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OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

**Identification and Care of HIV-Exposed and HIV-Infected Infants, Children, and Adolescents in Foster Care**  
Committee on Pediatric AIDS  
*Pediatrics* 2000;106;149-153  
DOI: 10.1542/peds.106.1.149

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# AMERICAN ACADEMY OF PEDIATRICS

Committee on Pediatric AIDS

## Identification and Care of HIV-Exposed and HIV-Infected Infants, Children, and Adolescents in Foster Care

**ABSTRACT.** As a consequence of the expanding human immunodeficiency virus (HIV) epidemic and major advances in medical management of HIV-exposed and HIV-infected persons, revised recommendations are provided for HIV testing of infants, children, and adolescents in foster care. Updated recommendations also are provided for the care of HIV-exposed and HIV-infected persons who are in foster care.

ABBREVIATIONS. HIV, human immunodeficiency virus; AAP, American Academy of Pediatrics; PCR, polymerase chain reaction.

An estimated 500 000 children and adolescents in the United States are in foster care.<sup>1</sup> Entrance to the foster care system may occur as a consequence of parental substance abuse, neglect, physical abuse, sexual abuse, or loss of biologic parent(s) resulting from abandonment, incarceration, disability, or death. As many as 78% of children in foster care have a parent with a history of substance abuse, and as many as 94% of infants in foster care are born to women who abuse substances.<sup>2</sup> The number of women with human immunodeficiency virus (HIV) infection has increased substantially, and most of these women are of childbearing age. Approximately 7000 births occur annually in the United States to HIV-infected women, and most of these women have been infected through heterosexual contact or as a consequence of drug use.<sup>3</sup> Seroprevalence of HIV infection in pregnancy nationwide is 1.7 per 1000 pregnant women, and in New York, where all newborns are tested for the HIV antibody, seroprevalence is 4 per 1000 pregnant women.<sup>4</sup> An inner-city study found that newborns placed in foster care at the time of hospital discharge were 8 times more likely to have been born to HIV-infected women than were newborns discharged to the care of their mothers.<sup>5</sup>

In addition to the increased risk of perinatally acquired HIV infection for those in foster care, children and adolescents in foster care may have been sexually abused, placing them at risk for acquisition of HIV infection. Adolescents who use drugs or are sexually active are also at risk for acquisition of HIV infection, and adolescent risky behavior may precede placement in foster care or may occur while in foster

care. Although advances in antiretroviral therapy for adults have helped decrease the projections of 80 000 to 150 000 children and adolescents orphaned in the United States by the death of their mother to acquired immunodeficiency syndrome by the year 2000,<sup>6,7</sup> many HIV-infected women will still not survive to raise their offspring to adulthood, and their children may enter the foster care system as a consequence of maternal disability or death. Data from the Pediatric Spectrum of Disease project revealed that 45% of children born to HIV-infected women resided with a primary caregiver who was not the biological parent.<sup>8</sup>

Advances in the management of HIV infection include prenatal and postnatal administration of zidovudine to reduce the risk of infection of the infant, recommendations for initiation of *Pneumocystis carinii* pneumonia prophylaxis by 6 weeks of age for all infants born to HIV-infected women, variations in immunization recommendations for infected persons and infants at risk of infection, and recommendations for consideration of early and aggressive combination antiretroviral therapy for those who are infected.<sup>9-11</sup> The American Academy of Pediatrics (AAP) therefore issues recommendations in accordance with these recent advances to address the identification and care of HIV-exposed and HIV-infected infants, children, and adolescents in foster care.

### HIV TESTING OF A CHILD IN FOSTER CARE WHO IS 1 YEAR OF AGE OR YOUNGER

The AAP, the American College of Obstetricians and Gynecologists, and the US Public Health Service have recommended that all pregnant women in the United States receive counseling about HIV infection and the benefits to the mother and her infant of knowing her serologic status and that all pregnant women should undergo routine testing for HIV.<sup>12-14</sup> The Institute of Medicine recently recommended a nationwide policy of HIV testing during pregnancy (with right of refusal).<sup>4</sup> In addition, if the mother's HIV status was not determined during pregnancy, the AAP recommends that, after birth of the infant, the pediatrician discuss with the mother the benefits to the infant of knowing the mother's serologic status and recommend testing at that time.<sup>12</sup>

The management of the HIV-exposed infant is complex and includes continuation of zidovudine prophylaxis during the first 6 weeks after birth, initiation of prophylaxis for *Pneumocystis carinii* pneumonia by 6 weeks of age in all infants born to HIV-

