

# ABUSE, NEGLECT, AND THE HIV-INFECTED CHILD

JANINE M. JASON

Chief, Applied Communications Research and Evaluation, National AIDS Information  
and Education Program, Centers for Disease Control, Atlanta, GA

## INTRODUCTION

THIS MEETING concerns an issue that is close to my heart, child abuse prevention. Child abuse is the problem I would most like to see resolved in the coming decade, despite the reality that we are far from this goal.

I will first give an overview of the problem of human immunodeficiency virus (HIV) infection as it affects the child and then discuss some of the abuse- and neglect-related problems we may be seeing because of HIV infection in the coming decade and into the 21st century. This presentation will not dwell upon the international aspects of this infection, for it is drawn mainly from United States data. However, the issues brought up are pertinent to many developed countries. The HIV-related problems in some less developed countries, especially in Africa, are even worse than those of the U.S., but will not be gone into here.

The effect of HIV on child abuse prevention must be considered on two different levels. The first consists of indirect effects, the extent to which this infection will be a burden on the health care, social service, and public assistance systems in this and other countries, leading to decreasing resources for child abuse prevention. The second is the direct effect the HIV epidemic will have in terms of abuse and neglect of HIV-infected children.

## IMPACT OF HIV ON THE HEALTH CARE SYSTEM

When we think of what we want done to prevent child maltreatment in the 21st century, the financial burden of HIV must be considered, for it will indirectly affect funding to many other programs and this effect must be dealt with quickly. The following data will make this issue clearer. The data presented first are from a Public Health Service meeting in Coolfont, West Virginia, in June 1986. The purpose of that symposium was to make projections of HIV-related health care needs in coming years and to estimate the current HIV infection rate in the United States. Remember that these estimates were presented in June 1986, when the symposium took place. At that time, between one and one and one-half million people were estimated to be infected with this virus. This figure was not broken down by risk groups and the data as shown in Table 1 needs expansion in at least 2 pediatric-relevant areas: (1) We do not have accurate rates of HIV infection in hemophilic patients, many of whom are school-aged children; and (2) there are still very little data on rates of HIV infection in infants. The states of Massachusetts and New York probably provide the best information on infant rates (see

**Table 1. Estimates of Prevalence of HIV Infection in the United States, 1986**

Population	Estimated Size	Approximate Seroprevalence	Estimated Number Infected
1. Exclusively homosexual throughout life*	2,500,000	18%	450,000
2. Other homosexual contact*	2,500,000 to 7,500,000	10%	250,000 to 750,000
3. Intravenous drug abusers**	750,000	30%	225,000
4. Other (less frequent) IV drug abusers**	750,000	10%	75,000
5. Other (hemophilic patients, transfusion recipients, infants, heterosexual contacts)	?	?	?
Total Infected			1,000,000 to 1,500,000

Note: \* Size estimate derived from Kinsey, et al., 1948.

\*\* Size estimate from the National Institute of Drug Abuse.

Tables 2a and 2b). Related to these two specific deficiencies is the fact that there are no national figures on the rate of HIV infection, as opposed to AIDS, in infants or older children.

While the overview of pediatric AIDS presented here consists of only those with end-stage disease and thus does not represent cases of asymptomatic HIV infection in children, the demographic information does provides us with a picture of all infected children. It allows us to begin to think about what might be needed for prevention and intervention, realizing every step of the way that we are seeing numbers that represent the proverbial tip of an iceberg, since the symptoms of HIV infection range all the way from CDC-defined AIDS down to years-long asymptomatic HIV infection.

