Social, Medical, and Legal Implications of HIV Testing in Foster Children

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I dedicate this thesis to social workers and health care workers involved in caring for HIV-affected children and their families.

GENERAL INTRODUCTION

Children have been dying of AIDS since the first days of the epidemic. Although not reported by the Centers for Disease Control (CDC) until December of 1982, cases of AIDS in children have been reported retrospectively in San Francisco and New York from as early as 1978.[1] Children with AIDS and HIV infection have medical and social problems that require special attention--these children often come from families suffering from the effects of poverty, racism, and drug abuse. Subsequently, children from these families frequently come to the attention of child welfare agencies. This paper provides a comprehensive overview of HIV infection in foster children, and explores in detail some major public policy issues regarding such children.

The first two chapters of this paper lay the groundwork by describing the basic virology, pathology, and epidemiology of pediatric AIDS. The third chapter gives a short history of the foster care system in the United States and describes the impact of the AIDS epidemic on this system.

Then begins a discussion of the crucial and unsettled policy issues which are important to foster children with HIV infection. Specifically: what does testing or screening for HIV infection mean and how should it be carried out for this population of children? What are the social, medical, and legal implications of such testing?

In the final part of the paper, a specific region of California serves as a case study. First I will examine the individual responses of six San Francisco Bay Area counties to the problem of HIV infection in foster children. Then I will describe an innovative effort

to improve these responses in a collaborative fashion and to design a comprehensive set of guidelines for the counties to use in order to best assist these children. I will argue that this effort may serve as a model to other regions of the country which are searching for effective and humane ways to respond to these difficult issues.

CHAPTER I: AN INTRODUCTION TO AIDS AND HIV INFECTION IN CHILDREN

Acquired Immunodeficiency Syndrome (AIDS) was first publicly described in June of 1981.[2] In 1983, the virus thought to cause this new disease was identified and is now known as the Human Immunodeficiency Virus or HIV. In this chapter, I will discuss the basic virology and pathology of HIV infection in children as well as describe some of the current techniques for diagnosing pediatric HIV infection. In addition, an overview of the current understanding of perinatal transmission and the effects of HIV infection in infants will be reviewed.

It is important to understand that infection with HIV causes a spectrum of illnesses--from an asymptomatic infection to the usually lethal syndrome called AIDS. The CDC has established strict criteria for the case definition of AIDS,[3] but many children with symptomatic HIV infection are excluded from the official CDC count. Children with AIDS or symptomatic HIV infection may present with a complex clinical picture that is not readily identifiable as HIV infection. The CDC has revised its classification system for children under the age of thirteen in an attempt to incorporate standards for assessing both AIDS and HIV infection (Appendix A); however, the confusion surrounding an exact diagnosis for many children infected with HIV remains.[3]

Common clinical features of HIV infection in children include failure to thrive, lymphadenopathy, hepato-splenomegaly, chronic

diarrhea, pneumonitis, and bacterial and viral infections. In addition, many of these children experience neurological and developmental problems that may mimic other illnesses or clinical syndromes. Death may occur in an infant with HIV infection before enough criteria are met to definitively establish the diagnosis of AIDS.[4,5,6]

There is a difference between having symptoms of HIV infection and being an asymptomatic carrier of the virus. Children may be asymptomatic for several years. Therefore, the presence of HIV antibodies does not mean the child is presently ill.[4,6]

The risk of infection for a baby born to an HIV-infected mother has not been firmly established. Between one-third and one-half of HIV-infected women may pass the virus to their unborn children.[7] The presence of maternal antibodies may obscure the child's true state of infection until he or she is fifteen months old. A positive HIV test in asymptomatic children under the age of fifteen months only establishes risk of HIV infection. Obviously, in a child who shows symptoms of HIV infection, the presence or absence of HIV antibodies will confirm the diagnosis of HIV infection.

