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## ***TO TEST OR NOT TO TEST***

### ***Why healthcare providers don't routinely test youth for HIV***

#### **A Qualitative Research Study on HIV Testing in the Bronx**

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# CONTENTS

INTRODUCTION .....	1
SUMMARY OF KEY FINDINGS/RECOMMENDATIONS .....	6
CHAPTER ONE: Factors Influencing HIV Testing Practices .....	11
CHAPTER TWO: Obstacles To HIV Testing .....	21
CHAPTER THREE: Information and Resource Needs .....	30

## INTRODUCTION

The U.S. Centers for Disease Control and Prevention (CDC) estimates that at least half of all new HIV infections occur in young people between the ages of 13 and 24<sup>1</sup>—as many as 20,000 new HIV-positive youth each year,<sup>2</sup> and the majority of them are infected sexually.

The HIV epidemic continues to disproportionately impact teens and adolescents in urban communities of color. Youth in the Bronx are highly vulnerable to HIV infection, as the Bronx has the second-highest cumulative AIDS rate of all boroughs in New York City. The Bronx, with 16% of New York City's population, accounts for 17% of all AIDS cases among men, 27% of cases among women and 28% of cases among children.

In the Bronx, 1,567 new AIDS cases were reported in 1999 (26% of the New York City total) and 1,228 new cases in 2000 (21%). Data for 2001 are incomplete. The Bronx has some of the highest cumulative levels of people living with AIDS in New York City,<sup>3</sup> with Fordham/Bronx Park and Crotona/Tremont among eight New York City neighborhoods with the highest incidence of AIDS.<sup>4</sup> In 2000, 1,688 young people (ages 13 to 24) were reported with AIDS in the United States, bringing the cumulative total to 31,293 cases of AIDS in this age group, the majority of whom became infected with HIV in their teens.

Adolescents everywhere are at high risk for HIV as well as other sexually transmitted diseases (STDs) for a multitude of reasons. Common factors that leave them vulnerable include the fact that, in the heat of the moment, many sexually active teens fail to adequately protect themselves; many are unaware of their risk; and, in contrast to children and older adults, adolescents are less likely to have regular or routine healthcare.<sup>5</sup> While all adolescents grapple with these factors, Bronx teens are at increased risk of running into the virus because of the high prevalence of HIV in their communities.

Yet, the CDC estimates that at least one third of all HIV-infected people have not been tested and are unaware of their infections.<sup>6</sup> These numbers may be higher in adolescents. In a New York City study of young men who have sex with men, 80% of those who were HIV-positive were unaware of their infection.<sup>7</sup>

Recognizing that early awareness of HIV status is critical to HIV prevention and treatment, the American Academy of Pediatrics and public and private agencies across the country have made concerted and ongoing efforts, including innovative social

marketing programs, to increase access to and encourage HIV testing among teens.<sup>8,9</sup> But it is the providers who see sexually active adolescents who are in a unique and key position to identify undiagnosed HIV-positive youth and link them to care.

This report presents the findings of a qualitative research study designed to investigate the motivators and barriers that impact healthcare providers' HIV testing of adolescents. It was conducted by the Adolescent AIDS Program, Children's Hospital at Montefiore, in the Bronx, New York, in collaboration with Michaels Opinion Research, Inc., and was funded in part by HRSA/HAB and the New York/Virgin Islands AIDS Education and Training Center (H4A HA0004).

Through a series of in-depth, confidential interviews with 55 Bronx-based healthcare providers and administrators treating adolescents in a variety of public and private settings, the research examines current attitudes, experiences and approaches to HIV testing:

- What professional judgments and criteria do providers use to determine which teens are encouraged to be HIV tested?
- What barriers do providers confront?
- What facilitates and deters HIV counseling and testing of teens?
- What personal and clinical issues do providers think contribute to teens' willingness or refusal to accept HIV counseling and testing?

While the research focuses geographically on the Bronx, a New York City borough with a high rate of HIV, AIDS and STDs, we believe the findings presented here have implications nationally and will build on a growing body of academic recommendations and research with application in communities throughout the country.

This research represents Phase I of an initiative sponsored by the Adolescent AIDS Program (AAP), Children's Hospital at Montefiore, to investigate and recommend changes to the HIV testing practices of providers who treat adolescents. Using the findings of this research, the AAP will develop and launch a series of provider training programs in the Bronx and will design adolescent-friendly HIV counseling and testing materials during Phase II of this initiative.

## Methodology and Profile of Participants

It is important to note that the findings of qualitative research such as this are not intended to provide statistical incidence data. The interviews conducted for this research are highly qualitative by design and elicit information about factors that may influence or be indicative of attitudes or behavior. It cannot be assumed, however, that the information revealed is either definitive or representative.

To satisfy the research objectives, and to encourage a high degree of candor from participants, this study employed a series of confidential, in-depth telephone interviews. A total of 55 interviews, each lasting approximately 60 minutes, were conducted in January and February, 2002, with healthcare professionals in the Bronx.

Nearly 300 potential participants, targeted from particularly high-risk neighborhoods in the Bronx, were initially contacted by letter from the Adolescent AIDS Program, Children's Hospital at Montefiore. They included providers and administrators in a variety of healthcare settings, including private practice, hospital-affiliated medical practices, school-, hospital- and community-based clinics, women's health services, emergency rooms and foster care agencies, as well as providers at substance abuse, juvenile justice, mobile outreach and STD testing centers.

- Participants in the telephone interviews were screened to ensure that all were healthcare professionals who serve Bronx adolescents from age 13 to 19 and, in a few cases, as old as 24, either as their primary clinical focus or, more typically, as part of a broader patient base. Among the 55 interviewed, 26 care for both children and adolescents, eight treat only teenagers, 17 have patients of all ages and four treat patients age 18 and older.

Healthcare providers participating in this research represented a total of 43 different clinics, institutions and practices in the Bronx. Of those interviewed:

- 12 provide services to teens in various hospital-affiliated medical practices
- 11 in school-based clinics
- 11 in free-standing community or hospital-affiliated clinics
- 6 with adolescents in foster care agencies
- 4 in private practice
- 4 at in-hospital clinics
- 3 in hospital emergency rooms
- 2 at STD testing centers
- 1 at a substance abuse treatment center
- 1 at a mobile outreach van

Interviews were conducted with physicians and administrators, as well as with other healthcare providers who have intimate contact with adolescents, including:

- 12 pediatricians
- 8 advanced practice nurses, nurses and physicians' assistants
- 8 clinic or foster care administrators
- 7 medical or nursing directors
- 6 family or general practice physicians
- 5 adolescent medicine specialists
- 3 emergency medicine practitioners
- 2 internists
- 2 obstetrician/gynecologists
- 2 clinical social workers

The number of adolescents for whom these healthcare providers and administrators provided services in 2001 ranged from less than 100 to well over a thousand. Although 9 participants were unable to estimate the number of teens they served last year:

- 18 providers treated 1,000 or more adolescents last year
- 9 treated between 400 and 900
- 12 treated between 100 and 400 adolescent patients
- 7, most often those in smaller foster care agencies, treated less than 100 teens last year.

The vast majority of healthcare providers and administrators interviewed (37) had not had an adolescent test HIV-positive in their practices or at their facilities in 2001. Nine providers were not able to detail HIV test results among adolescents, but of other professionals interviewed:

- 5 had one or two new HIV-positive adolescents in 2001
- 3 estimated having five new HIV-positive adolescents in 2001
- 1 treated 10 adolescents testing HIV-positive in 2001

Interviews were conducted following a structured discussion guide that allowed researchers the discretion to probe for deeper and more detailed information as it occurred in the context of the discussion.