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 women, monitoring of hematologic and immunologic parameters, specific laboratory testing to determine HIV infection status (DNA polymerase chain reaction [PCR] or viral culture), and variations in immunization recommendations.<sup>9</sup> Advances in laboratory diagnosis (DNA PCR and viral culture for HIV) enable physicians to determine infant infection status by 28 days of age in as many as 96% of infants born to HIV-infected women.<sup>15,16</sup> Published data suggest that RNA PCR may prove useful for early identification of infant infection status.<sup>17,18</sup> Prompt identification of infected infants permits early initiation of aggressive antiretroviral therapy with the potential to prevent the rapid progression of illness seen in some HIV-infected infants.

Thus, to provide appropriate medical care for the infant, it is necessary that foster care agencies obtain information about HIV exposure status, if known, for infants placed in foster care. If the maternal serologic status is unknown, the HIV exposure status of infants in foster care, including infants placed in foster care at nursery discharge and infants placed in foster care who are 1 year of age or younger, should be determined by testing the infants for HIV antibody. When the authority to consent to medical care has been transferred from the biological parents to a foster care agency, and the HIV-exposure status of the infant is unknown, the agency should provide consent for HIV testing of the infant and have an established mechanism to facilitate testing and to allow exchange of confidential information with appropriate persons (eg, physician, nurse, caseworker coordinating care for the foster child, biological parents, and the foster parents). Occasionally, legal restrictions may prevent testing of the infant in foster care without maternal consent. In such cases, the physician may need to consult with the foster care agency and legal authorities. Efforts should be made to educate the biological mother, if available, of the potential benefits to herself and to her infant of knowing maternal serologic status. Communication of information about any positive test results to the biological parent(s) or the foster parent(s) should occur in a health care setting with appropriate social service support available at the time of the meeting. Infants who are identified as HIV-exposed (born to an HIV-infected woman) should be managed in accordance with established guidelines.<sup>9</sup>

#### **HIV TESTING OF CHILDREN IN FOSTER CARE WHO ARE OLDER THAN 1 YEAR**

HIV-infected children may remain asymptomatic for years or have mild nonspecific symptoms (anemia, poor growth, developmental delay) that are not recognized as secondary to HIV infection. In a cohort of HIV-infected children, 32 (17.7%) of 181 HIV-infected children were first diagnosed at 4 years of age or older.<sup>19</sup> In another cohort of 42 perinatally infected long-term survivors between the ages of 9 and 15 years, 36 had no symptoms until after the age of 4 years.<sup>20</sup> Two children with perinatally acquired HIV infection have remained asymptomatic for almost 13 years.<sup>21,22</sup> In addition, transfusion-acquired HIV infection may be associated with an asymptomatic or a

minimally symptomatic phase of illness, thus delaying diagnosis of HIV infection.<sup>23</sup> Because of the increasing recognition of HIV infection among older children, foster care agencies should create policies to facilitate testing of older children. Testing for HIV should be performed for all children in foster care with symptoms or physical findings compatible with HIV infection and for all children with a sibling or parent who is HIV-infected. Because factors that lead to placement of children in foster care frequently are associated with an increased risk of HIV infection in the child and parents, determining the status of all older children who are in the foster care system whose maternal serologic status is unknown may be prudent.

Diagnosis of HIV infection is made in a child 18 months of age or older when antibody testing by enzyme-linked immunosorbent assay and the Western blot technique is positive or when the child meets diagnostic criteria for the younger infant (positive HIV-specific diagnostic assays, ie, DNA PCR or viral culture on 2 separate blood specimens from the infant). Results of tests should be provided by the child's physician to foster parents, biological parents (if possible), foster care agency, and the child (if old enough to comprehend and if disclosure is appropriate to the developmental level of the child).<sup>24</sup>

#### **HIV TESTING OF SEXUALLY ABUSED CHILDREN**

Annually, more than 125 000 children and adolescents are sexually abused in the United States, and sexual abuse has been the mode of acquisition of HIV infection in at least 26 children younger than 13 years.<sup>25</sup> As part of sexual abuse evaluation, laboratory testing when performed should include HIV testing. Testing for HIV should be performed at the time of the initial assessment with repeated serologic testing at 6 weeks, 3 months, and 6 months after the incident of sexual abuse for children whose initial test results are negative.<sup>26</sup> Testing also should be repeated if symptoms suggestive of HIV infection occur. Foster care agencies should develop mechanisms to ensure that initial and follow-up serologic tests are obtained when indicated.