Pathogenesis of HIV Infection and Acquired Immunodeficiency Syndrome

Acquired Immunodeficiency Syndrome is caused by a human T-cell lymphotrophic retrovirus. Human retroviruses use reverse transcriptase to transcribe DNA from the viral RNA. This DNA is then incorporated into the human cellular DNA producing a persistent and lifelong infection with HIV. The virus may remain dormant for months to years, but after an unknown activating event, viral

proteins are made and are released from the cell via cell lysis. The free virus then infects other cells directly or infection occurs through cell fusion.[8,9]

Experimental evidence suggests that the virus preferentially infects T-cells and monocyte/macrophages bearing CD4 receptors. The monocyte/macrophage appears to be the initial cell infected and may serve as the source of viral replication and persistent infection. It is thought that the virus may also infect neuroglial cells which may help explain the neurotropism or affinity for nervous tissue of HIV.[5,6,8]

HIV has been isolated from blood, semen, vaginal fluid, saliva, breast milk, cerebrospinal fluid, and urine. However, HIV is found in the highest concentration in blood.[8]

HIV infection of immune cells may result in immunodeficiency by several mechanisms. Direct cell killing of HIV-infected cells by cytotoxic T-cells and direct interference with immune function are some of the mechanisms thought to result in immunodeficiency.[4,6] HIV infection of T-cells may produce secondary defects such as abnormal monocyte/macrophage function, decreased natural killer cell activity, decreased antibody formation, and decreased T-cell immunity. Because of the macrophage's central role in T- and B-cell immunity, abnormal macrophage function may play a primary role in early immunodeficiency.[4,6]

Perinatal Diagnosis of HIV Infection

The diagnosis of HIV infection during the neonatal period is crucial in identifying infants who may benefit from early

intervention and treatment. The diagnosis of HIV infection in infants is complicated by the presence of maternal IgG antibodies, the difficulty in performing viral culture, and the lack of reliable tests for HIV-specific IgM.[10] Recently Ou et al. have applied the technique of polymerase chain reaction to amplify viral DNA in HIV-infected cells of infants, and while the technique is promising, it still needs to be refined and further tested before it will be widely available.[10]

HIV infection is usually diagnosed by the enzyme-linked immunosorbent assay (ELISA) test. The ELISA detects antibodies to all HIV proteins.[8,11] As previously mentioned, infants under the age of 15 months may have received passive transfer of maternal antibodies and have a positive ELISA test, but may not be infected with HIV. In addition, some HIV-infected infants become hypo-gammaglobulinemic and are unable to generate an adequate antibody response which leads to a falsely negative test.[6] Another problem with the ELISA test is the possibility of false positive tests results--the ELISA is highly sensitive and as such is designed to detect as many truly HIV-positive people as possible. Because of this high sensitivity, a certain percentage of people will test positive who are truly HIV negative. The predictive value of the ELISA test is dependent upon the prevalence of HIV in the population--false positives are more likely to occur in low prevalence populations.[6] A positive ELISA test result is confirmed by the more specific Western blot techniques.[6,11] The Western blot detects antibodies against specific viral proteins rather than all viral proteins (as does the ELISA), but technical difficulties and differing criteria for interpretation of the Western blot can lead to invalid results.[12]

HIV infection in infants can be confirmed by the direct identification of virus in blood or tissue.[6,8] This is done either by direct viral culture or serologic antigen (rather than antibody) detection method. However, viral culture for HIV is not readily available in most clinical settings and the diagnosis of HIV in infants remains elusive. Clinicians often use other laboratory tests, such as T4 lymphopenia, anemia, and total lymphopenia to help confirm the diagnosis of HIV in symptomatic infants under the age of 15 months or in those children who are seronegative, but would be antigen positive if the test were available.[6]

The age at diagnosis varies between children infected perinatally and children infected from blood transfusions. The median age at diagnosis for children born to high-risk mothers is eight months and for children receiving blood transfusions it is nineteen months.[8]

Diagnosing HIV infection as soon as possible in infants has become more crucial. Infants infected with HIV can now be treated with antiviral and other medications as they become available.[13] In addition to facilitating medical intervention, early diagnosis may help elucidate exactly when maternal-infant transmission occurs.