The research was designed by Dr. Donna Futterman of the Adolescent AIDS Program, Children's Hospital at Montefiore in the Bronx, New York, in collaboration with Maureen Michaels, president of Michaels Opinion Research, Inc., a New York City-based public opinion research firm.

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NOTES:

<sup>1</sup> Centers for Disease Control and Prevention HIV/AIDS Fact Sheet: *Young People at Risk: HIV/AIDS Among America's Youth*. Updated March 11, 2002.

<sup>2</sup> Centers for Disease Control and Prevention HIV/AIDS Update: *A Glance at the HIV Epidemic*. Updated May 2001. Available online at [www.cdc.gov/nchstp/od/news/At-a-glance.pdf](http://www.cdc.gov/nchstp/od/news/At-a-glance.pdf)

<sup>3</sup> New York State Department of Health AIDS Institute (2000), *New York State AIDS Institute Community Needs Index*, Albany, NY: New York State Department of Health.

<sup>4</sup> Office of AIDS Surveillance (1999) *AIDS in Boroughs and Neighborhoods of New York City*, v. 3, New York: New York City Department of Health.

<sup>5</sup> Department of Health and Human Services: *CDC Fact Book 2000/2001*. September 2000.

<sup>6</sup> Bozette SA, Berry SH, Duan N, et al. for the HIV Cost and Services Utilization Study Consortia (HCSUS). The care of HIV-infected adults in the United States. *N Engl J Med* 1998;339:1897-904.

<sup>7</sup> Valleroy LA, MacKellar DA, Karon JM et al. for the Young Men's Survey Study Group. "HIV Prevalence and associated risks in young men who have sex with men." *JAMA* 2000; 284:198-204.

<sup>8</sup> American Academy of Pediatrics: "Adolescents and Human Immunodeficiency Virus Infection: The Role of the Pediatrician in Prevention and Intervention (RE0031)" *Pediatrics*, Volume 107, Number 1, January 2001, pp 188-190.

<sup>9</sup> Futterman DC, Peralta L, Rudy B et al. "The ACCESS Project: Social Marketing to Promote HIV Testing to Adolescents, Methods and First Year Results From a Six City Campaign." *Journal of Adolescent Health* 2001; 29S:19-29.

## SUMMARY OF KEY FINDINGS/ RECOMMENDATIONS

This research was designed to reveal factors that both hinder and motivate providers to recommend HIV testing to adolescents. The issues identified by providers who participated in this research will serve to inform an initiative being sponsored by the Adolescent AIDS Program (AAP), Children's Hospital at Montefiore, that aims to improve the HIV testing practices of providers who treat adolescents.

The central goal of the initiative is to make HIV testing a routine part of healthcare for all sexually active youth. To achieve this objective, the initiative intends to develop educational materials and a series of provider training programs in the Bronx, using information and addressing concerns that were gleaned from this research.

While this research focuses geographically on the Bronx, the findings have implications nationally. Materials produced by the AAP will be designed to have application in communities throughout the country.

Key findings of this research, and AAP's recommendations and response, include:

- ***FINDING: Although the American Academy of Pediatrics recommends that HIV testing be encouraged for all sexually active adolescents, and the CDC recommends that HIV testing be routinely recommended in communities where HIV prevalence is 1% or greater, the research strongly indicates that most providers only recommend testing if an adolescent self-reports high risk behavior or presents clear symptoms of a sexually transmitted disease.***

Among the providers interviewed, most have not diagnosed an adolescent case of HIV, and while they recognize that HIV infections are higher in the Bronx than in other parts of the country, there were generally no strong assumptions or suggestions from providers that adolescents, particularly young adolescents, are at high risk for HIV.

Notably, providers themselves frequently recommended that there be greater efforts to heighten their awareness and "help them remember" the importance of HIV testing among adolescents.

Moreover, a key finding of this research is the general lack of consistency among Bronx providers in the manner in which they approach gathering information to assess adolescent risk for exposure to HIV. Indeed, only a few providers indicate that they begin asking patients at age 12 about sexual activity, while most other providers reveal that such information is not sought until a physician has reason to suspect a patient is sexually active, a patient self-reports or volunteers being sexually active, or there is evidence of an STD.

- ***RECOMMENDATION: As an initial step toward increasing HIV testing rates, local providers need to have better-compiled and more concise information that is distributed on a regular basis in a format that is designed for quick reading and use, as well as clarity and currency on issues and medical recommendations.***

To fill this need the Adolescent AIDS Program plans to produce a set of materials that will both inform and motivate providers to increase the level of HIV testing among adolescents.

These communications materials will provide:

- Epidemiological evidence to Bronx providers that outlines the risk of HIV infection among adolescents in the US and more specifically, in the Bronx. The information will be designed to provide current and local data that both demonstrates and heightens the perceived need for and benefits of routine HIV testing among sexually active adolescents.
- Straightforward facts about HIV testing and testing recommendations that are specific to their adolescent patient populations, including the age at which patients should be questioned about sexual activity and cultural competency guides for addressing sexual orientation.
- The adolescent HIV testing recommendations that have been written by key medical groups such as the American Academy of Pediatrics.

- ***FINDING: The research reveals that providers are using multiple methods and approaches to assess adolescents' risk for HIV and that these methods range from highly subjective to deficient to non-existent in some cases. Often, the result is that incomplete and inaccurate information from youth is being used to determine HIV risk.***

Providers described a wide variety of methods that are being utilized to assess an adolescents' potential exposure to HIV. Some providers readily admit that they rely on visual observations (body piercing, tattoos, STD symptoms) and verbal cues from patients to determine risk factors such as sexual activity, drug use or sexual orientation.

Others say they verbally (and privately) ask a set of screening questions to determine sexual activity and other HIV risk behaviors, while some distribute "screening questionnaires" to be completed by adolescents. The research also indicates the strong possibility that the younger the patient, the greater the likelihood that printed risk screening questionnaires are not distributed or if they are distributed, that they may not contain truthful information because they may be completed by patients' parents.

Moreover, the research finds that providers do not verbally ask or distribute for completion a standard set of screening questions and that many screening efforts do not probe adolescents about sexual orientation.

- ***RECOMMENDATION: In response to this finding, the AAP will design, distribute to Bronx providers and make available to other healthcare providers a standardized adolescent risk assessment instrument.***

This assessment tool will be culled from various leading adolescent care sources, including the Guidelines for Adolescent Prevention Services (GAPS) questionnaires devised by the American Medical Association.

- ***FINDING: The research discovered a common perception among providers that unlike other health screening tests, an HIV test involves undue time and resource burdens in order to satisfy informed consent, pre- and post-test counseling, and test result delivery guidelines and requirements.***

Providers, in some cases, said they felt “unqualified” to provide the mandated counseling, or that time constraints or institutional policies required that other trained staff be provided to conduct HIV testing and counseling.

Moreover, as evidenced by provider remarks, there appears to be some confusion about what constitutes and differentiates HIV testing *requirements* from HIV testing *guidelines*.

For example, most of the providers interviewed believe that HIV pre-test counseling is very time consuming and they also believe that they are required to deliver HIV test results to patients in-person.

Some providers, though not all, believe the benefits of delivering HIV test results to patients over the telephone outweigh the drawbacks, including having more young people being informed of their test results, more receiving prevention counseling and, overall, diminishing the burden of time and resources on understaffed inner city healthcare providers.

- ***RECOMMENDATION: For providers with limited time and resources, a streamlined adolescent HIV counseling and testing paradigm will be developed.***

HIV testing can be conducted in two ways, either strictly as a tool to screen for the HIV virus or as a more complete approach that encompasses both screening and prevention counseling. Although the AAP supports a testing protocol that encompasses both screening and prevention counseling, it also recognizes that this is not always possible and, in actual practice, not always successfully completed.

