

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Pediatric AIDS

## Surveillance of Pediatric HIV Infection

**ABSTRACT.** Pediatric human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) surveillance should expand to include perinatal HIV exposure and HIV infection as well as AIDS to delineate completely the extent and impact of HIV infection on children and families, accurately assess the resources necessary to provide services to this population, evaluate the efficacy of public health recommendations, and determine any potential long-term consequences of interventions to prevent perinatal transmission to children ultimately determined to be uninfected as well as for those who become infected. Ensuring the confidentiality of information collected in the process of surveillance is critical. In addition, expansion of surveillance must not compromise the established, ongoing surveillance system for pediatric AIDS. An expanded pediatric HIV surveillance program provides an important counterpart to existing American Academy of Pediatrics and American College of Obstetricians and Gynecologists recommendations for HIV counseling and testing in the prenatal setting.

### BACKGROUND

The goals of surveillance for pediatric human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) are to 1) determine the scope of the pediatric HIV epidemic and collect data on trends in the incidence of pediatric infection, 2) characterize the spectrum of disease and modes of transmission, 3) assess when children are identified in the course of their disease so that linkage with needed medical and social services can be improved, 4) project the course of the epidemic to provide needed resources, 5) evaluate the impact of public health recommendations and programs, and 6) facilitate evaluation of the impact of in utero exposure to therapies to reduce perinatal transmission on the long-term outcome of HIV-infected and uninfected children.

The Centers for Disease Control and Prevention (CDC), in conjunction with the Council of State and Territorial Epidemiologists (CSTE), has proposed expanding national surveillance for pediatric HIV infection by adding standardized, confidential reporting of HIV infection in children to the current reporting system for pediatric AIDS.<sup>1</sup> In 1989 and 1993, the CSTE recommended that all states conduct surveillance for HIV infection in children by instituting uniform reporting requirements under policies

that maintain confidentiality and security of HIV/AIDS surveillance data. In 1995, the CSTE recommended adding pediatric HIV infection to the national public health surveillance system, and since January 1996, data on reported cases of pediatric HIV infection have been provided in *Morbidity and Mortality Weekly Report*.

Currently, >50% of states conduct confidential surveillance of HIV infection in children. Most of these states also conduct surveillance for perinatal HIV exposure (reporting of HIV antibody positivity). State and local health departments then follow up these cases to determine the child's ultimate infection status and progression to AIDS. The pediatric HIV/AIDS case report form currently allows for reporting at multiple time points for children (ie, at perinatal exposure, HIV infection determination, AIDS diagnosis, and death).

This statement reviews the purposes of the HIV/AIDS surveillance system and discusses the advantages and limitations to the public and to individual children and families of expanding HIV surveillance for children, and recommends the level of surveillance appropriate at this time.

### PURPOSE OF SURVEILLANCE

A public health surveillance system should provide ongoing, systematic collection, analysis, evaluation, and dissemination of data describing and monitoring important public health events. These data are used to determine the need for public health interventions and to plan, implement, and evaluate resulting programs and actions. Surveillance systems should be simple and acceptable to those reporting the health event. The majority of cases under surveillance should be detectable in a timely manner and therefore should represent the occurrence of the health event over time and its distribution in the population.<sup>2</sup>

The CDC and state and local health departments have conducted surveillance for AIDS in children and adults since 1981. Such surveillance has provided essential data for characterizing the AIDS epidemic, evaluating trends in opportunistic infections such as *Pneumocystis carinii* pneumonia (PCP), allocating resources for prevention and treatment, and projecting the future impact of disease. The characterization of AIDS is empiric and captures only patients with severely symptomatic HIV infection and therefore detects only a portion of the population

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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infected. Reporting limited to AIDS patients severely underestimates resource needs for the increasing population of HIV-infected and HIV-exposed children.

#### **DISTINGUISHING BETWEEN INDIVIDUAL TESTING AND INFECTION SURVEILLANCE**

It is important to distinguish between testing of an individual and surveillance for infection or disease. HIV testing of pregnant women or their newborns that is linked to patient identifiers is performed for clinical care and should be conducted only with consent. The purpose of named HIV testing is to engage a woman in continuing care for herself and her infant. Compliance with medical care is likely to be greatest when the woman feels she has made an informed judgment regarding HIV testing for herself or her infant. The AAP and American College of Obstetricians and Gynecologists (ACOG) recommend that all pregnant women receive HIV education and counseling as part of regular prenatal care. Additionally, it is recommended strongly that HIV testing be performed in all pregnant women with their consent, with documentation in the event of refusal of testing.<sup>3,4</sup> HIV testing under such conditions provides direct benefit to the woman and child.