Diagnosis of HIV infection in Children

HIV infection in children over the age of fifteen months is usually diagnosed by the enzyme-linked immunosorbent assay (ELISA) test and confirmed by Western Blot techniques. Some children never make antibody to HIV and diagnosis then depends upon a positive viral culture or demonstration of p24 antigen.[6] Viral

culture is not always successful and, as previously mentioned, not all medical centers are equipped to perform viral culture. Promising techniques, such as polymerase chain reaction, may help solve some of the dilemmas in obtaining an accurate diagnosis of HIV infection in children.[10]

Perinatal Transmission of HIV

Transmission of HIV to children has occurred primarily from perinatal exposure and blood transfusions.[14] Most of the clinical and immunological data has been collected from children identified only after symptoms of HIV infection have developed. Little is known about the mechanism of perinatal transmission, the times during gestation when the virus is transmitted, the factors influencing the rate of transmission, or the rate of transmission.[5] Evidence suggests that perinatal transmission may occur via transplacental passage of the virus in utero, exposure to infected maternal blood and vaginal fluids during labor and delivery, and the post-partum ingestion of breast milk containing the virus.[4,10] The virus has been identified in a 15 week-old fetus which suggests that intrauterine transmission may occur.[15] Less is known about infection acquired during vaginal delivery or breast feeding.

Previous studies have shown that 30 to 50 percent of infants born to women with HIV infection will acquire the virus from their mothers, but these studies were primarily retrospective. In several prospective studies, estimated rates of transmission have varied. The European Collaborative Study involving 271 children born to HIV-infected mothers in eight European centers estimated a vertical

transmission rate of 24% after 15 months of age.[16] The Italian Multicentre Study of 544 infants estimated that 32.6% of children born to HIV-positive mothers were considered to be infected after 15 months of age.[17] Blanche et al. followed from birth a group of 308 infants whose mothers were HIV-seropositive.[18] Initial results showed an estimated perinatal transmission rate of 33% after 18 months of age. Ryder, et al. followed 475 infants born to HIV-positive women in Zaire and found a conservative rate of seroconversion to be 39% after 12 months.[19] In a study of HIV-positive women in New Haven, Andiman found a maternal-infant transmission rate of 11% after one year in a cohort of 50 infants.[20]

The results from these prospective studies are varied. Reasons for the variation in results may include size of the cohort studies, geographic location of the studies, variations in the extent of maternal AIDS, and maternal risk factors for HIV. The next section will discuss some of the factors affecting perinatal transmission of HIV.

Factors Affecting Risk of Perinatal Transmission of HIV

Until recently, there has been little information available on what clinical and biologic features in an HIV-positive mother influence the risk of HIV transmission to her unborn child. Few studies have been done following mothers with symptomatic HIV infection. Some early studies have suggested that the risk of infection in an infant is greater when the mother's disease is at an advanced stage.[18,21] Ryder, et al. found that seropositive women in Zaire with more advanced HIV-related disease or T4-cell counts less than

400/cubic centimeter were more likely to transmit HIV-1 infection to their babies.[19] However, more recent data from the European Collaborative Study found no association between the mother's clinical symptoms and the infant's outcome.[16]

Blanche et al. found no difference in the infection rate in infants with respect to maternal risk factors (Intravenous drug users [IVDU] vs heterosexual) or the mode of delivery (cesarean vs vaginal).[18] However, they did find that 5 out of 6 or 83% of infants who were breast fed became infected as compared to 25% of infants who were bottle fed.[18] Ziegler et al. reported from Australia that breast feeding during seroconversion (mothers infected post-partum via blood transfusion) was actually more risky to the infant than breast feeding after antibody positive pregnancy perhaps because of the high viremia which occurs during seroconversion.[22] The European Collaborative group found no evidence that the mode of delivery or breast feeding influenced transmission rates.[16]

Pregnancy Outcome: Infants

Several studies have looked at the effects of HIV infection on pregnancy outcomes. Again, the results have been varied. Selwyn et al. looked at seropositive and seronegative birth outcomes among New York IV drug users (IVDU). They found no difference between the two groups with respect to preterm delivery, stillbirths, or low birth weight.[23] The European Collaborative Study found that apart from problems related to prematurity, perinatal findings were unremarkable.[16] In both studies, low birthweight outcomes were attributed to the mother's drug use and not her HIV infection. Other

researchers have suggested that the effects of maternal drug use and HIV infection might be synergistic.[23]

Blanche et al. found that maternal risk factors did affect some birth outcomes--specifically birth weight and head circumference.[18] Those babies born to IVDU mothers weighed significantly less, had decreased length, and had a smaller head circumference than those with mothers who had another mode of infection. In addition, they found that 9 out of 10 infants born with birth defects were born to IVDU mothers. The rate of premature births did not differ between the two groups.