- ***FINDING: Despite increasing and alarming HIV rates in older adolescents, many providers perceive adolescents as low risk for HIV infection and still rely on an individual diagnosis of a STD to offer an HIV test. Still, STD screening practices vary, including a strong gender bias to screen young women for STDs far more often than young men.***

Despite providers' perceptions that rates are low, rates of STDs in Bronx clinics are among the highest in New York City, signaling missed opportunities for HIV and other STD screening. In addition, despite recommendations from the American Academy of Pediatrics that all sexually active adolescents be encouraged to be tested for STDs, including HIV, this recommendation is not universally known or is unevenly followed.

According to providers, sexually active young women, in the course of gynecological exams, are far more likely to be screened "routinely" for STDs than are sexually active young men. When asked why young men are not routinely tested, providers are apt to say young men resist because of fears that the test is painful.

Importantly, the presence of an STD is not the only indicator of HIV risk because HIV can exist in a patient who presents with no other STD. With providers heavily relying on an HIV screening protocol focused on STDs, with its application skewed toward young women, it's inevitable that providers will miss early diagnosis of HIV infection among adolescents.

- ***RECOMMENDATION: The AAP will design a medical education initiative that teaches providers to look beyond STDs as the key indicator that an HIV test is warranted.***

It will also design education materials and messages aimed at diminishing young men's resistance to STD testing.

- ***FINDING: Providers often recognize that increasing HIV testing of adolescents also requires specific outreach efforts and healthcare environments that are “teen friendly.”***

Several noted, for example, the need for more immediate adolescent access to trained counselors through an expansion of the number of hours those counselors are available, as well as by increasing the number of counselors who can intercept adolescents in waiting rooms and at school-based clinics.

It is also noteworthy that the vast majority of providers interviewed do not utilize current “painless” HIV testing technologies such as oral testing.

- ***RECOMMENDATION: To encourage more adolescents (especially young men) to agree to HIV and other STD testing, the AAP will supply information to providers about painless oral and urine-based testing technologies, such as OraSure and Calypte.***

## CHAPTER ONE: Factors Influencing HIV Testing Practices

Most of the Bronx healthcare providers interviewed for this research initiative report having the ability to conduct HIV testing on site at their facilities. These providers represent the full spectrum of healthcare settings targeted for this research and include private practice offices, community clinics, school clinics, outreach services and hospital-affiliated clinics.

**We don't do HIV counseling and testing in the ER.** We refer them over to the adolescent or GYN clinics.

*Physician, hospital emergency room*

**This is a small [hospital-affiliated] community clinic.** We send them to the [hospital's] HIV clinic. We pre-counsel them and then send them.

*Pediatrician, community-based clinic*

The few providers who report they do not directly offer HIV counseling and testing include those in emergency care facilities, two hospital-affiliated community health centers, a foster care agency and a private practice office. In all cases, these providers say they refer adolescent patients to other locations for HIV testing, which in most cases are affiliated with their practices or located within the same medical complex.

Among factors influencing adolescent HIV testing practices that were explored in these interviews, healthcare providers reveal that:

- The cost of HIV testing is not generally perceived to present a barrier to adolescents
- Symptoms of an STD or admission of risky sexual behavior are key triggers in provider decisions to offer HIV testing to adolescents.
- Providers rely on adolescents' self-reported sexual activity to determine the need for STD and HIV testing
- Questions about sexual orientation are not regularly asked of adolescents in assessing risk
- Providers are divided over perceptions of adolescent truthfulness in responding to risk screening questions
- STD testing is not routine for sexually active young men, yet the presence of an STD plays a strong role in prompting HIV test recommendations
- Assurances of confidentiality and the recommendation to take the test by a provider are key in encouraging adolescents to have an HIV test
- Overall, most providers lack direct experience with HIV positive youth

**It's a rarity to have a teen who is HIV positive without strong high-risk factors.** The adolescent U.S. Public Health Service recommendation is to focus time on what can be most productive.

*Nurse practitioner, school-based clinic*

**[Judgments are made about HIV testing based on] the level of sexual activity**—with more than one partner, without protection, alcohol or drug use, because of altered behavior under those influences.

*Health coordinator, foster care agency*

**If a physician sees repeated episodes of STDs, they should test for HIV.**

*Physician, hospital-affiliated medical practice*

**I'm not sure if routine HIV testing is recommended or not.** But differentiating between who to test or not to test is not a good thing.

*Pediatrician, private practice*

## Deciding Who Gets Offered HIV Tests

Although HIV testing is widely available in the clinical and office settings of these providers, recommendations or offers of HIV testing to adolescents appear to be strongly influenced by factors relating to patients' age and healthcare providers' perceptions of their sexual activity, drug use or sexual orientation.

- ***HIV testing is by no means considered routine for adolescents. Overall, the prerequisite conditions or standards being used by Bronx providers to determine which adolescents are tested for HIV are symptoms of an STD or admitted sexual activity that puts them at risk, such as not using condoms.***

Only a small number of the providers interviewed say they encourage HIV testing for all sexually active adolescent patients.

For many providers, sexual activity alone does not constitute "high risk," nor is it sufficient to prompt recommendations for HIV testing. More typically, providers target for HIV testing those sexually active adolescents they judge to be at "high risk," and they make those risk assessments using combinations of other factors that vary from provider to provider and from patient to patient. In their own words, different providers say, for example, that they recommend HIV testing to sexually active adolescents if:

- *They have a history of STD tests, IV drug use or if they are pregnant.*
- *Patients say they don't use condoms, test positive for an STD or have multiple partners.*
- *They report a relative with HIV or AIDS, illegal drug use, IV or not, a history of STDs or TB, reported multiple partners.*
- *They are "promiscuous" and admit unprotected sex.*
- *They have been tattooed or had body piercing.*
- *Appear to be gay.*

**Once they become sexually active, we'll discuss at age 12.** They get the STD talk every six months and are asked if they want to be tested for STDs and HIV.

*Medical director, foster care agency*

**They first have to fill out a registration form and get it signed by their mother.** Some will come in then and say they're aren't sexually active, but the next time you see them, they'll be more honest.

*Nurse, school-based clinic*

**I ask, "How many partners have you had?"** I don't go into details about sexual orientation. I guess I should be asking about types of sex and sexual orientation.

*General practitioner, private practice*

**All the questions are on the form, but I always ask, too.** They fill out the form with parents, so they're not forthcoming. But I ask when I'm alone with them later.

*Physician, community-based clinic*

- ***Overall, healthcare providers at these Bronx facilities frequently rely on adolescents' self-reported sexual activity to determine who they will test for STDs or offer HIV testing.***

The age at which questions about sexual activity are posed to adolescents varies widely. Several physicians indicate they begin asking sexual behavior questions as early as age 12. Others more routinely ask "teenagers," or comment that their observations about an adolescent's physical and emotional maturity determines when they begin asking questions about sexual activity.

Providers report that screening questions about sexual and other risk behaviors are typically asked in the privacy of the examination room, even when adolescents have been given medical history or intake forms to complete.

As part of the routine physical and history, some providers say they ask adolescents directly whether they are sexually active, about how many partners they've had, what types of sex they engage in, their use of condoms and birth control and whether they've used IV drugs. It is the answers to these questions that providers use to counsel behavioral change, make professional judgments about risk for HIV and, as noted earlier, ultimately determine who is offered HIV testing.

- ***At least a third of the providers interviewed admit that questions about sexual orientation are not among the questions regularly asked of adolescents.***

Those who do ask about sexual orientation most often pose the question in the most neutral terms possible: "Have you ever had sex with men, women or both?" Among those not asking about sexual orientation, one physician confessed that he had been "counseled" to ask, while another claimed simply, "I can tell" if a young person is gay or heterosexual.