Surveillance usually has indirect benefits to the individual through general improvement in the public health. The surveillance process occurs independently of the individual patient, and is accomplished by reporting of selected conditions detected by the health care provider, along with identifiers, to local and state health departments. In recommending that any condition be deemed reportable to public health agencies, it is important to weigh the public health benefits of surveillance, the extent of provisions for confidentiality and security of the information reported on individuals, and how acceptable reporting is to providers.

#### **RATIONALE FOR PEDIATRIC HIV INFECTION SURVEILLANCE**

Early in the HIV epidemic, surveillance was limited to end-stage disease, AIDS, because an agreed-on syndrome was defined for which no diagnostic test existed and the etiology was not known. Even when diagnosis of HIV infection became possible by serologic testing, interventions were not yet identified that could change the course of the disease. Initial reports of pediatric HIV infection indicated that AIDS progressed rapidly in most HIV-infected children; the epidemic was newly recognized, and only symptomatic disease, primarily in young children, was appreciated. It was expected, therefore, that surveillance for AIDS would provide a good surrogate for evaluating the magnitude of HIV infection in children.

As it became possible to make a definitive diagnosis of infection in the absence of symptoms, it was discovered that not all children with HIV infection die in the first several years of life. Current natural history studies clearly document a bimodal age distribution for the survival of children with pediatric HIV infection. The median age at onset of HIV-re-

lated symptoms is 14 months, but the rapid progression to AIDS during the first year of age occurs in only 10% to 30% of perinatally infected infants. Most children infected do not develop AIDS until a median age of 4 to 6 years or older,<sup>5-8</sup> and a significant minority of infected children may survive beyond the age of 8 to 9 years without developing AIDS.<sup>9-11</sup>

Substantial medical and social service resources are needed for the care of children who are exposed to and infected with HIV. The CDC estimates that 12 240 HIV-infected children were living in the United States at the end of 1993, only 22% of whom had developed AIDS.<sup>12</sup> On an annual basis since then, an estimated additional 6500 infants have been born to HIV-infected women, 1630 of whom, in the absence of intervention, were infected each year based on an estimated 25% vertical transmission rate. Use of zidovudine during pregnancy and labor and in the neonatal period theoretically could lower the number of infected children born annually to 520, and this is recommended by the US Public Health Service (PHS) and the AAP.<sup>13-16</sup> However, health care resources are still required for the larger group of HIV-exposed infants for monitoring during the initial 6 weeks of zidovudine prophylaxis, initiation of prophylaxis to prevent PCP as per the current PHS recommendations,<sup>17</sup> and diagnostic testing during the first 6 months of age to determine infection status. Additionally, all children with in utero exposure to antiretroviral drugs require follow-up for any long-term consequences of such exposure.<sup>16</sup>

In recent years, various technologic and medical advances have been made in the detection and treatment of pediatric HIV infection. Current tests permit HIV infection to be diagnosed in nearly all perinatally infected infants no later than age 6 months,<sup>18,19</sup> and most such infants have positive virologic tests by 1 month of age. Early intervention with prophylaxis for PCP<sup>17</sup> has been shown to decrease the occurrence of this infection significantly and reduce early death.<sup>20</sup> There have been important changes in the recommendations for prophylaxis against PCP in children. Prophylaxis should start in all infants born to HIV-positive women at 4 to 6 weeks of age (which may be before infant HIV infection status has been determined definitively), and should be discontinued in children subsequently found to be uninfected continued in all HIV-infected children through at least the first year of age regardless of the CD4<sup>+</sup> lymphocyte count.<sup>17</sup> Antiretroviral therapy has prolonged life and, with other supportive therapeutic modalities, modified the course of disease.<sup>21-24</sup>

Finally, the results of AIDS Clinical Trials Group Protocol 076 indicate that a regimen of zidovudine given during pregnancy, labor, and delivery and to the newborn can reduce the risk of perinatal HIV transmission by two thirds.<sup>13</sup> These findings have led to PHS recommendations regarding use of zidovudine to reduce perinatal transmission<sup>15,16</sup> and for HIV counseling and voluntary testing of all pregnant women in the United States.<sup>3,25</sup> With the availability of specific interventions for the prevention and treatment of HIV infection and the complications associated with infection, surveillance for AIDS alone is

less useful for projecting resource needs and planning intervention programs.

HIV infection in children usually is indicative of HIV infection in a family unit. Regardless of the symptom status of the child, considerable health and social service resources are necessary to meet the needs of such families. Therefore, data on the numbers of children born to HIV-infected women and of HIV infection in children would have great usefulness.