As of October 5, 1987, there were 584 cases of CDC-defined pediatric AIDS. Of these, 54% were in blacks and 24% were in Hispanics (Table 3). This is an ethnic distribution not unfamiliar to many working in the child maltreatment area. The age distribution seen in Figure 1 shows a predominant occurrence in infancy and a secondary increase in cases at the adolescent ages. The largest transmission categories (Table 4) represented here are perinatal infection from HIV-infected parents, infection through blood transfusions, and infection through blood clotting components. The geographic areas with the highest prevalence of pediatric AIDS are those also most affected by AIDS in the adult age group, namely, New York, New Jersey, Florida, and California (Tables 5 and 6). Approximately 20 other states have at least 1% of all pediatric AIDS patients each, and almost every state in the United States has at least one case of pediatric AIDS (Table 6). Figure 2 shows the proportion of children who developed AIDS each year since 1980 who have died. Obviously, the longer a child has had AIDS, the higher his probability of death. With no available treatment, mortality from AIDS is virtually 100%.

**Table 2A. HIV Seroprevalence Rates Newborn Blood Samples in Massachusetts\***

Area	Rate per 1000 Live Births
Inner city	8.0
Urban/suburban	2.5
Suburban/rural	0.9
Overall	2.1

\* Done by heel sticks (From *New England Journal of Medicine*, 1988).

**Table 2B. HIV Seroprevalence Rates in Cord Blood Samples in New York**

Area	Rate per 1000 Live Births (LB)	
Bronx	23.4	1 in 43 LB
Manhattan	19.6	1 in 51 LB
Brooklyn	17.4	1 in 58 LB
Outside New York City	1.3	1 in 749 LB
New York State	8.6	1 in 177 LB

From *New York Times*, 1988 ( $n = 19,157$ ).

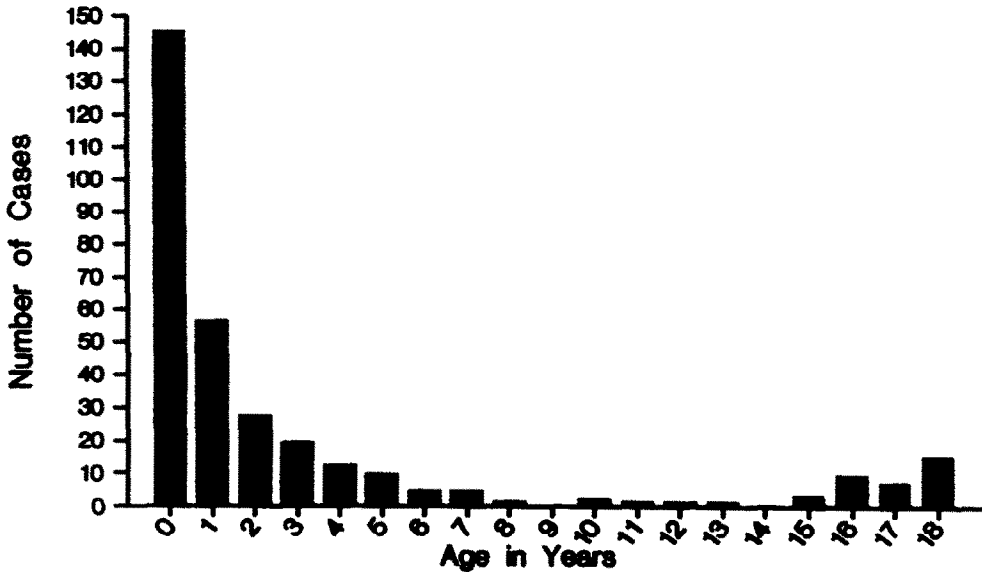
We should remember that these tables and figures concern only CDC-defined AIDS. There are at least two earlier stages of HIV disease: the healthy carrier state and the symptomatic, pre-AIDS state. In fact, HIV infection is best thought of as a spectrum, or continuum, of disease. The earlier stages include far larger numbers of infected individuals. When one thinks of dealing with the problem of HIV, one has to consider children at all stages of the disease, not just with AIDS. Also one needs to remember that the Coolfont Symposium estimated that one to one and a half million people are infected. Ten to 30% of infected people may be diagnosed as having AIDS after being infected more than five years. In addition, it is estimated that about a third of the infants borne by infected women will themselves be infected. When we consider that HIV is a virus with an incubation period of over five years, we realize we are very early on in this epidemic. We do not know what the upper limit of the incubation period is, nor the upper limit to the proportion of infected people who will develop AIDS. It is conceivable that a person's risk of developing AIDS once he has been infected with HIV will only be limited by his chances of dying of a competing cause of death. By the end of 1991, an estimated 270,000 cases of AIDS will be diagnosed in the United States, with an estimated—and this is a very rough estimate—direct cost for medical care of eight billion dollars.