- ***Few providers require that adolescents complete risk-screening questionnaires solely on their own.***

However, a few healthcare professionals say they have adolescents review these forms before asking the questions during the course of an examination. As one provider remarked: "They're more straightforward verbally. The forms get confusing to them."

**Earlier in my practice, most denied sexual activity.** Society is changing. Now, they're much more honest, but there is no way to verify what they say.

*Pediatrician, private practice*

**Ninety-five percent are upfront about sexuality.** They don't deny it. It is rare to have that situation.

*Physician, hospital-based clinic*

**They say they are using birth control and condoms, but they aren't.** In practice, safe sex isn't within the realm of what they're thinking about. Sex is a social experience for them.

*Internist, hospital-affiliated medical practice*

Several providers note specifically that they use the American Medical Association's Guidelines for Adolescent Preventive Services (GAPS) questionnaires to make risk assessments of the young people they treat.

In addition, physicians and administrators at child welfare and foster care agencies report that nurses and social workers consistently administer formal HIV risk-screening assessment questionnaires to adolescents every six months as required by New York City's Administration for Children's Services.

### Provider Perceptions of Youth

Importantly, providers express widely-varying opinions about young people's forthrightness in responding to questions about their sexual activities or drug use.

- *A majority of those interviewed believe that most of the young people they see as patients are generally truthful about sexual activities and other behaviors that would put them at risk for STDs and HIV.*

Many of the professionals interviewed, including a few who expressed some surprise, report that the vast majority of teens they see are very open about their sexuality.

In strong contrast, however, other physicians and health professionals say that many of the young people they see are very guarded about their sexual behaviors. They frequently assert that cultural and family mores make these adolescents very reluctant to admit to any sexual activity. They worry about breaches of confidentiality to their parents and they are often less than truthful about their use of condoms and birth control.

Physicians also acknowledge the need to rely on adolescents' "body language" to evaluate the veracity of responses to risk assessment questions.

**If I suspect they're sexually active, I'll do a physical and do STD tests.** I'll present the evidence of what happened later.

*Family practitioner, community-based clinic*

**With teens in foster care we need more time than with any other group.** They need individual attention to develop relationships and to keep those relationships going.

*Executive-director, foster care agency*

**They are in foster care. They have had sexual and physical abuse.** They are less willing to trust adults. Having sex with many partners gives them status and they want to be loved.

*Pediatrician, community-based clinic*

In several interviews, healthcare professionals described encounters with young patients who insisted they were not sexually active while having clear indications of an STD. In reaction, these professionals say they typically told teens simply that they would “test them for everything.”

- ***The unique circumstances and needs of young people in foster care are given special consideration by healthcare providers who interact with these adolescents.***

It is important to note that professionals who treat or administer to the needs of adolescents in child welfare and foster care agencies report that these young people are not only at high risk for STDs and HIV, but are especially distrusting of adults and not forthcoming about their behaviors. According to providers, they have significantly higher rates of STDs because their “need for affection and love” often precipitates “unprotected sex and sex with multiple partners.”

## STD Testing Prompts HIV Test Recommendations

As previously noted, the decision to conduct routine screening tests for STDs is nearly always a function of an adolescent's admitted risky sexual activity or, when apparent to the physician, the presence of STD symptoms. According to providers, young women are being tested for STDs at significantly higher rates than young men because they are more likely to receive healthcare services in general and gynecological care, specifically, when they seek birth control.

- ***Providers say sexually active young women are more routinely screened for STDs “because it’s standard protocol,” but not so for young men.***

A few providers also report that young women are not always fully informed that STD tests are being conducted. As one physician explained: “We simply tell them we’re going to do a Pap smear and some routine tests during the course of a gynecological exam. They might resist or become anxious if we tell them about testing for STDs.”

When asked why young men are not routinely tested for STDs when they are seen for other health issues, the consistent response among physicians is that “They don’t like it...they’ve heard about the long stick.” According to providers, with the exception of blood tests for syphilis, young men are usually only tested for STDs after a partner has been diagnosed or because they are experiencing symptoms of an STD themselves.

Notably, most providers who test adolescents for STDs, also treat them for these conditions as well. A few, however, indicate that when an adolescent tests positive for an STD, they are referred elsewhere for treatment, with young women usually being directed to a gynecologist.

According to most providers, diagnosis of an STD mandates a strong recommendation for HIV testing. And counselors and social workers are said to play a pivotal role in allaying the fears of nervous youth.

**For GYN exams, I do STD tests because it follows.** For males, I test them if they ask or if they're symptomatic. If they're asymptomatic, and if there's a question, it's just urinalysis and syphilis serology.

*Pediatrician, community-based clinic*

**We're better at screening girls than boys.** It's my bias, as well, [not to test for STDs] if a boy is not symptomatic. The boys are more resistant to the penis swab.

*Nurse practitioner, school-based clinic*

**In our school clinic, kids are more truthful because they don't come with their parents.** The confidentiality is explained to teens and that New York State guarantees them a right to treatment.

*Physician, school-based clinic*

**They come in with their mothers and the mothers want information that they're not entitled to.** It inhibits the teen from being open. The doctors will make every effort to make teens comfortable, but the parents want to be there. This happens frequently. . . It depends a lot on how long they've been in this country. They want to know every detail.

*Administrator, hospital-affiliated medical practice*

**Teens refusing STD tests doesn't happen often.** If they resist, there's not much more I can do except try to establish rapport. It's only a question of how much time you have to spend with them.

*General practitioner, private practice*

## Importance of Confidentiality and Role of Parents

Most health professionals recognize that, as a rule, adolescents are far more likely to be open about their sexual behaviors when their parents are not present.

With very few exceptions, healthcare providers say they insist that parents leave the room before adolescents are questioned about their sexual activities. In school-based settings, particularly, providers often note that "parents don't even know they're here."

Several physicians stress how problematic the presence of parents can be, noting that there have been strong parental objections, particularly from new Latin American and South Asia immigrants, when they are asked to leave the examination room.

Rarely, some providers admit they ask adolescents in the presence of their parents if they would prefer for them to stay or leave. Much more typically, however, providers are persistent in requiring privacy for their adolescent patients, even when parents show "great displeasure." One emergency room physician, for example, remarked that parental "resistance starts strong, but they let me do it when they realize I won't see their children otherwise."

The role of parents is not always cast in a negative light, however. A few providers estimate that the mothers of about half their adolescent patients are aware that their children are sexually active. Several providers also report that they often strongly encourage adolescents to "tell at least one" of their parents that they are sexually active and have been tested for STDs and HIV.

## Provider Impact in Encouraging Adolescents to Have HIV Tests

Providers offer conflicting reports of adolescent reactions to their suggestions for STD and HIV testing. Generally, providers report that most, but not all, sexually active adolescents do not resist being tested for STDs or HIV if it's recommended to them. Nevertheless, nearly all note that they have encountered adolescents who strongly resist suggestions that they be tested, and as many as three-in-ten providers see HIV testing as a delicate subject to raise with adolescents.

**If we suspect an STD and want them to be tested for HIV as well and they resist, we refer them to a social worker to work with them.**

*Administrator, community-based clinic*

**We don't accept private insurance.** About 25 percent are Medicaid. If [teens] don't have the money, none are refused, but they're encouraged to pay something.

*Administrator, STD testing center*

For adolescents who do resist, many providers, particularly those who diagnosed HIV in an adolescent in 2001, stress the value of having on-site counselors and social workers who can communicate the importance of STD and HIV testing.

## **HIV Testing Methods and Cost**

The vast majority of providers participating in this survey administer the standard HIV blood test. Only one in 10, most often those in school-based clinics, say they provide adolescent patients with the option of an oral HIV test.

