

# IDENTIFICATION AND AMBULATORY CARE OF HIV-EXPOSED AND -INFECTED ADOLESCENTS

## I. INTRODUCTION

The American Academy of Pediatrics defines adolescence as 13 to 21 years of age. The recommendations in this chapter pertain to both adolescents and young adults because many youth clinics treat patients 13 to 24 years of age. The patient age range will vary in youth clinics based on the needs of the community and the resources that are available.

The epidemiology of HIV infection and AIDS in the adolescent population in New York State reveals a diverse population requiring a variety of expertise to identify adolescents with HIV, bring them into care, and provide specialized primary medical, mental health, and case management services. The adolescents that comprise this population include both perinatally infected adolescents and sexually infected adolescents; straight, gay, lesbian, bisexual, and transgender adolescents; pregnant and/or parenting adolescents; adolescents in school and not in school; domiciled and homeless adolescents; and substance-using and non-substance-using adolescents. These adolescents have unique as well as overlapping clinical needs and service issues. The actual seroprevalence of HIV infection in adolescents in New York State is currently unknown, but much HIV and AIDS case data are available from a variety of sources that give insight into the unique epidemiology of HIV infection in this age group.

In the United States, it is estimated that the incidence of new infections among male and female adolescents is approximately equal. Heterosexual transmission is predominant in female patients, whereas same-sex transmission is predominant in male patients. Although intravenous drug use is a risk factor among adolescents, few adolescent intravenous drug users with HIV present for care. Racial minorities are impacted disproportionately.<sup>1</sup>

New York City AIDS surveillance data through March 2000 show that 12% of all adult cases are in the 20- to 29-year-old population (n = 14,669).<sup>2</sup> Given the clinical latency of HIV disease from the time of initial infection until the time of AIDS diagnosis, most persons in this age range would likely have been infected with HIV as adolescents. In the United States, 50% of people with AIDS acquired HIV when they were under 25 years of age.

Settings that have mandatory HIV antibody screening provide additional seroprevalence data among youths. Job Corps entrants in New York State from 1993 to 1997 yielded an HIV seroprevalence of 0.26% from 15,278 HIV antibody tests performed. The rate for New York City was 0.3% (from 11,152 tests) compared to 0.17% (from 4,126 tests) for the rest of New York State.<sup>3</sup> Military recruits in New York City from 1995 to 1999 had a seroprevalence of 0.17% compared to 0.04% for the rest of New York State and the United States as a whole.<sup>3</sup>

A study conducted from 1995 to 1999 using unlinked serosurvey data from a New York City homeless youth clinic yielded an HIV seroprevalence rate of 1.1% (54 of 4,895 positive HIV antibody tests).<sup>3</sup> In this population, male youths having sex with other male youths (MSM) yielded the highest risk, with 9.0% of those reporting this risk testing HIV positive.<sup>3</sup> Among black single MSM aged 13 to 21 years old, 12% tested HIV positive.<sup>4</sup> Most homeless female youths who were HIV infected reported heterosexual activity as the only risk for transmission, although those reporting intravenous drug use, use of crack cocaine, or exchange of sex for drugs or money had higher rates of HIV infection.<sup>3</sup>

With the improvements in AIDS survival rates in recent years, the growing population of long-term survivors of perinatal HIV infection reaching adolescence adds to the diversity of the adolescent HIV-infected population in New York State. In New York City through March 2000, perinatal infection was identified in 12.6% of all reported AIDS cases in the 13- to 19-year-old population (n = 54). However, given the decrease in the number of both HIV-exposed newborns in New York starting in the early 1990s and decreased HIV perinatal transmission rates in recent years, it is expected that, within 10 years, fewer adolescents with perinatal HIV infection will be identified.<sup>25</sup>

## **II. CASE IDENTIFICATION OF HIV-INFECTED ADOLESCENTS**

### **RECOMMENDATIONS:**

**Providers should counsel all adolescents and recommend HIV testing to adolescents with risk factors, including being sexually active, when they present for care.**

**Providers should take a sexual risk history at the annual physical examination.**

**Providers should assess risk issues, including sexual activity and substance use, as well as issues regarding home environment, history of violence, involvement in foster care, family history, and school, for those in care or undergoing HIV pre- and post-test counseling. Sensitivity should be given when asking questions about a history of physical and sexual abuse; sexual assault; and suicidal ideation, gestures, or attempts.**

**In most circumstances, HIV antibody testing should be deferred for adolescents who exhibit symptoms of major depression or symptoms of other severe psychiatric disorders until they have been diagnosed and treated.**

**Providers should be knowledgeable about New York State laws pertaining to adolescent consent and confidentiality and should educate their patients about these laws. Youths should be informed of the New York State Partner Notification Law as it pertains to HIV-infected individuals during HIV pre-test counseling and prior to obtaining consent (see Appendix 4-A). Providers should also offer assistance in disclosing HIV status to partners.**

**Providers who care for HIV-infected youths should develop linkages with testing sites where youths are initially diagnosed with HIV disease.**

**A supportive adult to whom the adolescent can safely disclose HIV-related information should be identified.**

In New York State, a minor's right to consent for or refuse HIV testing is based on his/her capacity to understand, without regard to chronological age, what an HIV antibody test actually tests for, the implications and consequences of being HIV infected, and why he/she is at risk for HIV. More information can be found in the New York Civil Liberties Union's *Teenagers Health Care & the Law: A Guide to the Law on Minors' Rights in New York*<sup>6</sup> and in *Comprehensive Adolescent Health Care*.<sup>7</sup>

Providers working with adolescents should be familiar with the broad variety of issues involved in identifying cases of HIV infection in this age group and should have linkages with organizations that perform outreach counseling and testing for the purposes of case finding. In addition to direct street outreach for youths that promotes adolescent-focused HIV counseling and testing services, community outreach to schools, religious institutions, and community-based organizations that serve youths is also essential.