Pregnancy outcomes in infants born to mothers infected with HIV have not been well studied. The majority of women infected with HIV are also IVDU and thus at increased risk for poor birth outcome.[23] Other women who are HIV-positive, but not IVDUs, are at increased risk for poor birth outcome due to reasons often beyond their control including poverty, poor nutrition, and the subsequent lack of access to prenatal care.[25] Further studies will have to be conducted before the effect of maternal HIV infection on fetal outcome is firmly established.

Other Modes of HIV Transmission in Children

Approximately 16% of children with AIDS acquired their infection via the transfusion of blood or blood products.[14] Most of these children were transfused with blood products in the neonatal period or had coagulation disorders. Donor screening procedures and heat treatment of coagulation products have greatly reduced transfusion-acquired HIV infection, but due to the delay between

transfusion and onset of HIV-associated symptoms cases of AIDS will continue to be reported in such children.

The CDC does not list sexual transmission as a category for children under the age of thirteen.[14] However, sexual assault in children does occur and it is possible for children to become infected with HIV via this route. One report described 18 children infected with HIV who had no other risk factor except sexual abuse.[26] Federal and state health officials have urged the coordination of data collection on sexual assault and HIV infection but information remains incomplete.

Summary

In this chapter I have given a basic overview of of the virology and pathology of HIV infection in children. While recent studies have helped to define some of the mechanisms involved in perinatal transmission of HIV, a larger number of prospective studies needs to be completed before we have a better understanding of this devastating illness. In understanding any disease process, it is necessary to define the population affected by the illness. The next chapter will examine the incidence and demographics of children and women with HIV disease; in this way, we can begin to understand the social context of HIV disease.

CHAPTER II: INCIDENCE AND DEMOGRAPHICS OF AIDS IN CHILDREN AND WOMEN

In the early days of the epidemic, AIDS was perceived as a disease of gay men and intravenous drug users. HIV infection in children was reported eighteen months after the first report in adults and though children are still a small percentage of the total cases of AIDS in the United States, their numbers are increasing. In this chapter, I will look at the incidence and demographics of children with HIV disease. In doing so, it also becomes necessary to examine HIV disease in women since the majority of infected children acquire HIV in their mother's wombs.

Incidence of AIDS in Children--United States

Children under the age of thirteen accounted for 1.7% of the 109,167 cases of AIDS reported through September 1989.[27] From October 1, 1988, through September 30, 1989, the total number of AIDS cases in the United States increased by 14% (surveillance was based on date of diagnosis rather than date of report). During the same period the number of diagnosed cases of AIDS in children increased by 38%. When 1988 and 1989 were compared based on cases diagnosed in comparable one year periods (October 1-September 30), cases of AIDS due to perinatal HIV exposure had the largest increase among HIV exposure groups.[28] If current trends continue, experts have predicted AIDS will be the fifth leading cause of death in children under the age of 5 years by 1992.[29]

Currently, children under the age of 13 account for 1.7% of the 124,984 cases of AIDS reported in the United States through February 1990--for a total of 2,116 cases.[14]

AIDS cases in children have probably been under-reported in the United States. The National Association of Children's Hospitals and Related Institutions (NACHRI) surveyed its members and found a far greater number of children with AIDS than officially reported.[30] While the CDC reported 584 pediatric AIDS cases in September of 1987, NACHRI hospitals found 648 cases in just 19 of its 126 member hospitals. NACHRI attributes the discrepancy to the CDC's narrow definition of pediatric AIDS. The CDC estimates that for every child reported with AIDS, an additional 2 to 4 suffer from complications of HIV infection, but do not fit the specific CDC AIDS case definition.[31] The CDC predicts that by the end of 1991, 10,000 to 20,000 children will either have AIDS or be infected with HIV.[29]

Most cases of AIDS occur in children under the age of 5. Eighty-two percent of the total pediatric AIDS cases reported through December 1989 were diagnosed in children less than five years old.[14]

Over eighty percent of children with AIDS have or had a parent with, or at risk for AIDS.[14] As mentioned in the previous chapter, 16% of children with AIDS were infected with HIV via transfusion with blood or blood products. Because the blood supply in the United States is now screened for antibodies to HIV, the number of new blood transfusion-related cases among children has dropped to almost zero. Therefore, the vast majority of new cases of HIV infection among children will be via maternal-infant or perinatal transmission.