#### IMPORTANT CONSIDERATIONS REGARDING PEDIATRIC HIV SURVEILLANCE

##### Surveillance of HIV-Infected and HIV-Exposed Infants

When contemplating nationwide expansion of pediatric HIV surveillance, it is important to consider whether reporting should include children who have been exposed to HIV, as well as those known to be infected. Children born to HIV-infected mothers may require evaluation for up to 18 months to determine definitively whether the child is uninfected. Continuing medical monitoring is necessary in such children, and appropriate clinical management dictates that certain interventions (eg, PCP prophylaxis) be initiated pending diagnostic evaluation. Therefore, to delineate fully the impact of HIV infection in children and estimate the medical and social service resources necessary for their care, reporting would optimally include infants of indeterminate status as well as those who are infected. Such data help evaluate the implementation and effectiveness of interventions to reduce perinatal transmission and of recommendations for prophylaxis against PCP. The ability to evaluate the potential long-term impact of such regimens on uninfected as well as HIV-infected children would be facilitated.

There are potential benefits for the mother (as well as other siblings and family members) of reporting of perinatal HIV exposure and/or pediatric HIV infection. The health department, the pediatric health care provider, and the maternal health care provider can work together to refer the mother to medical and social services for her own care, including appropriate counseling regarding HIV and its transmission, immunologic monitoring, antiretroviral treatment, prophylaxis for opportunistic infections, and evaluation of other family members for HIV infection.

Early treatment should be available to mothers and children. This will require enhancement of ambulatory specialized care in inner-city and rural areas and financial resources at local, state, and national levels to meet this obligation. Surveillance data are needed for determining resource allocation. The impact of HIV infection on children and the resultant health care requirements can be accurately determined by a surveillance system that includes reporting of children with perinatal HIV exposure as well as those with definite HIV infection and AIDS. Such data are critical to enable the most complete and reliable appraisal of current and future resource needs.

Many states have already implemented systems for surveillance of HIV-exposed infants. State and

local health departments have provided information to the health care providers who report the information on their patients about referrals to available health care and social service resources for the patient and his/her family members.<sup>26</sup> It also has helped to evaluate the implementation of public health recommendations. Additional information from these states will be important to evaluate the usefulness of surveillance of HIV-exposed children.

Important considerations in surveillance for HIV exposure include concerns about confidentiality, particularly for the majority of infants who will be found to be uninfected. The benefits and limitations of maintaining identifiers of such uninfected children in the surveillance system need careful consideration.

##### Confidentiality Concerns

The confidentiality of HIV/AIDS case reports is critical in HIV/AIDS surveillance. The CDC and state health departments have policies and procedures to maintain security and confidentiality of disease surveillance records, and most states have additional specific confidentiality laws for patient-related HIV data. At the federal level, no patient names are collected and surveillance records are protected by assurance of confidentiality that prohibits the unauthorized disclosure of individual identifying information. Names are removed from patient records and unique coded identifiers are assigned, and the encrypted data are transmitted to the CDC. Federal funding for HIV/AIDS surveillance to state and local health departments is contingent on the ability of the health department to ensure the security and confidentiality of personal identifying information collected as part of surveillance activities.

The reporting of named identifiers to the state or local health department ensures that health departments can eliminate duplicate reports, provide referrals to services, and conduct follow-up to monitor the occurrence of severe illness and death. The state also can evaluate completeness of reporting by matching AIDS case registries with birth and death registries or hospital discharge records, and investigate cases of epidemiologic importance, such as those with no identified risk or unusual laboratory and clinical characteristics.

Although there are clear benefits to named reporting, a concern that it might deter individuals from undergoing HIV testing has been raised. However, a study that evaluated the impact of state reporting policies on personal plans to seek HIV testing found no evidence that such name-reporting was related to a decrease in the numbers of people reporting previous and planned HIV testing.<sup>27</sup> In addition, such reporting has assisted in providing public health services to newly diagnosed HIV-infected persons and in attracting increased funding for outpatient care and support services.<sup>28</sup>

Specific confidentiality provisions are in place to prevent disclosure of surveillance data identifiers to outside parties in all states. However, individual states maintain the authority to legislate disclosure when deemed important for public health purposes.

For example, two state legislatures have issued statutes containing confidentiality provisions, but that require notification of selected parties by the health department regarding reported cases of pediatric HIV infection or AIDS. Statutes in Illinois and South Carolina require that health department officials give notice of the identity of a reported HIV-infected child to the principal of the school in which the child is enrolled (in South Carolina, this applies only to public schools). Legislation requiring that school officials be notified of a child's HIV infection status is not consistent with published policies of a number of medical, educational, and public health organizations, including the AAP<sup>29</sup> and the PHS.<sup>30</sup> These policies evolve from the beliefs that notification of school officials by state or local public health agencies without the knowledge of the family is not consistent with the interests of children or their families, and compromises the rights of families to inform or not inform the schools.