As most youths initially test positive for HIV infection in a setting where comprehensive medical services are not provided [e.g., Health Department test sites, mobile testing vans, sexually transmitted disease (STD) clinics], the linkage to HIV care is an essential component in the continuum of care. Medical providers seeking to link the highest-risk youths to care should develop linkages with community-based organizations with marginalized youth populations of high risk for HIV infection, such as homeless youths, drug-using youths, pregnant adolescent girls, and gay youths. Linkages with local health department HIV counseling and testing sites are one important component of an effective referral network for HIV-infected youths.

A supportive adult to whom the adolescent can safely disclose HIV-related information should be identified. The adolescent should be encouraged to keep this person involved in discussions concerning his/her care and other related issues.

An adolescent who exhibits symptoms of major depression or symptoms of other severe psychiatric disorders during pre-test counseling should be referred immediately for mental health services, and HIV testing should be deferred until the acute risk of suicidal behavior or other mental health issues have been appropriately addressed.

### **III. BASELINE MEDICAL HISTORY OF HIV-INFECTED ADOLESCENTS**

#### **RECOMMENDATIONS:**

**During the baseline visit(s), providers should obtain a complete medical history that is adolescent medicine–focused** (see Table 1).

**Medical providers engaging youths in HIV-related care should be familiar with a youth’s right to confidentiality and consent for such care.**

As obtaining a medical history is time-consuming and may decrease the likelihood of the patient returning for follow-up visits, the provider may choose to acquire all the elements of a history across the patient’s first few visits to the clinic.

### **IV. BASELINE PHYSICAL EXAMINATION FOR HIV-INFECTED ADOLESCENTS**

#### **RECOMMENDATION:**

**During the baseline visit(s), the provider should perform a full physical examination with emphasis on HIV-associated manifestations. The examination should include an external genital examination (sexual maturity on Tanner rating scale) and perianal inspection of male and female patients. A pelvic examination including STD screening is indicated for females who have had sexual intercourse, want a pelvic examination, or have an unexplained gynecologic problem.**

**A mental status examination should be performed, which includes assessment of general mood, depression, suicidal ideation and attempts, and an abbreviated examination for cognitive function.**

### **V. BASELINE LABORATORY EVALUATION**

#### **RECOMMENDATION:**

**When performing laboratory tests in HIV-infected adolescents, providers should follow the guidelines for adults.<sup>8,9</sup>**

The tests listed in Table 2 are always necessary to obtain a composite picture of the adolescent’s health. Although providers should always first obtain the CD4 count and viral load, the entire panel of tests is necessary for a complete assessment.

**TABLE 1**  
**ELEMENTS OF A BASELINE HISTORY FOR HIV-INFECTED ADOLESCENTS**

**Reason for referral**

**Reason for choosing to have an HIV test** (if relevant) or, if the patient is not newly diagnosed, length of time that the adolescent has been aware of his/her HIV status and has been in care

**Assessment of current HIV-related symptoms**, if any [identification of symptoms that might suggest acute infection (within past 6 months)]

**Sources of past medical care**, past medical history, including major and childhood illnesses, medications, psychiatric history, hospitalizations, allergies, immunizations, and history of tuberculosis (TB) or TB exposure

**Review of systems**, including menstrual history

**Growth and development**

**Social history**

- Living situation
- Sources of emotional and social support, including social service agencies and counselors and, if relevant, persons who know of HIV status; identification of a supportive adult with whom adolescent can disclose and discuss HIV-related information
- Peer relationships
- Education, learning disabilities
- Employment status
- History of violence
- Legal status (emancipated\*)
- Legal problems (e.g., incarceration)
- Citizenship, immigration status

**Sexual history**

- Age at initiation of sexual intercourse
- Pattern of sexual relationships, number and gender(s) of sexual partners
- Disclosure to partner(s) of known HIV status†
- Sexual orientation
- Types of sexual experiences, specifying oral, vaginal, and anal intercourse
- Contraceptive history and current practices, specifying frequency and condom use
- Self-assessment of safer sex practices
- Pregnancy history
- Sexual abuse (personal or family)
- STDs

**Substance use history**, history of use and abuse of alcohol, tobacco, marijuana (THC), ecstasy, cocaine, crack, opiates, steroids, hormones, and other substances, including identification of type, route, specifying injection history—amount, frequency, and treatment history

**Family history** (medical and psychological)

- Health care
- Custody arrangements

**Dietary history**

\* In New York State, examples of when a minor might be considered emancipated are as follows: if he/she is married, he/she is in the armed forces, he/she has established a home and is economically independent.