### HIV-RELATED CHILD ABUSE ISSUES

Now that we have a general view of what is known about the demographic characteristics of HIV infection in children, we will discuss four HIV issues that have direct child abuse or neglect implications, starting with the issue of school attendance, moving on to hospitalization of the HIV-infected child, then to foster placement, and finally to a very brief discussion of HIV and the sexually abused child. I do not claim any solutions to these problems; rather, I raise them as issues to face in the coming years.

**Table 3. Cases of Pediatric AIDS, By Race and Age, Centers for Disease Control, October 5, 1987**

Race	Age Group in Years		
	Under 5	5-12	13-19
White	89	32	71
Black	290	27	63
Hispanic	124	16	32
Other/Unknown	4	1	4
Total	507	76	170



\*includes children under 13 years of age reported as of May 20, 1986

\*\*includes teenagers between 13 and 19 years of age reported as of May 20, 1986

Figure 1. Age distribution of pediatric\* and adolescent\*\* AIDS cases, United States.

### *Ostracism in School*

The first HIV-related child abuse issue is the potential ostracism of an HIV-infected child enrolled in school. In this discussion, we must first differentiate between the HIV-infected child who does not have AIDS and the infected child with AIDS. This distinction is important in a couple of respects, but society—the public at large—has trouble intellectually differentiating between an infected child without severe symptoms and one with severe HIV-related disease. The public often limits its thinking to, “If a child has AIDS, keep that child away from my children.” Clearly, this is inappropriate for any HIV-infected child. But by distinguishing symptomatic and asymptomatic children, we can address an appropriate concern involving an HIV-infected child in the school setting. Our concern should not be what is the risk of an HIV-infected child infecting others in a school setting. A child with HIV infection, whether he

**Table 4. Transmission of Human Immunodeficiency Virus in Children**

1) Young Children $\leq 5$ years of age
Perinatal transmission
in utero
intrapartum
postnatal
Transfusion of blood/blood products
2) Children 6–12 years of age
Hemophilic patients
Children undergoing transfusion therapy
3) Adolescents (very much like adults)
Sexual contact
IV drug use
Transfusion of blood products
Hemophilic patients

**Table 5. Comparison of Reporting Trends for Pediatric AIDS\* in High and Low Prevalence Areas in the United States**

Year of Diagnosis	Number and Proportion of Cases Residing in Area					
	High Prevalence**		Low Prevalence***		Total Cases	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
1979-81	12	71	5	29	16	100
1982	16	67	8	33	24	100
1983	47	77	14	23	61	100
1984	53	73	20	27	73	100
1985	58	59	40	41	98	100
1986	12	57	9	43	21	100

\* Includes reported children under 13 years of age as of May 27, 1986.

\*\* New York, New Jersey, Florida, California.

\*\*\* All other states.

has AIDS or not, cannot infect anyone through casual contact. Rather, the question is what is the risk of a school setting to an HIV-infected child? This is not a question for parents and teachers, however. It is a medical question that can be monitored only by a particular infected child's physician. Depending on the child's stage of HIV-related disease, being in school may present a risk to his own health. The child with AIDS may be at risk of infections with which he may come in contact in the school setting. These risks associated with school attendance may differ for a preschool child with a relatively immature immune system from the risks associated with the school attendance of a grade school child. Again what needs to be concentrated upon is not the risk to the community—the needless worry that the community tends to concentrate on—but rather the risk, if any, to the infected child and how that risk compares to the positive aspects of his being in school and with other children.

