/adv_perinatal_factsheet.pdf

IL Exceptions to Consent and Pre-Test Information Requirements

- Written informed consent and pre-testing information are not required when, in the judgment of the treating physician, such testing is **medically indicated** (i.e., cases where obtaining consent is impossible and HIV is suspected based on clinical indicators).
- State law allows HIV testing without consent in a few other circumstances:
 - Individuals involved in a blood or other bodily fluid exposure with a healthcare worker, police officer, or paramedic
 - Individuals convicted of a sex crime
 - newborns whose mother's HIV status is undocumented

Community perspectives on the CDC recommendations

Overwhelming Agreement

- **We must address missed opportunities:** Too many people learn their diagnosis late in disease
- **Testing must modernize:** Testing modalities can and must be streamlined
- **Testing must be readily available:** Patients will benefit from routinely offered testing—without regard to identified risk
- **Testing alone cannot end the HIV/AIDS crisis**

Concerns with recommendations

- **Approaches to testing should be context specific**—i.e., opt-out testing is not indicated in all settings and for all populations
- **A brief pre-test dialogue benefits patients**
- **Written consent is valuable, doable, and not a barrier to testing acceptance**
- **Testing is not an end unto itself**—without linkage to care, expanded testing shortchanges patients and fails to realize its potential

Implementation challenges

- Leveraging needed reimbursement/funding for testing expansion
- Leveraging needed funding for expansion of HIV-related healthcare, prevention, and support services
- Ensuring expanded testing is of the highest quality
- Ensuring providers are prepared and equipped
- Ensuring patients benefit and are not harmed

Written, informed consent is required when the benefits and risks are not well known

Written, informed consent is still warranted because of these risks:

- Stigma
- Eviction
- Workplace discrimination
- Violence
- Criminal transmission charges
- Uninsurability
- Domestic violence

Written, informed consent promotes ethical medical practice and builds trust: Tuskegee continues to generate tremendous mistrust of the medical establishment and hinder HIV care and prevention efforts.

According to the American Medical Association

“Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention. To protect yourself in litigation ... it is important that the communications process itself be documented. Good documentation can serve as evidence in a court of the law that the process indeed took place.”

Written, informed consent IS NOT a barrier to testing acceptance

- **The vast majority of people counseled about the benefit of HIV testing accept it.**
- **61% surveyed said the leading reason for not being tested was that they didn't feel they were at risk (Kaiser, 2006).**
- **Smaller shares of those who haven't been tested say it is because their doctor never recommended it (21%) or they worry about confidentiality (10%).**
- **New York City hospitals increased testing 63% in 2006 without eliminating the requirement for written consent.**
- **Illinois expanded testing among pregnant women and newborns from 73% to 100% in 2006 with outreach, training, and technical assistance for clinicians.**

Lacking basic information, the general public benefits when offered testing with written, informed consent:

According to a 2006 national survey by Kaiser Family Foundation:

- 37% surveyed mistakenly believed that HIV could be transmitted through kissing.
- 22% mistakenly believed that transmission could occur through sharing a drinking glass.
- 16% mistakenly believed that transmission could occur through touching a toilet seat.
- And more than 4 in 10 adults held at least one of the above misconceptions about HIV transmission.

Assisting the undiagnosed— a critical analysis

Number Estimated to be Living with HIV/AIDS and Undiagnosed with HIV, 2003

	Low Estimate	High Estimate	Estimated Undiagnosed
Illinois	36,656	41,807	10,452
Ohio	16,853	19,221	4,805
Michigan	14,286	16,294	4,074
Indiana	9,434	10,760	2,690
Missouri	12,956	14,777	3,694
Wisconsin	4,728	5,392	1,348
Minnesota	4,863	5,546	1,387
Iowa	1,860	2,121	530
Kansas	2,878	3,282	821
Nebraska	1,527	1,742	436
South Dakota	270	308	77
North Dakota	146	166	42
United States	1,039,000	1,112,000	278,000

Source: Calculations and methodology performed by AIDS Foundation of Chicago using Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report*, 2003. Undiagnosed estimates are calculated at 25% based on CDC's 24%-27% estimate.

At a 1% average yield ...