† If HIV status has not yet been disclosed to partner(s), provider should offer assistance with partner disclosure.

**TABLE 2**  
**BASELINE LABORATORY TESTS FOR HIV-INFECTED ADOLESCENTS**

**HIV antibody test**

Retesting should be provided if written documentation of the positive test result is not available, if an initial positive test has not yet been confirmed, or if the patient requests it

**Immunologic assessment**

CD4 lymphocyte count, percentage, and CD4:CD8 ratio; to produce reliable results, the same testing method should be used consistently

**Virologic assessment**

- Quantitative HIV-RNA testing for viral load assessment (performed twice)
- HIV genotypic/phenotypic resistance testing may be considered at baseline evaluation, during acute infection, when antiretroviral (ARV) therapy failure is suspected, and during pregnancy\*

**Tuberculosis evaluation**

Skin test for TB [intradermal purified protein derivative (PPD)], 5TU (not necessary for a patient with a known positive or previously documented TB)

**Additional baseline tests**

- White blood cell (WBC) count with differential
- Platelet count
- Hemoglobin level and hematocrit
- Serum liver enzymes, creatinine, blood urea nitrogen (BUN), total protein, and albumin
- Screening test for syphilis
- Hepatitis B screening
- *Toxoplasma gondii* antibody screening
- Hepatitis A antibody screening (only indicated if patient is from an endemic area or is a male who has a history of having sex with other males)
- Hepatitis C antibody screening
- Serum CPK, lipase amylase, cholesterol levels, and triglycerides (if not initiating ARV treatment, these tests can be deferred)
- GÓPD screening
- Cytomegalovirus antibody

**Tests for sexually active adolescents**

- Cervical Papanicolaou (Pap) smear†; colposcopy, if dysplasia is noted
- Culture or DNA amplification test for gonorrhea (depending on the sexual behaviors reported or suspected, oral and anal cultures may be indicated, as well as cervical or urethral cultures)
- Culture, immunofluorescence or DNA amplification test for chlamydia
- Wet preparation for trichomonads, clue cells, and WBCs
- Pregnancy test as indicated

\* The issue of testing at baseline and during pregnancy remains controversial.<sup>10-12</sup>

† The New York State Department of Health AIDS Institute recommends that a Pap smear be performed at least annually in HIV-infected women, and those with a history of an abnormal Pap smear should receive more frequent follow-up with repeated Pap smears at least every 6 months.<sup>13,14</sup> The Centers for Disease Control and Prevention (CDC) and the Agency for Health Care Policy recommend for HIV-infected women a gynecological evaluation with pelvic examination and Pap smear, a repeat examination at 6 months, and then annually thereafter.<sup>15</sup> The American College of Obstetrics and Gynecology (ACOG) recommends Pap smear every 6 months for HIV-infected women.<sup>16</sup>

For patients with abnormal Pap smear, colposcopy during follow-up examination should be done. Other tests yielding the presence of an active STD should receive appropriate follow-up treatment. Anergy testing at the same time as PPD may be considered. The tests and immunizations listed in Tables 3 and 4 should be performed when clinically indicated.

**TABLE 3**  
**ADDITIONAL BASELINE ASSESSMENTS FOR HIV-INFECTED ADOLESCENTS**  
**(IF CLINICALLY INDICATED)**

- Chest x-ray if anergic or PPD is positive
- Hemoglobin electrophoresis (if relevant)
- Urinalysis, urine culture
- Epstein-Barr virus (EBV) antibody profile
- Rubella antibody [optional, as all adolescents should receive measles, mumps, rubella (MMR) vaccine]
- Cryptococcal antigen titer
- Blood culture (for bacterial or *Mycobacterium avium* complex infections)
- Varicella antibody
- Herpes culture of oral, anal, or genital lesions
- KOH preparation for “whiff” test and *Candida hyphae*

**TABLE 4**  
**IMMUNIZATIONS FOR HIV-INFECTED ADOLESCENTS**

<b>Immunization</b>	<b>Patients Who Should Receive Immunization</b>
MMR	Routine for all adolescents without documentation of 2 previous doses
Hepatitis B	Routine for all adolescents (if not immune)
Tetanus booster (Td)	Routine for all adolescents
Pneumococcal vaccine	HIV-infected adolescents (every 5 years)
Influenza vaccine	HIV-infected adolescents (yearly)
Hepatitis A vaccine	Male youths engaging in sexual behavior with other male youths; patients with chronic liver disease; travelers to countries with high endemicity of infection; patients who live in a community experiencing an outbreak of HAV infection; illicit drug users, particularly injection drug users; patients with clotting-factor disorders; and patients at occupational risk for infection
Varicella vaccine	Non-immune adolescents without evidence of significant immunosuppression
Meningococcal vaccine	May be considered for adolescents in crowded living situations (e.g., college dormitories)

## **VI. TREATMENT: HIGHLY ACTIVE ANTIRETROVIRAL THERAPY**

### **RECOMMENDATIONS:**

**In an individualized manner, the provider should directly educate the adolescent about ARV therapy and seek to make the adolescent a “partner” in the decision-making process.**