In thinking of school attendance of the HIV-infected child, again reflect upon the most common routes of transmission for different pediatric age groups: perinatal transmission and transmission through blood and coagulation products. At this time, the majority of perina-

**Table 6. Cases of Pediatrics AIDS, By State, Centers for Disease Control, October 5, 1987**

State	Percent
New York	36.3
New Jersey	13.2
Florida	11.5
California	6.7
Puerto Rico	3.9
Texas	3.3
Massachusetts	2.7
Connecticut	2.4
Georgia	2.2
Illinois	1.9
Pennsylvania	1.9
Maryland	1.9
District of Columbia	1.4
Virginia	1.4
Michigan	1.0
Alabama	1.0
Louisiana	1.0

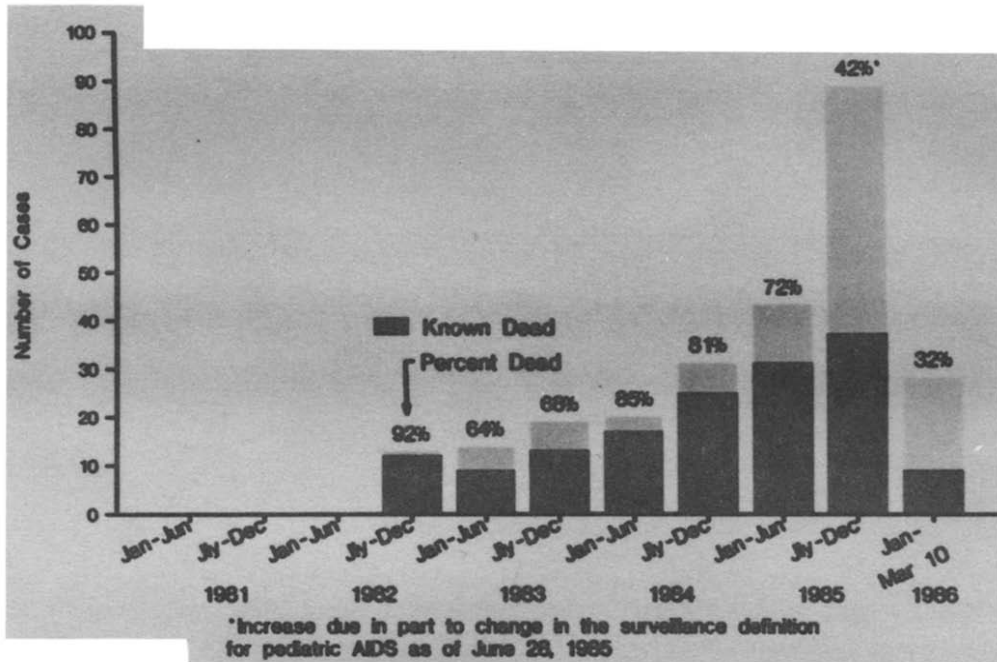


Figure 2. Pediatric AIDS: Case-fatality rate by half year of report to CDC, United States, March 10, 1986.

tally infected children are of preschool-age or younger. The HIV-infected group that is now of school age consists of (1) hemophilic children who acquired their infections through the blood components they must use, (2) adolescents acquiring their infections through sexual contact or intravenous drug abuse, and (3) children infected through blood transfusions. Since 1985, blood donors have been screened for HIV antibody, and blood factor products are now treated to inactivate HIV. So blood product recipients and hemophilic patients are now no longer at risk of HIV infection. This unfortunately does not resolve the problem of those infected prior to 1985.