### **Impact on Mothers and Families Identified Through Pediatric HIV/AIDS Reporting**

All infants with perinatal exposure to HIV have HIV-infected mothers, and reporting of HIV exposure or infection in infants constitutes indirect knowledge of maternal serostatus. It has been speculated that some women might be deterred from having their infants evaluated for HIV for fear of identification of their status and potential social stigmatization. However, this has not been substantiated, and the knowledge that a regimen of zidovudine can reduce significantly the risk of perinatal HIV transmission has provided a strong impetus for pregnant women to learn their HIV infection status early in pregnancy.

### **Seroprevalence Surveys**

Serologic testing of blood specimens that are not linked to individual patient identifiers for the purposes of surveillance has provided important information regarding the extent of the HIV epidemic in pediatrics, because the presence of HIV antibody in the newborn reflects the infection status of the child's mother, the unlinked testing of neonatal filter paper blood specimens for HIV antibody has provided information regarding the distribution and prevalence of HIV infection in childbearing women. The population-based National HIV Survey in Childbearing Women, which was suspended by the PHS in May 1995, was used to examine HIV infection trends among women and children and to identify geographic areas in greatest need of prevention and treatment resources. Data from this survey, for example, demonstrated an increase in HIV infection among childbearing women in rural areas of the southeastern United States and was used to target and obtain funding for epidemiologic studies and prevention/service programs for these areas.<sup>31</sup>

With recommendations that PCP prophylaxis begin at 4 to 6 weeks of age and the discovery that zidovudine given to pregnant women and their infants can reduce significantly the risk of perinatal transmission, a few states have instituted or are con-

sidering legislation to require mandatory HIV testing of all newborns, with subsequent identification and informing of seropositive mothers. However, it is critical to recognize that testing of newborn blood specimens does not identify infected mothers early enough to permit initiation of zidovudine therapy during pregnancy to reduce perinatal transmission and therefore prevent HIV infection in children. Recognizing this, rather than mandating newborn HIV testing, a few states have passed legislation to require routine prenatal HIV education and HIV testing for all pregnant women, an approach more likely to reduce perinatal HIV infection.

The conduct of the serosurvey of childbearing women is important to evaluate trends in HIV infection in childbearing women and project resource needs. In conjunction with surveillance of HIV exposure, such a serosurvey permits evaluation of counseling and testing recommendations and validation of the efficacy of the surveillance system.<sup>32</sup> The PHS, AAP, and ACOG recommend that all women receive HIV education and counseling as part of their regular prenatal care. Additionally, it is strongly recommended that HIV testing be performed in all pregnant women with their consent, with documentation in the event of refusal of testing.<sup>3,4,25</sup> In areas in which pregnant women have been provided the opportunity to gain knowledge of their HIV serostatus, concerns about the conduct of an unlinked serosurvey would be diminished. Therefore, the AAP supports reinstatement of the serosurvey in areas in which the PHS, ACOG, and AAP recommendations for HIV counseling and testing in the prenatal setting have been implemented.

### **CONCLUSION**

The AAP believes that there would be significant benefits to expanding surveillance for pediatric HIV infection nationwide through the addition of confidential reporting of perinatal HIV exposure and HIV infection in children to the ongoing surveillance of AIDS. However, confidentiality is crucial, and such information must be safeguarded and protected from unwarranted disclosures.

### **RECOMMENDATIONS**

1. The AAP supports expanding HIV/AIDS surveillance in children to include reporting of HIV infection and AIDS status in all states and territories of the United States. This expansion must include appropriate safeguards for confidentiality.
2. With confidentiality provisions and adequate resources to ensure that there is no detrimental effect on ongoing surveillance for HIV infection and AIDS, the AAP supports additional expansion of HIV surveillance to include reporting of HIV-exposed infants.
3. The AAP opposes linkage of pediatric HIV infection reporting with disclosure to school and child care personnel as well as to other nonpublic health service organizations.
4. The reporting format should be simple and easy to implement for the health care community responsible for reporting to the health department.

5. The AAP reaffirms that all pregnant women should receive HIV education and counseling as part of regular prenatal care, and recommends strongly that HIV testing should be performed in all pregnant women with their consent, with documentation in the event of refusal of testing.
6. In areas in which AAP, ACOG, and PHS recommendations for HIV education, counseling, and testing in the prenatal setting have been implemented, seroprevalence surveys to determine the rate of HIV infection among childbearing women should be reimplemented.
7. Access to care for HIV-infected children and mothers is essential. However, the availability of resources to facilitate such access may depend on data documenting the extent of the problem in these populations. Therefore, expansion of HIV/AIDS surveillance should not be delayed until access problems have been resolved completely.

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