- ***Reported fees for HIV testing varies from facility to facility, from nothing to as much as \$30, with providers frequently noting that there are sliding scales for adolescents.***

Often, however, physicians and other health professionals interviewed are not at all well informed about HIV testing fees or how they are billed at their facilities.

Providers at school clinics and foster care agencies are those most likely to say there are no fees involved when they offer HIV testing to youth, while others indicate that HIV testing is included with office visit charges.

If adolescent patients are covered by Medicaid, there are reportedly no associated fees for HIV testing. Nevertheless, one health professional did express concern that adolescents covered by managed care and other forms of private health insurance may be deterred from HIV testing because of fears that the insurance claim process may alert parents that they had been HIV tested.

Importantly, at no time while discussing adolescent HIV-testing issues did providers perceive cost to be a significant deterrent to young people being HIV tested in the Bronx. As one physician noted, "There are many places where young people can be tested for free if they want it."

**I've heard that the HIV population has grown among teens, but I have not seen any [statistics].**

*Nurse practitioner, school-based clinic*

## **Direct Experiences With HIV Positive Youth**

Among the providers interviewed, there is strong recognition that the Bronx communities they serve may be at higher risk for HIV than other communities within New York City or State. Nevertheless, most of the professionals interviewed for this research study did not test an adolescent that was HIV-positive in 2001, even though more than a third say 5% or more of their adolescent patients tested positive for an STD in the same period.

- ***Notably, most of the professionals who did see adolescents testing HIV-positive in 2001 are associated with institutions focused on or reaching out to high risk youth. These included:***

- An administrator at a women's health agency with a street outreach van
- The director of health services at a foster care agency
- A physician's assistant at a substance abuse clinic
- Two physicians and an administrator at community-based clinics, and
- A physician at a hospital pediatric infectious disease center

Often, the newly infected HIV-positive adolescents seen by these providers are described as “older adolescents, age 18 to 20,” “the disenfranchised—out of school and in trouble with the law,” “mostly women” or “gay youth.”

One of these physicians noted that among the five new adolescent HIV cases he saw last year, “the majority were newly-arrived immigrants from West Africa who were pregnant.” And the 10 new cases of adolescent-HIV diagnosed through testing at an outreach van were described as: “Teen moms, substance abusers, but not necessarily IV drug users, or sex workers . . . with a profile similar [to adolescents with] STDs.”

Providers diagnosing HIV-positive adolescents at community-based clinics also cite the high incidence of HIV in the communities they serve, with one administrator observing that “HIV has gone over the limit and we see more [HIV] than other areas.”

Nearly without exception, providers who have recently seen adolescents testing HIV-positive strongly assert that they offer HIV tests to all sexually active adolescents. In the words of one pediatrician at a community-based clinic, “I routinely [encourage HIV tests] with all sexually active teens because I had that one patient who was HIV positive.”

Additionally, providers who have tested HIV-positive adolescents often note that they are making specific efforts to encourage higher levels of HIV testing among adolescents, including, for example:

- Using a staff HIV clinician-specialist to train other physicians
- Holding regular team meetings to discuss HIV testing requirements
- Providing HIV tests “on the spot,” without delay
- Developing a written policy that all adolescents are to be considered at high risk for HIV and offered testing
- Presenting HIV testing to adolescents as part of a “package” of routine tests performed for good, general healthcare

Among these Bronx-based providers, the research does find a direct correlation between high adolescent STD rates and the incidence of HIV-positive tests in young people. Fully two-thirds of those who had an adolescent test positive for HIV in 2001 report STD rates above 10% among the young people being treated at their facilities.

Importantly, providers who diagnosed an adolescent with HIV in 2001 are far more likely to be informed about the rates of STDs among the adolescents served by their facilities. They are also more apt to believe that the incidence of STDs is increasing among their adolescent patients.

Bronx providers who did not diagnose an adolescent with HIV in 2001 are mainly providers whose practices focus on pediatrics, adolescent and family medicine. More than half say at least 2% of their young patients tested positive for an STD in 2001 and only one in 10 report *no* cases of STDs among their adolescent patients.

- *Yet, even a high incidence of STDs among young people being seen in a healthcare facility or practice does not necessarily predict that HIV testing will be routinely offered to all adolescents.*

Indeed, many of the providers who report that the incidence of STDs among their adolescent patients is over 5% still maintain that, on a case-by-case basis, self-reported sexual activity or the diagnosis of an STD is used to determine when HIV testing is recommended to an adolescent.

## CHAPTER TWO: Obstacles to HIV Testing

While most of the healthcare providers interviewed for this research study report having the capability of conducting on-site HIV tests—they regularly draw blood from their adolescent patients for any number of reasons—HIV testing of adolescents is not routine, even when they acknowledge being sexually active.

Indeed, providers consistently report that their decisions to offer or recommend HIV testing are the product of professional judgments about whether an HIV test is necessary or prudent. And while practitioners appear to use similar sets of factors to make those judgments, such as symptoms of, or testing positive for, an STD, it is adolescents, themselves, who are the ultimate decision-makers regarding where, when and if they are HIV tested.

But providers in this study are sharply divided in their experiences and perceptions of adolescent acceptance or rejection of HIV testing. As subsequent findings reveal, some providers perceive, or assume, that teen attitudes toward HIV will be a significant barrier inhibiting testing when it is offered. Others dismiss widespread adolescent refusal or fear of HIV testing as a myth.

In addition to their views on young people's reactions to being HIV tested, healthcare providers also described other key barriers to increased HIV testing among adolescents. Specifically:

- Adolescent confidentiality concerns
- A lack of institutional policies actively encouraging HIV testing of adolescents
- Mandated pre-test counseling
- Time barriers in clinical settings
- Post-test notification and counseling
- Lack of physician training
- Lack of outreach to adolescents, especially those most at risk

**With some young people you must handle the subject of HIV with care . . .** They've seen horrible deaths. Other kids are matter-of-fact about being tested. In the past five years, I've only had 12 kids who refused testing.

*Clinical social worker, school-based clinic*

**[HIV testing] is a very delicate subject with teens.** Some are not well-informed, but they are aware of discrimination by society.

*OB/GYN, hospital-affiliated medical practice*

**Most teens say, "Oh, test me, it's good to know."** One girl gets tested even without risky behavior. Everyone else being tested for STDs says, "test me for everything." These kids are not afraid.

*Nurse, school-based clinic*

**If they ask for [an HIV test], it is given to them.** If they don't, we offer it. It's very straightforward.

*Physician, STD testing center*

## Adolescent Reactions To Being HIV Tested

One area that was specifically investigated in this research as a potential issue inhibiting higher levels of HIV testing is adolescent resistance. Other research studies with young adults and teens have indicated that HIV testing touches a multitude of emotional issues with young people and often intensifies insecurities relating to self-worth, relationships with others and even life itself.

Understandably, the providers interviewed for this research study seem keenly sensitive to the issues that come into play for young people when HIV testing is recommended to them, including their fears of dying, of being stigmatized and of being rejected by peers, lovers and family members.

- ***Yet, the research finds sharply conflicting views among providers over the degree to which young people will agree to be HIV tested.***

On one side, several Bronx providers believe that one of the major reasons adolescents are not HIV tested at higher levels is that they refuse testing when it is offered because of their fears of the consequences of HIV and AIDS.

At the same time, it is the experience of other Bronx providers that even though young people are uncomfortable with the prospect of an HIV test, they rarely resist the test if it's offered by a healthcare professional or trained counselor who stresses the health benefits and confidentiality of testing. This attitude is particularly shared by health professionals who diagnosed an adolescent with HIV in 2001.