**The provider should assess a youth’s readiness to start and ability to adhere to treatment prior to dispensing any medications.**

**Decisions pertaining to ARV therapy should be weighed against clinical factors (e.g., CD4 count, viral load, and HIV-related symptoms) as well as non-clinical factors (e.g., living environment, mental health, HIV disclosure to others, pregnancy, and health beliefs).**

**Adolescents beginning on ARV therapy should be seen at least 1 month after starting therapy to monitor for issues such as adherence, toxicity, and proper dosing.**

**An assessment of treatment adherence should be performed at routine visits.**

For adolescents, medical interventions may include a range of current prophylactic, therapeutic, and ARV treatments for HIV-related infections and illnesses. The dosage, route of administration, and duration of treatment may differ from those for young children. As a general guideline, adolescents in Tanner growth stage I, II, or III should be begun on pediatric dose schedules and those in Tanner stage IV or V on adult schedules. Adolescents in Tanner stages I, II, or III should be monitored particularly carefully because they are at the time of growth-spurt hormonal changes. Adolescents who are pregnant should receive ARV therapy to treat their disease and prevent perinatal transmission in the same manner as adult women. For further information, refer to the New York State Department of Health AIDS Institute’s *Prevention of Perinatal HIV Transmission: Clinical Guidelines*.<sup>17</sup>

Some adolescents may need to be seen sooner than 1 month after starting therapy (e.g., 1 or 2 weeks after beginning therapy) to monitor for issues such as adherence, toxicity, and proper dosing. As the regimen may be complicated, the adolescent may need further guidance in taking the medication properly and may need additional and earlier support during the initiation of treatment. Some providers advocate the use of surrogate pills (e.g., large vitamin pills) as a training regimen prior to starting the antiretroviral regimen; however, there are no data to support that the use of surrogate pills is beneficial.

When starting ARV medications with an adolescent, many clinicians recommend utilizing regimens with a low number of pills and a low frequency of administration. Combination pills, such as Combivir and Kaletra, work well with adolescents for this reason. When possible, drugs should be recommended on bid dosing schedules. As an adolescent’s ability to adhere is often a major concern, Combivir in combination with non-nucleoside reverse transcriptase inhibitors (NNRTIs) (e.g., nevirapine or efavirenz) works well with adolescents. Recommendation of this combination should be balanced with clinical factors, such as CD4 count and viral load as well as concerns that poor adherence will lead to resistance to this class of medications.

For further information about ARV therapy, refer to the New York State Department of Health AIDS Institute guidelines and the federal guidelines.<sup>8,9,18</sup>

## **VII. TREATMENT ADHERENCE**

### **RECOMMENDATIONS:**

**Prior to offering medications, the provider should educate the adolescent about ARV medications and how they work.**

**Once ARV therapy has been initiated with an adolescent, the provider should assess treatment adherence at routine visits.**

For psychosocial reasons, many adolescents may not be initially ready or will refuse to start ARV therapy despite clinical indicators, such as low CD4 counts and high viral load. Some adolescents will initially be more successful in adhering to opportunistic infections (OI) prophylaxis and only later accept ARV therapy. The ability to successfully engage an adolescent in a dialogue about ARV therapy requires that the provider addresses equally the complexities of the psychosocial issues the adolescent faces in his/her daily existence.

Some adolescents may require frequent clinic visits to monitor adherence. Modalities to improve treatment adherence in adolescents include message beepers, medication alarms, and peer support groups.

## **VIII. ONGOING MEDICAL EVALUATION**

### **RECOMMENDATIONS:**

**Adolescents should be seen for routine visits at least every 3 months. An interim history of HIV-related symptoms, ongoing risk behaviors, and psychosocial issues should be obtained during each routine visit.**

**Laboratory evaluations should occur on a routine basis.**

**The provider should discuss on an ongoing basis issues regarding birth control, safe sex, and partner disclosure and should offer to assist with partner disclosure.**

**For youths who previously declined to start ARV therapy, each routine visit should be viewed as an opportunity to review treatment options.**

Laboratory evaluations during routine visits should include CD4/CD8 counts, viral load testing, complete blood counts (CBC) with differential, expanded serum chemistries (to include liver function tests, total protein/albumin), syphilis serology screening, and urinalysis (see Table 5). If a significant change in CD4 is noted, the test should be repeated for confirmation. Viral loads may be elevated after an acute illness or immunization; therefore, caution should be taken when interpreting results from a sample that is obtained after an acute illness or a vaccination.

Providers may choose to perform screening for toxoplasmosis titers, cryptococcal antigen, or mycobacterial blood culture if clinically indicated. Pregnancy tests should be considered for all sexually active female patients. An assessment of treatment adherence to previously prescribed medications should be performed. Treatment education should be repeated prior to writing any prescriptions.