In addition to considering the current ages of those infected, we remember that these infected children will be getting older. Infected pre-teen hemophilic children will soon be adolescents, and perinatally infected infants will increasingly survive to reach school age, because of therapeutic developments. So pediatric HIV infection is a growing problem that will not only worsen with time, but also change in its characteristics. Without forgetting that point, we look at some information concerning a small but currently predominant population of school-aged HIV-infected children—hemophilic boys.

Hemophilia A is a genetically based deficiency of Factor VIII, a protein normally found in the blood and needed in clotting. Hemophilia B is a deficiency of Factor IX, another protein found in the blood and needed for clotting. Both hemophilia A and B have a sex-linked inheritance and thus occur almost exclusively in males. The vast majority of people with severe hemophilia A or B, ("severe" is defined as having less than 1% normal clotting activity), will have significant problems with clotting when they bleed. They do not bleed spontaneously. In the United States there are approximately 6,800 people with severe hemophilia A. These patients' bleeding can be controlled with factor infusions; decontamination of any external bleeding can be easily done with ordinary household bleach.

Factor concentrate products have been available since the mid-1970s. With the development of concentrate technology, the life outlook of a child with hemophilia underwent a radical reversal. In the 1960s, a child with hemophilia could expect a life of debilitation and an

early death. With the availability of factor concentrate products in the mid-1970s, a hemophilic child could suddenly look forward to a fairly normal life with a fairly normal life span. Sadly, with the decade of the 80s, some blood donors became infected with HIV. Factor concentrates pool the contributions of thousands of donors, so hemophilic patients became exposed to HIV contaminating these life-saving products over a matter of several years. Suddenly—just as suddenly as 5 to 10 years earlier—everything again changed. Hemophilic patients' outlooks again reversed, now to the most grim of futures. HIV infection has been devastating to hemophilic patients. By 1984, approximately 72–90% of people with severe hemophilia A had already been infected with HIV and approximately a third to a half of the people with moderate to mild hemophilia A or hemophilia B had become infected. In 1984, it was shown that heating would inactivate HIV, and in 1985 blood donor screening for HIV antibody was initiated. Thus, the epidemic in the hemophilic population was virtually over in 1984. Sadly, the majority of these patients had already been infected, although hemophilic infants and toddlers, not yet treated with factor products, are not infected. Seroprevalence rates thus are very low for hemophilic infants, and HIV infection will be present in an aging population of patients exposed before 1985. Thus, these infected hemophilic children will soon become a small population of sexually mature, infected adolescents and young adults.

When we consider an even younger group—perinatally infected children, we see that perinatal infections are occurring at an increasing rate, but in addition currently infected infants are aging. The survival of infected children will improve as HIV therapeutic regimens are developed. Current therapies have so far not decreased the mortality rate for AIDS, but they have prolonged life. So it is reasonable to expect that perinatally infected children will eventually be living long enough for society to be increasingly confronted with their attendance in preschool and elementary school.

Again we ask whether there is any reason to ostracize these children. No study to date has disclosed a case of HIV transmitted through casual contact. Our own ongoing studies concerning transmission in hemophilic households now include over 200 household members having intense and prolonged, nonsexual contacts with hemophilic patients, including the administration of their factor products. None of these individuals have become infected with HIV. When our own data are added to date from other studies, we find that there are over 1,000 persons studied who had prolonged nonsexual contacts with HIV-infected persons, without a single seroconversion. Casual, nonsexual interactions with an HIV-infected child are of no risk to schoolmates and teachers.

The most appropriate place to start concerning the issue of maltreatment of the HIV-infected child in the school setting should be a determination of the extent of the problem. To date, we have only anecdotal information concerning the ostracism of HIV-infected school children. Of the cases about which we have been contacted, most have been eventually resolved by the child's acceptance into school. The one well-known exception is the case of three hemophilic boys in Florida. That case is a good example of why HIV-risk education should be given to school and community members before a specific HIV-infected child becomes identified. If education is attempted after the fact, so to speak, irrational fears may already be so aroused that people may quite simply be unable to pay attention to facts and reality. Future problems must be prevented by educating the community, teachers, and students, before any specific child becomes involved in an abusive situation. Intervention and prevention techniques must involve the community, the school, the parents, and other school children.