**27.8 million HIV tests will need
to be administered to identify
278,000 undiagnosed
individuals**

Targeted efforts still makes sense

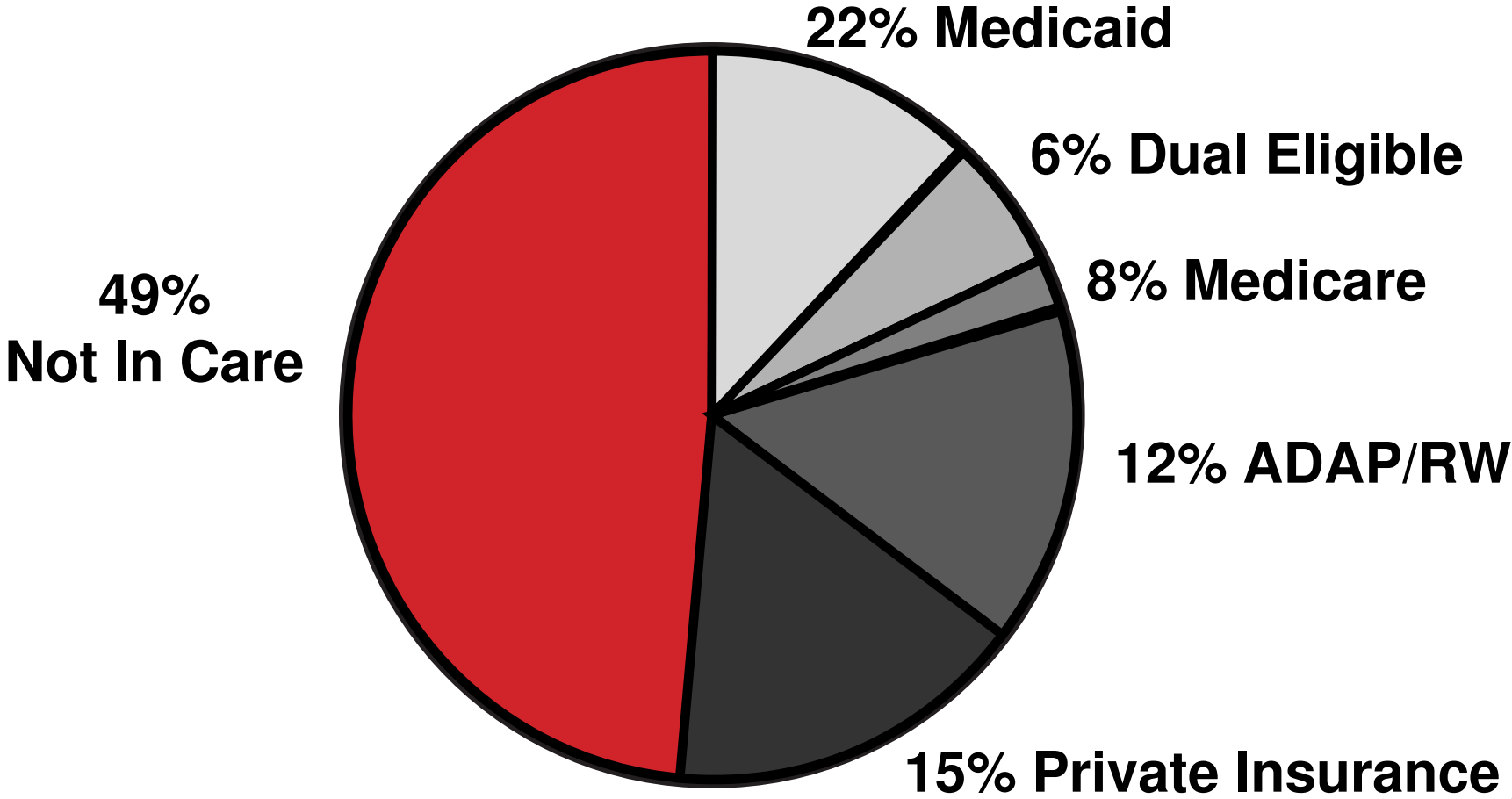
- Establishing routine testing will take time, vast new resources, and dedicated outreach to clinicians and healthcare settings
- First priority should go to settings likely to have the highest yield
- E.D. settings and community clinics have documented 1.3% - 2.3% yield

Implementation Strategies Must Address Logistical and Capacity Challenges

Examples:

- Cook County Hospital ER sees over 200,000 patients each year. Testing each for HIV would cost more than \$3 million for test kits alone, not including staff
- Chicago Department of Public Health STD clinics report having an estimated 200 turn-aways a month
- Heart of Illinois AIDS Clinic in Peoria tested 36% more HIV+ people in the first 9 months of 2006 than in all of 2005 — clinic officials report no capacity to provide more services