**TABLE 5**  
**ONGOING LABORATORY TESTS**

**Immunologic assessment (every 3 months)**

CD4 lymphocyte count, percentage, and CD4:CD8 ratio (this should be performed more frequently if clinically indicated); to produce reliable results, the same testing method should be used consistently

**Virologic assessment (every 3 months)**

Quantitative HIV-RNA testing for viral load assessment (this should be performed more frequently if clinically indicated)

**Tuberculosis evaluation (annually)**

Skin test (intradermal PPD) for TB

**Tests for sexually active adolescents (every 6 months or if STD-related symptoms are present)**

- Pap smear\*; colposcopy, if dysplasia is noted
- Culture or DNA amplification test for gonorrhea
- Culture, immunofluorescence, or DNA amplification test for chlamydia
- Screening test for syphilis (at least annually)
- Wet preparation for trichomonads, clue cells, and WBCs
- KOH preparation for “whiff” test and *Candida hyphae*
- Pregnancy test, as indicated

**Additional ongoing tests**

- CBC (every 3 months)
- Creatinine, BUN, total protein, albumin (every 3 months)
- *Toxoplasma gondii* antibody titers

**Additional ongoing tests for patients on ARV therapy**

- CPK levels
- Serum liver enzymes, amylase, lipase, cholesterol levels, triglycerides

\* The New York State Department of Health AIDS Institute recommends that a Pap smear be performed at least annually in HIV-infected women, and those with a history of an abnormal Pap smear should receive more frequent follow-up with repeated Pap smears at least every 6 months.<sup>13,14</sup> The Centers for Disease Control and Prevention (CDC) and the Agency for Health Care Policy recommend for HIV-infected women a gynecological evaluation with pelvic examination and Pap smear, a repeat examination at 6 months, and then annually thereafter.<sup>15</sup> The American College of Obstetrics and Gynecology (ACOG) recommends Pap smear every 6 months for HIV-infected women.<sup>16</sup>

## **IX. ONGOING PSYCHOSOCIAL INTERVENTION**

### **RECOMMENDATIONS:**

**The provider should play a central role in coordinating a multidisciplinary care approach for the HIV-infected adolescent.**

**Ongoing assessments of the adolescent’s housing situation, education, family issues, sexual partners, safe sex practices, drug use (if applicable), the adolescent’s parenting skills (if applicable), and other issues should be integrated into the adolescent’s medical care.**

**When making referrals to drug treatment programs, community-based organizations, and counseling and support programs, the provider should try to identify agencies with adolescent-focused services.**

**Providers need to be familiar with New York State laws pertaining to an adolescent’s right to consent for certain forms of health care.**<sup>6,7,19,20</sup>

A multidisciplinary care approach should include professionals who have expertise in working with adolescents, including nurses, nurse practitioners, physicians’ assistants, psychologists, psychiatrists, social workers, and case managers.

Age-appropriate and developmentally appropriate psychosocial interventions for support and risk reduction include individual counseling, family counseling, and group therapy. Many adolescents who are HIV positive are estranged from their parents or do not want to disclose their HIV status to their families. They should be encouraged to identify a supportive adult to whom disclosure can be made.

## **X. SPECIAL POPULATIONS**

### **RECOMMENDATION:**

**As HIV-infected youths are a diverse population, medical providers working with them need to be sensitized and develop skills to work with groups of adolescents with special needs. These groups include perinatally infected adolescents, gay adolescents, transgender adolescents, pregnant adolescents, substance-using adolescents, and homeless adolescents.**

Medical providers, whether they are pediatricians, family practitioners, or internists, should have the sensitivities and skills required to work with HIV-infected youths. These skills could be developed by establishing a relationship with an adolescent medicine specialist. The diverse issues that affect this population (e.g., risk behaviors, chronic disease, emerging sexuality, contraception, pregnancy, mental illness, substance use, violence, and survival sex) are important components of adolescent medicine training and expertise. As such, adolescent medicine specialists could serve as a valuable resource for providers from other disciplines seeking to develop their own expertise in working with adolescents. If expertise in working with specific populations (such as gay youths or substance-using youths) is needed, this could be developed by working in a clinic that specifically serves these populations.

### **A. Perinatally Infected Adolescents**

#### **RECOMMENDATIONS:**

**Perinatally infected adolescents should be assessed for risk behaviors regardless of their developmental stage. The interventions employed for risk reduction should be individualized for the adolescent's developmental stage.**

**Clinical issues, such as adolescent sexuality, contraception, substance use, adolescent gynecology, and adolescent treatment adherence patterns, should be addressed.**

**If disclosure has not already occurred, the perinatally infected adolescent should be told his/her HIV status.**

**The provider should begin to shift some of the emphasis for discussing treatment from the family/caregivers directly onto the perinatally infected adolescent in an age-appropriate manner. Providers should be respectful of an adolescent's request to stop treatment even if this desire is contrary to the family's wishes.**

The vast majority of perinatally infected adolescents (13-24 years of age) receive their medical care in pediatric clinic settings. Although these patients benefit from the long-standing relationship with a medical provider who knows them well, certain aspects of their care need to be adapted to an adolescent care model. Certain clinical services may be made available by pediatrician referral. These services would include gynecology, contraception/family planning, STD screening, substance use assessment and treatment, and adolescent-focused mental health services. Alternatively, pediatricians could further develop their own skills to provide these services themselves. Specific training to develop these skills can be obtained by rotations through specialty clinics that provide these clinical services. This model for care integrates adolescent services into a specialized pediatric HIV clinic session for adolescents only. A second model for care of these patients is to transition them to an adolescent clinic with expertise in treating HIV disease.