### *Hospitalization of the HIV-Infected Child*

We next consider the issue of the HIV-infected child in the medical setting. The perinatally infected child is the one most commonly hospitalized. To those who have worked in child

**Table 7. Pediatric AIDS: Clinical Manifestations March 10, 1986 (N = 256)**

Opportunistic Disease	#	%
<i>P. carinii</i> pneumonia	147	57
Chronic interstitial pneumonia	121	47
Disseminated cytomegalovirus	45	18
<i>Candida</i> esophagitis	40	16
Disseminated <i>Mycobacterium avium</i>	20	8
Cryptosporidiosis	15	6
Chronic herpes simplex	14	8
Others	18	7

abuse treatment, the HIV-infected infant can be recognized as looking very much like a child with failure-to-thrive. And indeed, failure-to-thrive is a major medical problem of HIV-infected children. In addition, after approximately the age of 6 months, these children have chronic and recurring serious opportunistic and bacteria infections (Table 7). What are the maltreatment concerns surrounding the HIV-infected child in the medical system? Again, we must remember that the HIV epidemic in infants is growing, not stagnant. Furthermore, the problems will differ between in-patient, as opposed to out-patient, settings and between private and public hospitals. For example, personnel in a private hospital may not have as great a familiarity with HIV-infected children as do those in a public hospital. Thus, in a private hospital setting health care providers may exhibit a greater amount of irrational fear. An HIV-infected child in a public hospital setting must often face very different problems—the typical problems of public hospitals (i.e., inadequate hospital staffing and overworked health care workers), creating an environment of almost inevitable neglect. Education must be specifically targeted to each of these settings. The type of education and the extent of other activities required to eliminate neglect differ between these two settings. Neglect of the hospitalized HIV-infected child, be it due to fear or to caretaker exhaustion, must be prevented. Furthermore, it must be dealt with in a medical system in which some health care providers may be more concerned with their own safety than for their infected patients' well-being. Again remember the cost of the HIV epidemic to the health care system is going to be great. By the year 1991 there will be approximately 1,000 cases of pediatric AIDS, and this figure includes only children less than 13 years of age, not adolescents.

### *Foster Placement*

Moving from the problems of the HIV-infected hospitalized child, we come to the issue of foster placement or non-hospital care of the HIV-infected child. Finding foster care for an perinatally infected child is even now a not infrequent problem for the social services system. Recall that most of these infants are children of drug-abusing parents (Table 8). These infants frequently come from minority populations immersed in poverty. It must be remembered that the mothers of these perinatally infected infants are themselves HIV-infected. Thus, in addition to having social and drug abuse problems that might preclude their caring for their children, these mothers themselves may become ill or die of HIV infection. Foster placement is a very real issue with these children and will become increasingly serious as therapies prolong life in coming years. These are children from populations traditionally difficult to place in foster care. In addition, not all placements would be acceptable in light of these children's state of immunologic deficiency. Children with significant effects upon their immune systems are at heightened risk of infection in certain placement and settings. For example, it may be unwise to place them in foster settings with a large number of other young



**Table 8. Risk Categories of Mothers of Children with Perinatally Acquired HIV Infection\***

Category	Number	Percent
Intravenous drug abuser	136	60
Haitian-born	40	18
Sexual contact with:		
Intravenous drug abuser	29	17
Bisexual male	7	13
Infected partner of unknown risk category	1	<1
Received blood transfusion	4	2
Mother infected but of unknown risk category	9	4

\* Includes children under 13 years of age reported as of May 20, 1986.

children, who may become infected at one time or another with any number of common childhood pathogens. Finally, many of these children have neurologic symptoms of HIV infection that will affect their development, behavior, and ability to be placed. These neurologic problems may even present as sudden and irreversible developmental deterioration, adding additional problems in finding and retaining foster placement.