Healthcare Access for 1 Million HIV+ Americans



AFC's Five-Year HIV Testing Expansion Proposal

- Development of new models and standardized tools
- Provider training and technical assistance
- Testing-expansion grants for healthcare settings serving large numbers of uninsured
- Requesting **\$2M increase** in state funding to administer 45,000+ tests diagnosing 900-1100 new cases per year and implement expanded testing

Illinois Legislation recently sent to
Governor Blagojevich

Senate Bill 929 (Rep. Ford/Sen. Ronen)

- **Pre-test information:** requires healthcare providers to deliver brief pre-test information to patients about HIV and the meaning of test results. Patients must have the opportunity to ask questions.
- **HIV testing may be done only with the knowledge and informed consent of the person being tested:** the proposal preserves the requirement that patients give their informed consent before they receive HIV testing.
- **A patient's verbal consent is sufficient to order an HIV test:** Departing from current law, patients may give their informed consent to testing in writing or verbally. In either case, the consent must be documented by the healthcare provider.

Illinois 2007 Testing Legislation

continued

- **A separate HIV testing consent form is not required:** Doctors may ask patients to sign consent forms that include both general medical care and HIV testing, although doctors who wish to continue to use separate forms which incorporate pre-test information and written consent are free to do so.
- **Opt-out testing allowed:** Doctors must tell patients in writing or verbally that they will be tested for HIV unless they refuse. Doctors must tell patients how to refuse testing and may not force patients to receive HIV testing.
- **HIV-positive results delivered in person:** Consistent with CDC recommendations, but not previously required by Illinois law, doctors must give HIV+ results in person.
- **Counseling and healthcare referrals required for newly diagnosed patients:** Consistent with CDC recommendations, but not previously required by Illinois law, doctors must refer individuals who test HIV-positive to counseling and medical services to ensure they receive the follow-up assistance needed.

Illinois 2007 Testing Legislation

continued

- **Penalties for violating the AIDS Confidentiality Act:** The proposal doubles the minimum financial damages individuals may collect for violations of the AIDS Confidentiality Act, including testing without informed consent. A reckless or intentional violation of the patient protections of the Act will now carry a minimum civil damages award of \$10,000.
- **Focus on implementation:** The proposal requires IDPH to lead important statewide implementation activities, including clinician training, technical assistance, and development of standards for the delivery of HIV test results.

Reaction

"No one should be tested for HIV without their understanding and consent. This compromise ensures that patients, not their doctors, will continue to make their own decisions about HIV testing."

--Ann Hilton Fisher, AIDS Legal Council of Chicago

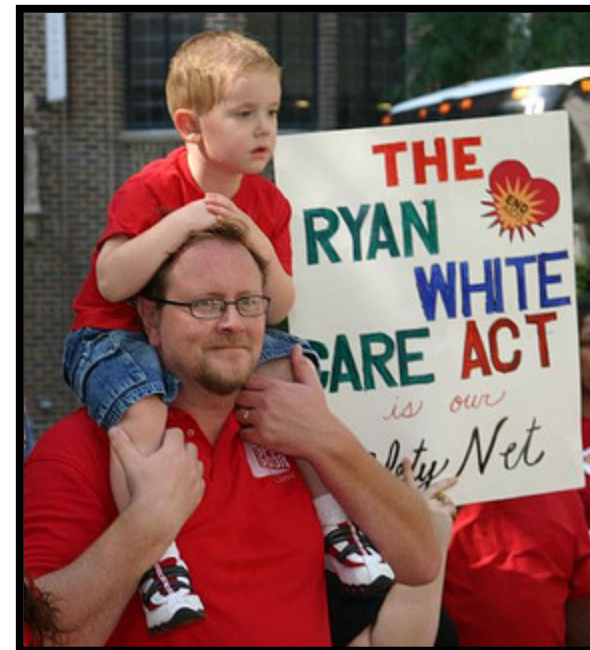
Key questions and considerations

Key questions

How to expand testing with flat/decreasing funding & low reimbursement for HIV care?

How to change the knowledge and behaviors on clinicians not versed in HIV testing?

How to reach people disenfranchised from the healthcare system?



David Ernesto Munar
AIDS Foundation of Chicago
www.aidschicago.org

Testing page:
www.aidschicago.org/advocacy/testing.php