Perinatally infected patients do not need to be segregated from behaviorally infected youths in peer support groups, with the exception of perinatally infected patients who are develop-

mentally delayed. Although such developmentally delayed youths may engage in the same adolescent risk behaviors as other teens, they do not mix easily with other teenagers. As a result, peer support groups for this population need to address issues relevant to these adolescents.

Most perinatally infected adolescents have the capacity to understand the meaning of an HIV diagnosis and should be informed of their diagnosis. Disclosure and knowledge of HIV diagnosis is an essential component to the perinatally infected adolescent's care. The multiple reasons for this include issues involving medication adherence, counseling about sexuality, mental health, and ethical reasons. Many families object to informing a youth of his or her HIV status. These families need to be appropriately targeted as early as possible for counseling regarding disclosure issues, as lack of disclosure can have deleterious implications for the health and well-being of the non-disclosed perinatally infected adolescent.<sup>21</sup>

Many perinatally infected adolescents have been heavily exposed to ARV medications in the past. As a result, the provider is often faced with a patient who has exhausted all ARV treatment options. If a particular ARV treatment regimen fails, the list of available treatment options may be short. Thus, the provider is faced with beginning a more complicated regimen (e.g., greater pill burden, greater number of times per day taking medication) with an adolescent who given the circumstances may exhibit non-adherence with medications.

Some perinatally infected adolescents will request to stop ARV therapy. Such adolescents should be questioned for their reasons, and patients' families should be included in the discussion when appropriate. Reasons for requesting to stop therapy may include excessive medication and pill burden, futility of care, clinical depression, acting-out behavior, and other issues. In such circumstances, the provider may suggest temporarily interrupting all medications until the issues can be resolved. Mental health interventions may result in the adolescent being able to resume treatment. If a perinatally infected adolescent has requested that treatment be stopped, the provider should assess whether the adolescent understands the potential adverse consequences of this decision. If the adolescent clearly understands the consequences of his/her decision, the provider should respect this decision, advise the adolescent that he/she may change his/her mind at any point in the future, and address the topic of restarting treatment during future clinic visits. Providers may need to counsel or mediate with families in situations in which the adolescent's desire to stop treatment does not coincide with those of the parent/guardian.

## **B. Gay Adolescents**

### **RECOMMENDATIONS:**

**Providers should assess for psychosocial issues in gay adolescents and should facilitate referrals for mental health care when indicated.**<sup>22-24</sup>

**The provider should be part of a support network for a gay adolescent who is more likely to experience feelings of alienation, rejection, and ostracism as compared to his/her same-age peers.**

**The provider should be able to counsel the gay adolescent about issues of disclosure of his/her sexuality as well as his/her HIV status. If necessary, the provider should facilitate safe disclosure to parents and other family members.**

**Providers should be able to counsel gay youths on risk reduction in a manner that is nonjudgmental and is consistent with the youth's sexuality.**

**Providers should be competent to screen for sexually transmitted diseases in this population.**

**Providers should be able to detect the warning signs for adolescent suicide.**

As males having sex with other males continues to be the leading risk transmission category for adolescent males infected with HIV in New York State<sup>1,24</sup> and other epicenters of the

AIDS epidemic, providers need to become competent to address gay adolescents' needs. Same sex behavior and same sex identity are often separate phenomena for adolescents, and many youths are unsure of sexual identity at this age. Mental health issues are at the forefront of these needs, as gay youths experience their sexuality in a developmental context and may be confused. Medical providers working with gay youths should seek continuing medical education for addressing the mental health issues of gay youths. This can be achieved by attending conferences and symposia on these issues. Medical providers could also develop a relationship with a mental health provider who specializes in working with gay youths, which would enhance the medical provider's insight into these mental health issues. The risk of adolescent suicide may be higher in this population, and the provider needs to be able to detect the warning signs for this. The provider should directly ask gay adolescents questions about whether they are feeling depressed or isolated, whether they have supportive individuals to whom they can turn, and whether they have had any recent suicidal ideation or gestures. Those assessed to be at high risk for suicide should be referred for appropriate mental health services. Referral to peer support groups for gay youths can play an invaluable role in building a supportive network.

Infections such as anal human papilloma virus, hepatitis A, intestinal parasites, and syphilis occur with greater frequency in males having sex with other males and require a certain level of expertise for the purposes of both detection and treatment.

### C. Transgender Adolescents

#### RECOMMENDATION:

**Health care providers working with transgendered youths should be capable of addressing the specific issues associated with this population, such as mental health, gender identity, hormonal therapy, and sexuality needs.**

Many transgendered youths may be taking injectable hormonal therapy that has been bought "on the street" and may be engaging in needle-sharing practices. The risks from these behaviors are multiple, including HIV transmission, hepatitis B and C transmission, drug interactions among HIV-related medications and illicit hormones, and adverse reactions to illicit hormones that are being used in an unmonitored setting.

Health care providers should become familiar with community-based organizations in their local area that provide services to transgendered individuals. An excellent source of information concerning transgendered issues can be found on the internet at <http://www.nyagra.org/links.htm>.