It is also important to note that adolescents who seek services at reproductive health clinics are often choosing these and other "walk-in" facilities for the very purpose of being HIV tested. One provider, in particular, stressed that "word of mouth about good clinics" has a strong influence on young people's willingness to be HIV tested. Moreover, young people who ask providers for HIV tests typically have concerns about potential exposure to the disease based on information about a partner or reasons relating to their sexual practices or failure to use protection.

**Having an STD is a wake up call and they want to be tested for everything.** A few have come in wanting an HIV test. Then we work backwards [to STD tests].

*Physician, school-based clinic*

**Some [adolescents] have sex education in school and they know quite a lot and are aware [of HIV].** We are in the role of reinforcing that and trying to deepen their knowledge.

*Pediatrician, community-based clinic*

**Usually, if you're tactful and don't sound judgmental, it's not a problem getting an adolescent to be HIV tested.**

*Physician, community-based clinic*

- ***According to providers, adolescents are more likely to agree to be HIV tested if they are diagnosed with an STD.***

Providers report that adolescents' concerns about possible exposure to HIV are heightened when they are diagnosed with an STD. Generally, providers contend that although young people fear the consequences of HIV and AIDS, most are motivated to be HIV tested when they contract STDs. Providers attribute this willingness and, in some cases even, insistence on HIV testing to several factors: general adolescent awareness through school and the media of HIV risk and the benefits of testing, as well as to increasing acceptance of testing among their peers.

However, several providers have had young patients who still resist HIV testing, even when diagnosed with an STD because of their overwhelming fears of the disease and its social consequences. As previously noted, counselors become especially important in guiding these teens to change their minds about an HIV test.

- ***Several providers report that adolescents' reactions to being tested for both STDs and HIV are often related to the comfort level of physicians who broach the subject with them.***

Numerous providers in these interviews stress the need for sensitivity when recommending any kind of an STD test, including HIV, to adolescents. They also indicate that providers must assume the responsibility of creating the atmosphere and bonds of "trust" with young people in general and, especially, with those in foster care.

## **Concerns About Confidentiality**

Adolescents' generalized anxiety about the consequences of testing HIV-positive contribute to what providers say is another significant obstacle among adolescents: their underlying concerns about confidentiality.

- ***Notably, providers who diagnosed HIV positive adolescents in 2001 are especially likely to say that confidentiality issues are a significant obstacle among young people being tested for HIV.***

**We agree to keep everything confidential.** The policy is written, but we haven't found a way to contact them without notifying parents. We plan to catch them at the next visit. We're muddling through on this issue.

*OB/GYN, community-based clinic*

**Beyond the standard patient confidentiality, I write "confidential" on the chart so a bill is not sent home.**

*Physician, hospital-based clinic*

**There was an adolescent on the in-patient floor that wanted HIV-testing.** But she refused when they told her they would tell her parents. I was confused. It doesn't need parental consent! I offered to do it myself, but at that point she decided she didn't want it done.

*Physician, hospital-based clinic*

**There are not really any [hospital] guidelines.** Some doctors are just uncomfortable and there are too many forms, additional forms from other departments that are not state required.

*Physician, hospital-based clinic*

They report that adolescents who are uncomfortable at the thought or suggestion of an HIV test need very strong assurances that the information will remain confidential. And in this regard, they claim, skilled and sensitive health professionals make all the difference in guiding a young person through the process of HIV testing.

Nevertheless, despite strong beliefs that confidentiality issues are a barrier to testing, many providers say they have been surprised that the new partner notification laws have not been a barrier to HIV testing among adolescents. Rather, they report, young people are far more concerned about their parents becoming aware of their sexual activity because of their decisions to be HIV tested.

Importantly, most providers interviewed say their institutions have confidentiality plans for adolescents who have been HIV tested. Nonetheless, there were several who believe their facilities require parental consent for HIV tests of minors and that this was discouraging testing at their institutions.

## **Institutional Barriers**

- ***Most of these Bronx providers, however, report that there are no policies at their institutions that discourage HIV testing of adolescents, but neither there are specific policies that encourage HIV testing of adolescents.***

Because of the complex health, emotional and social issues related to HIV and AIDS, virtually all providers participating in this research believe their institutions recognize there are important benefits to ongoing HIV education, counseling and testing of youth.

Nevertheless, nearly half of those interviewed say they are not aware of any specific policies or guidelines at their respective institutions that *encourage* HIV testing of youth. Notably, only health professionals serving adolescent populations with high rates of STDs report being "very familiar" with New York State guidelines.

**The counseling in and of itself makes it more complicated.** They have to leave and talk to someone else [the HIV test social worker]. They have to be willing to stay. I can do the counseling if I don't want to tell them they have to come back when the social worker is here.

*Family physician, community-based clinic*

**It is time consuming because of the counseling.** It all takes about 20 minutes. Sometimes I don't have time to do that, especially when there are no counselors around to do it for me. The question becomes, is it worth it for the actual prevalence of HIV?

*Physician, school-based clinic*

**There is a mentality that you need special training to do HIV testing and counseling.** That it is specialized.

*Clinical social worker, school-based clinic*

## Pre-Test Counseling a Major Concern

- *At the center of provider concerns about HIV testing procedures is pre-test counseling requirements and, to a lesser extent, the procedures involved in post-test counseling.*

Indeed, when providers are asked to identify what they believe to be the greatest barriers to HIV testing, pre-test counseling is most often mentioned.

- *Physicians consistently cite a lack of time to conduct the required pre-test counseling themselves.*

Despite the fact that physicians are permitted to give pre-test counseling without the required formal training, few report that they deliver the pre-test counseling themselves. According to physicians, the process of counseling and obtaining informed consent is “time consuming.” A waiting room filled with patients simply requires that other trained staff be provided to counsel adolescents and obtain the mandated informed consent document in advance of HIV testing.

As a practical matter, then, HIV counseling and testing is sometimes seen as “a specialized task” with providers relying on the availability of trained counselors.

- *As a result of the pre-test counseling requirements, the interaction between the adolescent and physician is disrupted.*

Many providers report that patients are typically moved from the examination room to another room at the facility to be counseled and tested. Moreover, if a qualified social worker or nurse is not available at the time an adolescent agrees to be tested, another appointment for testing is usually scheduled. Consequently, several providers report, many young people simply fail to return for the test. According to one professional, “only 40% will keep the appointment.”

**The whole [pre-test counseling] procedure is painful, but necessary, because of the seriousness of HIV.** They know HIV is different. It discourages some, but only one has refused. They usually understand.

*Physician, private practice*

**Stigma affects everything.** Teens say, "It's fatal" and "It's like AIDS and you'll die."

*Administrator, foster care agency*

- ***Nevertheless, many providers strongly stress that counseling is an extremely important dimension of the HIV testing process to ease any underlying adolescent fears and misconceptions about the disease.***

Providers express deep concerns about the emotional reactions of patients who may, in fact, test positive. Several physicians and other health professionals hold the view that without appropriate counseling and discussion about treatment advances and options available to HIV-positive patients, young people could potentially hurt themselves or others if given the news they are HIV-positive. They believe pre-test counseling affords health professionals the opportunity to assess an adolescent's understanding of the disease and their possible reactions if they test positive.

Despite strong sentiments from several providers that young people are better educated about HIV and that negative perceptions of the disease have diminished in intensity compared to a decade ago, other providers contend that adolescent fear and ignorance of HIV and AIDS continue to be barriers to testing.

## **Post-Test Notification and Counseling**

- ***A few providers also believe that "post-test" counseling is overly-complicated as well.***

In fact, many providers assume people who have been HIV tested can only receive their test results in person, at a follow-up appointment. They believe it's necessary to have a trained professional advise patients of treatment recommendations if they are positive, or to educate adolescents on safer sex and repeat testing guidelines if they are negative.