#### **HIV TESTING OF ADOLESCENTS IN FOSTER CARE**

HIV-infected adolescents may be unaware of their infection status. Adolescents in foster care, just as those who are not in the foster care system, may acquire HIV infection as a consequence of their own sexual activity or illicit drug use or may have been infected by previous sexual abuse or, rarely, by perinatal transmission. Adolescents who have been victims of sexual abuse are more likely to engage subsequently in sexual behavior that may place them at increased risk for acquiring HIV infection and other sexually transmitted diseases.<sup>27</sup> Homeless adolescents frequently engage in prostitution in exchange for money, food, or shelter, and a period of homelessness may occur before an adolescent is placed in foster care. In a New York City shelter for homeless adolescents, 6% of the residents were seropositive.<sup>28</sup> Intravenous drug use has long been recognized as a risk factor for HIV infection. Cocaine use also has

been reported as a risk factor for HIV infection because it may involve the exchange of sex for drugs or engaging in risky sexual behavior while under the influence of the drug.<sup>29,30</sup> It is important, though, to recognize that the epidemiology of HIV infection is changing and that there is an increased incidence of HIV transmission in the adolescent population through homosexual and heterosexual contact.

For adolescents in foster care (as for adolescents who are not in foster care), HIV testing should be recommended for those who have symptoms or physical findings suggestive of HIV infection and for those who have any of the following known risk factors for HIV infection: a sibling, or parent who is HIV infected, a current or past sexual partner who is HIV-infected or at increased risk of HIV infection; receipt of a blood transfusion before 1985; a history of sexual abuse; a diagnosis of a sexually transmitted disease; or a history of illicit substance use or abuse. In addition, HIV testing should be considered for all adolescents in foster care who are sexually active or have a history of sexual activity and for those whose medical history and family history are unavailable or inadequate for assessment of the aforementioned risk factors. Evaluation should be performed in the context of provision of comprehensive adolescent health care, and all adolescents should receive education and counseling from a health care professional about prevention of transmission of HIV infection.

All states allow adolescents to consent to confidential evaluation and treatment for sexually transmitted diseases.<sup>31</sup> In some states, adolescents may legally consent to confidential HIV testing and treatment. Testing of the adolescent should be performed with assent of the adolescent.<sup>32</sup> If testing of the adolescent is performed in association with evaluation for sexual abuse or because of high-risk behavior, foster care agencies and physicians providing such care should ensure that appropriate follow-up testing is obtained. Communication of positive test results to the adolescent should occur in the health care setting. State regulations may require consent of the adolescent for disclosure of test results to other individuals or agencies participating in the adolescent's care.

## **ISSUES RELATED TO THE CARE OF HIV-EXPOSED AND HIV-INFECTED INFANTS, CHILDREN, AND ADOLESCENTS IN FOSTER CARE**

### **Provision of Medical Care**

Foster care agencies should periodically review, with physician guidance, the agency policies pertaining to the care of HIV-exposed infants and HIV-infected infants, children, and adolescents. In addition, periodic review should occur of policies related to acquisition and communication of medical information and other confidential information for those in foster care, including infants placed in foster care at the time of hospital discharge. It is the responsibility of the discharging physician to provide records, including confidential HIV-related information, to the physician designated to assume care or to the agency for provision to the physician who will assume care. Similarly, when a child or adolescent

initially is placed in foster care, the agency should contact the physician providing care to obtain complete medical records and determine if there are acute or chronic medical problems that require medical follow-up, the immunization status, and whether the person is taking medication.

Maintenance of a "medical home" is important in the care of all foster children and is particularly beneficial for those with chronic health problems, such as HIV infection.<sup>33</sup> Foster care agencies should ensure, in the event of a change in physicians, that complete medical and immunization records are transferred to the new physician. Agencies providing foster care should minimize or eliminate barriers to sharing confidential information among counselors, mental health professionals, caseworkers, and the physician providing care to the child or adolescent. Comprehensive care for HIV-exposed infants and HIV-infected infants, children, and adolescents requires coordination of care among multiple health care professionals and social service agencies. Use of the "health passport" (a booklet summarizing medical information, including illnesses, medications, immunizations, family history, and names of current and previous physicians) for children in foster care can assist in communication of information if the child changes physicians or is placed in a new foster home.<sup>34</sup>

With the increasing identification of HIV infection among pregnant women, there also has been increasing use of prophylactic zidovudine to reduce the risk of perinatal HIV infection.<sup>35</sup> This regimen is considered safe for mother and child.<sup>36</sup> However, the long-term consequences of in utero exposure to zidovudine and other antiretroviral agents are unknown. It is critical that information about in utero exposure to antiretroviral drugs be included in the medical records of infants born to HIV-infected women. All such infants, whether infected or uninfected, should receive long-term follow-up.