### D. Pregnant Adolescents and Adolescent Parents

#### RECOMMENDATIONS:

**Providers should be able to discuss options with patients who are making decisions about carrying pregnancy to term or terminating pregnancy.**

**Providers should advise pregnant adolescents who choose to carry pregnancy to term on the benefits of ARV therapy in reducing perinatal transmission.<sup>17,25</sup>**

**Providers should have linkages with obstetrical services that can provide care to HIV-infected women during pregnancy; however, the provider may want to maintain the primary care of the adolescent during the pregnancy** (refer to the New York State Department of Health AIDS Institute's *Prevention of Perinatal HIV Transmission: Clinical Guidelines* for further guidance<sup>7</sup>).

The time of pregnancy is often the time when heterosexually HIV-infected adolescents are identified as being HIV positive. The recommendation for the practice of universal testing of all pregnant women, either prenatally or through expedited perinatal testing, has facilitated the identification of HIV infection in adolescent girls who become pregnant. Many HIV-infected adolescents lack the appropriate parenting skills to care for an infant or child,

which is a situation that may be further complicated when an infant or child requires ARV medication and frequent medical visits. Parenting skills training in this population should be made available. Providers are mandated to report child abuse or poor supervision.

As with adult women, treatment during adolescent pregnancy raises multiple issues and should be given by a provider experienced in care of HIV-infected pregnant patients.

## **E. Adolescent Substance Users**

### **RECOMMENDATIONS:**

**Providers should be familiar with programs that provide drug detoxification and maintenance as therapeutic modalities.**

**Providers should be able to detect alcohol and marijuana use and should be able to provide counseling as well as referral for treatment.**

**Providers should be familiar with both harm reduction–based and abstinence–based drug treatment programs for the purposes of referral.**

**Providers should be aware of drug interactions between HIV-related medications and “street” drugs.**

Substance use among HIV-infected adolescents is associated with issues that the provider should develop expertise in managing. Providers need to be able to detect substance use and be able to provide counseling as well as referral for treatment. Studies reflect significant alcohol and marijuana use among HIV-infected adolescents.<sup>26</sup> Alcohol and marijuana use, although not a direct HIV transmission risk, may often be present in situations in which the HIV-infected adolescent may be having sexual activity. Intoxication from these substances does impair the adolescent’s ability to negotiate condom use with partners, which not only increases the risk of pregnancy and other STDs but also increases secondary transmission of HIV infection. Youths who are known to be heavy alcohol and marijuana users also may have problems with school, employment, and personal relationships. For adolescents on ARV therapy, there is a risk of drug interactions among recreational drugs and ARV drugs. In addition providers should be aware that methadone interacts with NNRTIs.

Substance use with “harder” drugs (e.g., nasal or crack cocaine and heroin) poses a different set of clinical issues. As these drugs are addictive, obtaining them may cause the adolescent to be involved in criminal activity and to have legal problems in addition to a serious drug problem. Some youths may benefit from programs that provide drug detoxification and maintenance as therapeutic modalities. Some youths may require long-term residential treatment. Providers should counsel intravenous drug-using youths about their options for drug treatment as well as HIV transmission reduction and should make a serious attempt to refer these youths for drug treatment. Local syringe exchange programs where youths can be referred need to be identified (see Appendix 4-B).

## **F. Homeless Adolescents**

### **RECOMMENDATION:**

**Providers should work closely with case managers and social workers in helping homeless youths find appropriate housing.**

Many adolescents with substance use problems are homeless and are involved in trading sex for drugs, money, or shelter. A transient living situation will likely interfere with or greatly challenge medication adherence in an adolescent. Underlying mental health and substance use issues should be addressed as well.

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## APPENDIX 4-A

### SUMMARY—HIV REPORTING AND PARTNER NOTIFICATION

Chapter 163 of the Laws of 1998 amended Public Health Law (PHL) Article 21 (“Control of Acute Communicable Diseases”) to require the reporting of persons with 1) HIV, 2) HIV-related illness and 3) AIDS by New York State physicians and other medical providers (physician assistants, nurse practitioners, midwives) who make diagnoses and by laboratories performing diagnostic tests. (Note: HIV tests performed for research purposes only are not included.) The new law also requires that reports contain names of sexual or needle-sharing partners known to the medical provider or whom the infected person wishes to have notified.

The law reflects the recognized need, given new pharmaceuticals which delay the progression from HIV to AIDS significantly, to better track the epidemic in order to target resources and plan services appropriately. AIDS reporting alone is no longer an effective public health tool. Also, provisions requiring notification of exposed persons reflect a traditional public health intervention to limit the spread of communicable disease.