California and the San Francisco Bay Area

In California, children under the age of thirteen account for approximately 0.7% or 178 of the 25,035 cases of AIDS reported through February 1990.[32] Sixty-two or 35% of those cases were reported in the last twelve months.[32,33]

Over 56% of children with AIDS had a parent with, or at risk for AIDS.[32] This percentage increased by 7% in the last twelve months. Forty-two percent of California children with AIDS were the recipients of blood or blood products, but this proportion has decreased by 7% in the past year.[32,33] Therefore, as is true in the United States as a whole, the majority of new cases of AIDS among California children will be via maternal-infant or perinatal transmission.

The San Francisco Bay Area has seen relatively few cases of children with AIDS. The city of San Francisco reported 23 children with AIDS through February 1990.[34] As of February 1990, Alameda County had reported 7 cases of pediatric AIDS.[35] The Alameda County cases were diagnosed after August 30, 1988 and five of these children were diagnosed in late 1988. This may indicate that we are just now seeing the impact of pediatric AIDS locally. In fact, over 90 children with HIV infection who do not all meet the CDC criteria for pediatric AIDS are currently receiving medical assessment and follow-up at Children's Hospital in Oakland.[36] The majority of pediatric AIDS cases in Alameda and San Francisco counties are attributed to perinatal transmission.[34,35]

Table 1 lists the total number of AIDS cases in six San Francisco Bay Area counties as well as the number of AIDS cases among children.

TABLE 1: PEDIATRIC AIDS CASES BY COUNTY

COUNTY	TOTAL AIDS CASES	CHILDREN	% OF CASES[7]
SAN FRANCISCO	8,057[1]	23[1]	0.3
ALAMEDA	1,122[1]	7[1]	0.6
CONTRA COSTA	412[2]	1[2]	0.2
SAN MATEO	406[3]	1[3]	N/A
MARIN	301[4]	>1< 5[4,5]	N/A
SONOMA	382[6]	4[6]	1.0

1=As of 2/28/90, Alameda County Monthly AIDS Surveillance and San Francisco Department of Public Health
2=As of 3/31/90, Contra Costa County Health Services Department
3=As of 4/24/90, San Mateo County Department of Health Services, Surveillance Department
4=As of 4/24/90, Marin County Department of Health Services
5=County will not release exact figure, Personal Communication, Marin County Department of Health Services
6=As of 12/31/89, County of Sonoma Public Health Department
7=Numbers may be too small to be statistically significant

Incidence of AIDS in Women--United States

When assessing the incidence of HIV infection and AIDS in children, it is important to look at the incidence of AIDS in women. Eighty percent of pediatric AIDS involves perinatal transmission and 80% of AIDS cases in women have been diagnosed among women of reproductive age (15-44 years old).[36]

Women constituted approximately 9% or 9,724 of the 109,167 cases of AIDS in the United States reported through September 1989.[28] But incidence is growing faster in women that in men. When looking at the incidence of AIDS in women and men between October 1, 1987 and September 30, 1988 and comparing this with the

incidence in women and men between October 1, 1988 and September 30, 1989, the percentage increase for women was substantially greater than for men. The number of newly diagnosed cases of AIDS in women increased by 23% between 1988 and 1989. At the same time, the number of newly diagnosed cases in men increased by 13%.[28]

HIV-1 antibody prevalence studies in pregnant women have shown rates of infection as high as 1 in 23 in Newark, New Jersey.[37] Hospitals in New York City found 1 in 61 newborns had mothers infected with HIV; studies in Massachusetts have shown prevalence of HIV infection among pregnant women to be 1 in 476 statewide and 1 in 125 in inner city hospitals.[37,38]