- ***The need for a patient to return for a test result presents additional challenges.***

Providers also stress that adolescents often don't return for their HIV test results because they assume that if they were positive, clinic staff would make concerted efforts to contact them. In practice, teens and adolescents are correct in their assumptions. Providers report that while they will not relent on locating a teen who tests positive for HIV, they only make "three or four" attempts to reach teens who test negative.

**It's silly that we can't give negative results and counsel over the telephone.**

*Physician, community-based clinic*

**When I was in training, in 1981, there was no HIV.** For pre-test counseling and post-test counseling, I'm not well qualified. It's better for patients' sake to be referred elsewhere.

*Physician, private practice*

Many providers strongly questioned the relevance of this post-test counseling guideline in that it does not motivate initial acceptance of HIV testing and may, in fact, deter some adolescents by imposing additional obligations for in-person, follow-up appointments.

## **Lack of Physician Training**

- *Providers maintain that “teens are not being identified as being at risk” and that “doctors need more training about the need for testing.”*

Several providers assert another significant barrier to HIV testing is the lack of information being given to providers in the Bronx to heighten their awareness of the incidence of HIV among adolescents. According to one physician: “I lack information for myself on who needs to be tested.”

- *There are also strong beliefs among several providers that some of their colleagues are an obstacle to greater levels of HIV testing because they lack training in how to “talk to” and counsel young people about sexual behaviors and HIV testing.*

According to several providers, for example, they have colleagues “who don't believe it's their job to provide teens with HIV pre-test counseling,” and one pediatrician in private practice admitted to not feeling qualified to provide the required HIV counseling.

Indeed, most providers interviewed do not perceive that they lack adequate training on issues related to HIV risk and testing among adolescents. Nevertheless, a lack of physician training appears to be a critical barrier to increased levels of HIV testing among adolescents as evidenced by the number of providers recommending the development of programs to heighten physician awareness and provide HIV counseling and testing training.

As detailed in the following chapter, for example, one health services director noted that currently available HIV counseling and testing training programs, while not designed for the needs of physicians, have had a dramatic impact on increased HIV testing of adolescents by physicians who have attended those training sessions.

**Teens need to have exposure so they can ask questions.** That's difficult in the waiting room because there are all ages of patients and their family members there. Teens need a better setting, more adolescent clinics or areas for adolescents.

*Family physician, hospital-affiliated medical practice*

## Lack of Outreach

- *According to many Bronx healthcare professionals, the lack of outreach to adolescents most at risk presents additional challenges to greater HIV testing among youth.*

Many providers in these interviews acknowledge that they are not seeing populations of adolescents they believe to be most at risk for HIV. Not only do they perceive a lack of strong outreach to these teens, they also believe there is a need for more “teen-friendly” facilities providing access to healthcare in “a positive atmosphere for teens.”

Specifically, providers assert that greater efforts in these areas would increase HIV testing among adolescents because concerns about confidentiality would be better addressed, testing would be available at more convenient hours and, with more teen-friendly facilities, adolescents would be far more likely to return for their test results.

## **Conclusion: Providers Need To “Normalize” HIV Testing**

Several providers expressed very strong opinions that the required procedures for administering HIV tests have become more complicated than necessary and may, in fact, be inhibiting the levels at which HIV testing could be achieved among adolescents, especially sexually active adolescents.

These providers also argue that testing policies, overall, need to change if more adolescents are to be HIV tested. “HIV testing should be a part of routine care, general preventative adolescent care, as it now is with pre-natal care,” according to one clinical social worker. Others also suggest that there are no clear guidelines or information to help physicians determine, “Is it worth it or not? What is the incidence?”

- *Several providers strongly believe that HIV testing could be “normalized” among the adolescent population if it did not involve the “signed” informed consent process.*

Physicians and administrators contend that because an HIV test is a blood test, it is actually less involved or complicated to administer than routine tests for STDs, because “we’re drawing blood anyway.” They argue that the required pre-test counseling and informed consent process elevates HIV testing beyond “routine” healthcare and that the need to move the patient “down the hall” to be introduced to another staff member only serves to complicate the process and heighten the anxiety of young patients.

## CHAPTER THREE: Information and Resource Needs

The research strongly suggests that the vast majority of healthcare providers, particularly those who do not routinely offer HIV testing to their sexually active adolescent patients, are not opposed to encouraging higher levels of HIV testing. One physician at a community-based clinic, for example, conceded that “lots of HIV is being missed because [adolescents] are not being tested” and asked simply that “someone help us to remember” the importance of HIV testing among adolescents.

It is notable, then, that when healthcare providers are asked what types of information or resources would be most valuable to them in an effort to increase HIV testing of teens, nearly a third offer suggestions aimed at enhancing provider awareness, exposure and education on HIV testing and adolescents. Most providers also cite specific needs for programs and materials designed to inform and educate adolescents about the availability and importance of HIV testing.

### Provider Awareness

To heighten awareness among physicians, recommendations range from a suggestion by one internist that adolescent HIV testing be included in grand rounds during physician training, to many requests for enhanced continuing medical education (CME) opportunities. More specifically, healthcare providers see needs for:

- ***More information on current testing recommendations.***

Several physicians admit they are unaware of existing guidelines on HIV testing of adolescents, and many providers who do not routinely offer HIV testing say they simply need to be informed about current standards and practices. Others also comment on the value of receiving information on the practices of other physicians in their communities. Several note that basic data and statistics on the incidence of sexually active teens, pregnancy rates, STDs and HIV among the populations they serve would heighten their awareness of the risks of HIV among their adolescent patients.

**Is routine STD testing recommended?** If the incidence was high enough, I'd do it. That information would have to come through a CME, the Adolescent Medical Journal, a letter from a hospital, or even 20/20.

*Physician, private practice*

**[Provide us with] statistics:** the percent of kids who test positive, the percent of kids who are sexually active, teenage pregnancy rates for the Bronx. Get a speaker to talk to clinic staff or a newsletter from the Department of Health.

*Family physician, community-based clinic*

**Encourage more [HIV] testing as a standard of medical care.** There is interest and acceptance among teens.

*Physician, school-based clinic*

**If HIV tests were more mainstreamed, that would help raise consciousness in the public.** Regularize HIV, instead of leaving it so ostracized.

*Pediatrician, community-based clinic*

**We need more training for physicians on counseling and the need for testing.**

*Administrator, hospital-affiliated medical practice*

**It's just increasing physician awareness of pre-test counseling.** That works through CMEs and on videos—to have residents watch counselors doing the counseling or working one-on-one with the technicians

*Physician, hospital-based clinic*

**I try to seek out practice guidelines for care, but there are many guidelines.**

*Nurse practitioner, school-based clinic*

Because of what several perceive to be adolescents' general interest in and acceptance of HIV testing, other providers urge that routine HIV testing be more strongly encouraged as a standard of medical care for adolescents and that they be made aware of guidelines for testing of adolescents.

■ ***Encouraging a more “normalized” approach to HIV testing.***

A few providers also strongly recommend that physicians be encouraged to “normalize” HIV testing, both in the manner it is offered to adolescents and by routinely offering it to all adolescents without regard to risk assessments.

■ ***Offering physician-friendly training for HIV counseling and testing.***

The research also suggests that opportunities may exist to develop HIV counseling and testing training programs designed specifically for physicians. According to one foster care agency health services director, for example, physicians she required to take the New York State-approved HIV counseling and testing training course strongly objected to the experience because the program was not geared toward physicians. Despite those objections, the training “had a strong impact with doctors and HIV testing has increased dramatically.”