Briefly, the implementing regulations (10 New York Code Rules and Regulations Part 63) and protocols provide that:

- Physicians, nurse practitioners, physician assistants and midwives report identifying information including patient name on standard forms to the New York State Commissioner of Health, except in New York City where medical provider reports are to be sent into the New York City Department of Health (following the established protocol for AIDS reporting which has been in effect since 1985).
- Clinical laboratories (including blood banks) electronically report HIV tests to the New York State Commissioner. For the purpose of the regulation, reportable HIV tests include: HIV antibody tests, HIV nucleic acid detection tests, and CD4 lymphocyte counts <500 unless such tests are known to be performed for reasons other than HIV infection/diagnosis (e.g., related to cancer monitoring). Encryption and electronic security protocols (e.g., firewall, passwords) have been put in place for these transfers.
- Medical providers complete a timely report that 1) lists sexual and needle-sharing partners known to the medical provider (e.g., spouses) or partners whom the infected person wishes to have notified, 2) indicates whether notification of these partners has already been performed, and 3) identifies whether a domestic violence screening protocol has been conducted on the patient and/or the patient’s contacts. Trained public health staff (in some cases, state employees; in other cases, county/New York City health staff) may contact providers to verify information and, when appropriate, notify partners to ensure they are aware of their exposure. Such partners will be counseled and offered HIV testing. In all partner notification activities, the name of the infected person is never to be disclosed.
- Partner names will be maintained no longer than one year after case closure.
- Anonymous testing is specifically excepted from the reporting requirement; anonymous counseling and testing services will continue to be available.
- Disclosing existing HIV information in certain listed occupational settings to persons who have been exposed to blood and body fluids is permitted under the new statute and regulations [10 NYCRR § 63.8(m)]\* when:
  - the exposure incident occurred to staff/employees/volunteers in their employment or professional duties in a medical/dental office or a facility regulated by DOH, OMH, OMRDD, OCFS, OASAS, DOCS, or when the exposure incident involved an emergency response employee (e.g., fire, police).

\* Although these measures address disclosure of existing HIV information in a person's record, it does NOT permit testing of the source.

- the incident is documented with supervisory staff.
- a request for disclosure stating such information is necessary for decisions on treatment is made by the provider of the exposed person.
- the exposed person is HIV negative or has consented to an HIV test him/herself; however, if the test returns positive prior to disclosure, no disclosure will occur.
- documentation is placed in the chart of the exposed person; however, the name of the person whose HIV test result is released is not given to the exposed person.
- the medical provider for the source of the exposure determines that a risk of transmission is likely to have occurred.
- Liability provisions in PHL § 2136: good-faith reporting or disclosure shall not constitute libel or slander, or violations of the right to privacy, or protections of privileged communications. Immunity is granted with respect to civil or criminal liability for any person complying in good faith with the law.
- Disclosure of partners is a voluntary activity; no criminal or civil liability arises for non-disclosure of contacts by the patient.

# APPENDIX 4-B

## SYRINGE EXCHANGE AND ACCESS RESOURCES

### EXPANDED SYRINGE ACCESS DEMONSTRATION PROJECT (ESAP)

Pharmacies registered in New York State's Expanded Syringe Access Demonstration Program (ESAP) may now sell or furnish up to 10 syringes at a time to adults, 18 years or older, without a prescription. Under this program, health care facilities and health care providers (doctors and others who can prescribe syringes) may also furnish syringes.

Possession of syringes in accordance with the Public Health Law is legal. Persons legally possessing syringes are not subject to arrest or prosecution under the Penal Law.

To find syringe exchange programs or pharmacies participating in ESAP, call the New York State Department of Health HIV/AIDS Hotlines:

**English:** 1-800-541-AIDS

**Spanish:** 1-800-233-SIDA

**Deaf/TDD:** 1-800-369-AIDS

**MANHATTAN**

**New York Harm Reduction Educators, Inc.**

1991A Lexington Avenue  
New York, NY 10035  
(212) 828-8464

**Positive Health Project**

301 West 37th Street, 2nd Floor  
New York, NY 10018  
(212) 465-8304

**Foundation for Research on Sexually  
Transmitted Diseases (FROSTD)**

369 West 29th Street  
New York, NY 10001  
(212) 924-3733

**Housing Works Syringe Exchange  
Program**

130 Crosby Street  
New York, NY 10012  
(212) 966-0466

**Lower East Side Harm Reduction Center**

25 Allen Street  
New York, NY 10003  
(212) 226-6333

**BRONX**

**CitiWide Harm Reduction Program**

226 East 144th Street, 3rd Floor  
Bronx, NY 10451  
(718) 292-7718

**New York Harm Reduction Educators, Inc.**

903 Dawson Street  
Bronx, NY 10459  
(718) 842-6050

**St. Ann's Corner of Harm Reduction**

312-314 Cypress Avenue  
Bronx, NY 10454  
(718) 585-5544

**BROOKLYN**

**Association for Drug Abuse**

**Prevention & Treatment (ADAPT)**

815 Broadway  
Brooklyn, NY 11206  
(718) 782-5389

**Bushwick Community Service Society**

**COMRADES IN A.R.M.S.**

1420 Bushwick Avenue  
Brooklyn, NY 11207  
(718) 455-6010

**CENTRAL AND WESTERN NEW YORK**

**AIDS Rochester, Inc.**

1350 University Avenue, Suite C  
Rochester, NY 14607  
(716) 442-2220

**Kaleida Health/Project Reach**

777 Main Street  
Buffalo, NY 14203  
(716) 845-0172

**LOWER- AND MID-HUDSON VALLEY**

**Urban League of Westchester, Inc.**

61 Mitchell Place  
White Plains, NY 10601  
(914) 428-5407

**Urban League of Westchester, Inc.**

10 Fiske Place, Suite 429  
Mount Vernon, NY 10550  
(914) 667-1010