Currently, women account for 9% of the 124,984 cases of AIDS reported in the United States through February 1990--for a total of 11,401 cases.[14]

California and the San Francisco Bay Area

In California, women account for 3% or 764 of the 24,857 adult cases of AIDS reported through February 1990.[39] The total number of AIDS cases among women increased by 53% between February 1989 and February 1990.[32,39]

Seroprevalence studies among childbearing women indicate that HIV infection rates are lower in California than those found on the East Coast of the United States. According to two studies conducted during 1988, fewer than 1 in 1000 mothers were infected in California statewide.[40] In the San Francisco Bay Area the rate was

higher--1 in 610 Bay Area women who gave birth were infected with HIV.[41]

Incidence of AIDS among women in San Francisco, Alameda, Sonoma, Marin, Contra Costa, and San Mateo Counties is listed in Table 2.

TABLE 2 FEMALE AIDS CASES BY COUNTY

COUNTY	TOTAL AIDS CASES	ADULT FEMALES	% OF CASES
SAN FRANCISCO	8,057[1]	103[1]	1.3
ALAMEDA	1,122[1]	44[1]	3.9
CONTRA COSTA	412[2]	18[2]	4.4
SAN MATEO	406[3]	19[3]	4.7
MARIN	301[4]	14[4]	4.6
SONOMA	382[5]	7[5]	1.8

1=As of 2/28/90, Alameda County Monthly AIDS Surveillance and San Francisco Department of Public Health
2=As of 3/31/90, Contra Costa County Health Services Department
3=As of 4/24/90, San Mateo County Department of Health Services, Surveillance Department
4=As of 4/24/90, Marin County Department of Health Services
5=As of 12/31/90, County of Sonoma Health Services Department

The Changing Face of an Epidemic

In understanding any social or medical problem, it is important to identify the people who are at risk. In the early years of the epidemic, AIDS was seen as a disease of gay men. In fact, one of the early names for the syndrome caused by HIV was GRID or Gay-Related Immune Deficiency. Presently, gay men still make up the largest identified risk group--56% of reported cases in 1989.[28] However, the epidemiology of this disease is changing.

The number of new AIDS cases reported in the United States rose by 9 percent in 1989--the slowest increase ever.[28] While cases reported among homosexual and bisexual men continued to increase, the change is not as rapid as in previous years. Ruth Berkelman, chief of AIDS surveillance for the CDC, proposes that the leveling off of new cases of AIDS in homosexual and bisexual men reflects both a reduction in the number of new infections and the introduction of effective therapies (such as the drug AZT) in 1987, delaying the onset of AIDS among infected persons.[42]

However, as previously stated, cases reported among IV drug users, heterosexual contacts, and perinatal transmission do not show evidence of a reduction in new cases of AIDS.[28]

Demographics of Women and Children with AIDS

The majority of children infected with HIV will reflect the racial and socioeconomic backgrounds of women with AIDS. Fifty-two percent of women known to have AIDS in the United States are black and 20% are Hispanic.[14] As expected, 53% of children with AIDS in the United States are black and 25% are Hispanic. However, blacks comprise 12% and Hispanics comprise only 6% of the general population.[43] The cumulative incidence of AIDS between 1981 and 1988 was 13.6 times higher among black women and 10.3 times higher among Hispanic women than among white women.[9]

Among women with AIDS, approximately 52% have histories of IV drug use and 31% had sex partners at risk for AIDS (intravenous drug use or other risk factors).[14] The proportion of women with AIDS who had sex partners at risk for AIDS rose from 15% before

1984 to 32% in 1989.[9,26] Heterosexual transmission is now the only category where women outnumber men. And AIDS is the leading cause of death among women age 25 to 34 in New York City.[36] AIDS deaths among women have risen 75% in two years while AIDS deaths among men have risen only 42% during the same period.[45] A November 1989 CDC study indicated that AIDS ranks 8th among the leading killers of women of childbearing age.

AIDS incidence is highest in metropolitan areas of the U. S. Most pediatric AIDS cases are reported from the New York/New Jersey area and Miami.