Owing to rapid advances in management of HIV infection, involvement in clinical trials may provide benefit to HIV-exposed infants and HIV-infected infants, children, and adolescents in foster care. In addition, clinical trials that do not involve a therapeutic agent but provide long-term follow-up of HIV-exposed and HIV-infected children and adolescents provide important benefits. Agencies providing foster care should have established procedures for access to studies and to clinical trials.

### **Foster Parent Education**

Foster care agencies should provide education about HIV to all foster parents as part of their initial training. Such education should be updated periodically and should include infection control guidelines for use in the home setting.<sup>37</sup> Foster parents should be aware that there may be HIV-infected infants, children, and adolescents in foster care whose HIV status is unknown. Foster parents providing care to HIV-exposed infants should be educated about all issues in the management of the HIV-exposed infant that usually are discussed with the biological parent.<sup>9</sup>

Because provision of medical care for HIV-ex-

posed infants and HIV-infected infants, children, and adolescents is complex and requires frequent office visits, foster care agencies should develop procedures to ensure that those in foster care are seen at intervals deemed appropriate by the physician. If an HIV-exposed or HIV-infected child in foster care is transferred to a different foster home, the physician should be notified promptly (preferably before the transfer) to enable the physician to adequately inform the new foster parents about the child's health care needs, provide ongoing medication, and assist with additional education of new foster parents about HIV infection.

### Permanency Planning

Although many children born to HIV-infected women are already in foster care or in the care of relatives outside the foster care system before the onset of debilitating complications in the mother or maternal death, infected women may not have made plans for provision of care for their children. In addition to determining who will provide care, it is necessary that provisions be made for long-term access to health care (physical and psychological) for HIV-infected offspring and for uninfected offspring. Permanency planning is a coordinated effort involving health care professionals, mental health professionals, social workers, foster care agencies, legal personnel, the biological family, and the designated "second family."<sup>38</sup>

### CONCLUSION

These recommendations about HIV testing of infants, children, and adolescents in foster care and for enhanced coordination of care by physicians and foster care agencies are made to provide maximal opportunity for those in foster care to benefit from the dramatic medical advances in the care of HIV-exposed and HIV-infected infants, children, and adolescents.

### RECOMMENDATIONS

1. Physicians and foster care agencies should be jointly responsible for the determination of HIV exposure status and HIV infection status for all infants in foster care. If maternal serologic status during the most recent pregnancy is unknown, and the state has guardianship and the authority to consent to medical care, the infant should be tested for HIV antibody. Infants exposed to HIV should be managed in accordance with established guidelines.<sup>9</sup>
2. Testing for HIV should be performed for all children in foster care who have:
  - symptoms or physical findings suggestive of HIV infection;
  - been sexually abused;
  - a sibling who is HIV-infected; or
  - a parent who is HIV-infected or is at increased risk of HIV infection.

Testing for HIV also should be considered for all foster children whose maternal serologic status is unknown.

3. Testing for HIV (with assent of the adolescent) is recommended for all adolescents in foster care who have:
  - symptoms or physical findings suggestive of HIV infection;
  - a sibling who is HIV-infected;
  - a parent who is HIV-infected or at increased risk of HIV infection;
  - a current or past sexual partner who is HIV-infected or at increased risk of HIV infection;
  - received a transfusion before 1985;
  - a history of sexual abuse or a diagnosis of sexually transmitted disease; or
  - a history of illicit substance use or abuse.

Testing for HIV also should be considered for all adolescents in foster care who are sexually active or have a history of sexual activity and for those whose medical history and family history are unavailable or inadequate for assessment of the aforementioned risk factors.

4. Physicians and foster care agencies should take joint responsibility to ensure appropriate exchange of complete medical records and confidential information necessary for the management of infants, children, and adolescents in foster care.
5. All foster parents should receive education about HIV infection, and the content of such education should be updated regularly.
6. All foster parents should be informed of the HIV exposure or infection status of infants and children in their care. Disclosure of adolescent HIV status should legally require the consent of the adolescent.
7. Foster care agencies should have established procedures to provide access for HIV-infected and HIV-exposed foster children to treatment-related and non-treatment-related clinical trials.

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