■ ***Continuing medical education programs.***

Nearly one-in-four providers, most often those in private practice or with a patient base age 18 and older, suggest they would find particular value in continuing medical education opportunities focused on HIV testing issues and adolescents.

Importantly, the research also suggests that for many physicians, information on testing recommendations or opportunities for education and training must be delivered to healthcare providers, rather than simply being made available to them when they choose to seek it out. According to one physician, “You need to send me written material regarding who’s recommended for HIV testing.” Nevertheless, another pediatrician notes that he would take seriously information “from any institution” that sent him guidelines recommending routine HIV testing of adolescents.

**It would be better if we had more staff** to do the counseling properly. We need educators speaking aggressively to patients in the waiting room.

*OB/GYN, community-based clinic*

**We have an adolescent team here to help with interventions.** As a result, we often have kids coming in asking for the test and we have to slow them down to brief them.

*Family physician, community-based clinic*

**Having a short, heavily-illustrated brochure would be nice before they're even tested.** And they need to be replenished regularly.

*Pediatrician, community-based clinic*

## Materials and Programs for Adolescents

Under the current system of HIV testing, which requires pre-test counseling and signed informed consent, providers believe that trained counselors play an extremely important and valuable role in facilitating increased levels of adolescent HIV testing and are the pillars supporting the current system. Others reported that peer counselors and educators have effectively motivated increased levels of HIV testing among adolescents. As a consequence, several providers strongly recommend:

- *That existing programs that provide counselors and peer educators to school- and community-based clinics for adolescent patients be expanded.*
- *Increased funding for more social workers and counselors who could “prowl the waiting rooms” and “aggressively” encourage adolescents to be HIV tested.*
- *Provision within hospital environments, including emergency rooms and clinical departments, for increased and more immediate adolescent access to counselors and HIV testing, particularly by expanding the number of hours counselors are available on site in those departments.*

From a pragmatic perspective, given the environments in which they serve teens, providers most frequently ask for more or better materials and programs that are designed to encourage teens to be HIV tested. Often, their suggestions involve strategies that would take advantage of the time adolescents are in clinic or emergency waiting rooms. The needs outlined by healthcare providers include:

- *Printed materials for teens.*

While many providers note that, in their experience, adolescents have been regularly exposed to information about HIV in schools and through the media, others are just as likely to acknowledge that “there’s a wide range of awareness among teens.” According to one school-based provider, “Kids need information, the latest information. They think that drugs will cure HIV, so they’re not worried about it.”

**We need more printed materials.** There seems to be less now than there was a few years ago.

*Director health services, foster care agency*

**In context, if you have a teenager clinic, with few parents coming in, a video for teens would help [increase HIV testing].**

*Pediatrician, community-based clinic*

**Provide a skinny little one-page pamphlet that tells them that testing is available, free testing is available**—with the names of testing sites that are confidential.

*Physician, hospital emergency room*

**Get into the high schools and make them aware.** Teach kids how to tell other kids [about HIV testing]. Promote testing, increase awareness, tell them it's confidential. School's the best place for that.

*Pediatrician, hospital-affiliated medical practice*

Consequently, providers most frequently ask that better printed materials, “lots of brochures for teens,” outlining the benefits of and need for HIV testing be produced and made available to teens. Although several providers dismiss the value of these printed materials, remarking that “teens don’t take pamphlets,” others observe that teens do take and read flyers and brochures, particularly those that are left for them in waiting rooms.

Importantly, the logistics of acquiring pamphlets and making them available to teens is problematic for several, suggesting that routine distribution to providers of printed materials for teens would be a welcome service. One provider in a private practice setting noted, for example, that, “We don’t have the staff to go out and look for it and stock it.”

#### ■ *Information videos for teens.*

Specially developed informational videos for teens are suggested by several providers as being a valuable resource that could, like printed materials, be effectively utilized in waiting rooms. A few providers offer caveats: that they would most likely make videos available to teens only in areas where they would be segregated from older and younger patients, and that informational videos on STDs and HIV use “music video” techniques that would strongly attract teens.

#### ■ *Increasing awareness of HIV testing availability.*

One school-based clinic provider noted, for instance, that even within the school setting, many teens were unaware that free healthcare services, including HIV testing, are available on site. Expanding on a recommendation for more printed materials for teens, another provider strongly suggests producing and distributing a brief flyer for teens that simply listed local free HIV testing sites and also communicated that testing did not require parental consent.

#### ■ *In-school programs.*

Practitioners in settings other than school-based clinics note the value of in-school programs on STDs and HIV, because they give healthcare providers the opportunity “to see the same kids over and over.” As one community-based clinic physician remarked, “School is the best place to make kids aware, to promote testing, increase awareness.” To that end providers suggest that efforts be made to increase the availability of

**We need more in-school programs, in the classroom.** If they don't come to me, I can't get them. Kids are unaware that we are here.

*Nurse practitioner, school-based clinic*

**We need help to get a program focused toward adolescents.** Not a focus on HIV, but that we are here to provide a comprehensive range of services to adolescents, to encourage teens on a higher level.

*Administrator, community-based clinic*

programs that supply trained counselors to school-based clinics and that offer “teen-friendly” instructors for classroom settings.

■ ***Increasing public awareness.***

A few healthcare providers note that they perceive a recent decrease in the focus on HIV in the media. Consequently, these providers suggest a need for public service advertising campaigns in outlets popular with adolescents, including “more commercials, public health information, billboards and commercials on MTV.” More specifically, a few recommend that a public service campaign on HIV testing “generalize it. That it’s not a dreaded event. It’s part of healthy living, part of routine medical care.”

■ ***Developing community outreach programs and adolescent clinics.***

Consistent with other findings in this research, providers in school-based clinic, emergency rooms and foster care agencies most frequently volunteer that they saw a strong need to increase and develop community outreach programs and adolescent clinics that would provide access to healthcare services and HIV testing among “the most at-risk teens that we’re not seeing.”

## Where We Go From Here

There is a serious health crisis affecting our nation's youth. Half of all new HIV infections in the US occur in youth under the age of 25 years old. Yet despite concern among public health officials and key medical opinion leaders about the growing incidence of HIV among youth, this research highlights a number of factors that inhibit the routine practice of testing sexually active teens for HIV. While both the CDC and the American Academy of Pediatrics have issued statements urging providers to test all at-risk youth for HIV, the take home message from this survey is that many providers are either unaware that routine offering of HIV testing is now a standard of care for sexually active adolescents or they recognize the problem but feel that HIV testing entails undue burden and so is better left to their colleagues who are HIV testing specialists.

It is difficult to calculate the exact number of at-risk adolescents who pass through providers' offices each day without being screened for HIV. However statistics on the number of newly identified AIDS cases among young adults make it easy to calculate the number of opportunities providers miss to identify HIV infected adolescents and link them to care. The information gleaned from this study identifies two crucial needs that, if met, could greatly decrease the number of these missed opportunities. The first need is for a more effective educational vehicle to inform providers that HIV counseling and testing is now a standard of care for at-risk youth. Secondly, the myth of the HIV test as a mandated quagmire must be dispelled with a new paradigm that offers providers a road map to easily navigate HIV testing, putting it on par with most other diagnostic tests.

The Adolescent AIDS Program (AAP) of Children's Hospital at Montefiore is prepared to address these needs with materials that are guided by the feedback that was provided by participants in this survey. Included in the package of tools the AAP is creating are compelling epidemiological evidence of HIV infection among this population; straightforward facts about HIV testing as it relates to adolescents; a new set of adolescent HIV counseling and testing protocols: one streamlined for purposes of HIV screening only and a second more in depth version that also incorporates a prevention component; effective adolescent risk assessment tools; and a medical education training session that motivates providers to avoid missed opportunities to identify and link to care youth infected with HIV and other STDs.