#### *HIV Antibody Screening of the Sexually Abused Child*

Lastly, let me mention the issue of HIV infection and the sexually abused child. Information concerning other sexually transmitted diseases (STDs) occurring in the sexually abused child provide us with insights pertinent to this issue. As we do with other STDs, we must first assess whether the abuser was likely to have been infected with HIV. At this point in time, in most areas of the United States, a child abuser is unlikely to have been infected with HIV. However, in certain areas such as New York and parts of Florida, this may not be the case. Most important, it would be wise to consider the potential risk of HIV before the probability of an abuser being infected increases to the point that the problem is upon us.

Obviously, the functional question to be addressed is whether the sexually abuse child needs to be screened for HIV infection. By now we all understand enough about HIV transmission to know some of the questions that should be asked, not asked generically, but rather asked on an individual, case-by-case basis. Again, our experiences with other STDs provide us with guidance here. As already mentioned, the first set of questions concerns "How likely is it that the abuser might be infected?" In what area of the country did the abuse occur? Was it an urban or rural area? Was the abuser known or suspected of engaging in high-risk behaviors? The second set of questions concerns the nature of the abuse. Was there vaginal intercourse? Was there rectal intercourse? if not, the risk of HIV transmission, even if the abuser was infected, would be extremely low.

If the decision is made that the possibility of HIV infection must be dealt with, we must remember that infection status cannot be resolved immediately following an acute abuse incident. This is a point which is often forgotten in terms of other STDs and will frequently be forgotten in terms of HIV infection. Screening for HIV antibody immediately following an abuse incident provides information concerning the child's status prior to that particular abuse incident, not due to that incident. It takes approximately two to six weeks for an individual who has been infected with HIV to form antibodies to the virus. In rare cases it may take more than six weeks for an infected person to form antibodies to the virus; but for all practical intents and purposes, if a child is HIV antibody-negative several months following an abuse incident, the child can be considered uninfected with HIV. As with all HIV antibody testing, if an abused child is tested for HIV antibody, that testing should include a screening

**Table 9. Laboratory Tests for Infection with HIV**

---

1) Screening Test for Antibody: Enzyme immunoassay (EIA, ELISA)
2) Confirmatory Test for Antibody: Western blot assay or Immunofluorescence test
3) Viral Culture
4) Polymerase chain reaction for DNA

---

assay, usually done by an enzyme immunoassay. If that test is positive, the positivity must be confirmed by a second, more specific, technique. This confirmation is usually done by a western blot analysis (Table 9). If it has been decided that an abused child should be tested for HIV antibody, it must be remembered that that decision will almost certainly create great anxiety on the part of the parent and, if the child is old enough to comprehend the implications, the child as well. The HIV antibody test should therefore always be done in association with careful pre- and post-test counselling of the parents (and, if the child is an adolescent, the child as well). The counselling should be done by a well-trained individual and should include information about the meaning and implications of negative and positive findings.

To summarize, we have shared a brief overview of the epidemiology of pediatric AIDS and then discussed a number of other issues with possible child abuse or neglect implications. These included the management of an HIV-infected child in the school, hospital, and foster placement settings. In addition, we have considered broad suggestions as to how to address the question of whether and when a sexually abused child should be tested for HIV antibody. Hopefully these thoughts will be useful in our consideration of how HIV may affect child abuse prevention in the 21st century.

## REFERENCES

- Hoff, R., Berardi, V. P., Weiblen, B. J., Mahoney-Trout, L., Mitchell, M. L., & Grady, G. F. (1988). Seroprevalence of human immunodeficiency virus among childbearing women. *New England Journal of Medicine*, *318*(9), 525-530.
- Kinsey, A. C., Pomeroy, W. M., & Martin, C. E. (1948). *Sexual abuse in the human male*. Philadelphia: W. B. Saunders.