California

As of December 1989, 26% of women known to have AIDS in California were black, 17% were Hispanic, and 53% were white.[44] In November of 1988, only 20% of women known to have AIDS in California were Black, 14.8% were Hispanic, while 56% were white.[45] Thus, the proportion of AIDS cases among black and Hispanic women is rising while the proportion of cases among white women is decreasing. Black women are over-represented among AIDS cases--black women comprise 7.7% of the women in California, but over 26% of cases of AIDS among women. Hispanic women are 23.6% of the female population in California and 17% of cases of AIDS among women, but the proportion of AIDS cases among Hispanic women is rising.[45] White women are under-represented among AIDS cases--they are 59.1% of the female population, but only 53% of the cases of AIDS and this proportion is decreasing.[32,46]

Among California women with AIDS, approximately 33% have histories of IV drug use, 28% acquired HIV via heterosexual contact, and 28% acquired AIDS via transfusion with blood/products.[39]

As would be expected, California children with AIDS reflect the racial background of their mothers. White children are under-represented among children with AIDS--they are 45% of the total number of children under the age of 10, but only 36% of the AIDS cases. Black children are 9% of the population under the age of ten, but are over-represented among children with AIDS with 27% of the pediatric cases. Hispanic children comprise 35% of the population under the age of 10 and 34% of pediatric AIDS cases--but as is true with their mothers, this proportion is increasing.[32,45-47]

Summary

As Padraig O'Malley states in the Winter/Spring 1988 *New England Journal of Public Policy,*

> AIDS, therefore, is becoming increasingly a disease of the poor, of blacks and Hispanics, of women, and of children--the population groups we have traditionally neglected or forgotten--rather than of the middle-class white gay men who were primarily afflicted during the epidemic's early years.[48]

Given the demographics of women and children discussed in this chapter, it should not be surprising that many children coming from families affected by HIV disease enter the foster care system. In the

next chapter I will examine the impact of HIV infection upon the foster care system.

CHAPTER III: CHILDREN WITH HIV INFECTION AND THE FOSTER CARE SYSTEM

Children infected with HIV often come from families suffering from the effects of poverty and drug abuse.[6] Thus, it is not surprising that a large number of children at risk for HIV infection enter the foster care system. In addition, children without HIV infection are entering the system as a result of the disability or death of their parents from AIDS.[49,50] This chapter will give an overview of the foster care system in the United States, national and California trends in foster care, and the impact of AIDS/HIV upon the foster care system.

Overview of the United States Foster Care System

Foster care in the United States has its roots in the "placing out" system developed by Charles Loring Brace in the second half of the 19th century.[51] To "place out" meant putting children in foster homes rather than in institutions. Brace argued that the quality of life was better in family homes than life in the street or in orphanages--and cheaper. The current system of foster care grew out of the federal initiative *AID to Dependent Children* which was enacted as Title IV-A of the Social Security Act of 1935.[52] The program was originally designed to provide economic assistance to widows and widowers to avoid the breakup of families because of economic hardship.[52] In 1961, Aid to Dependent Children (ADC) was expanded into Aid to Families with Dependent Children (AFDC) to more accurately reflect families in need--including families in which

the father was living at home but unemployed.[51] The 1961 amendment also authorized funds to be used by states to support AFDC-eligible children in foster care.[51,53]

The current foster care system is designed to provide temporary substitute care to children when parents are unable to meet the needs of their children. Placement may be made voluntarily by the parents or by court order in cases of abuse and/or neglect. At the time of placement, services are supposed to be aimed at correcting whatever situation was preventing adequate parenting and preparing the family for eventual reunification.[52-54]

Concerns about the failure of the foster care system to adequately address underlying problems in the family (and to accomplish eventual re-unification) led to the the enactment of PL 96-272, *The Adoption Assistance and Child Welfare Act* of 1980.[52,53] PL 96-272 created title IV-E of the Social Security Act and was motivated by a concern that children spent too much time in foster care before being reunited with their biological families. The new federal policy mandated child welfare agencies to develop programs aimed at reuniting and maintaining children in their own homes. In addition, agencies were supposed to provide children with a sense of permanency in their lives.[53]

The reforms of 1980 are generally considered to have failed.[52,55] The foster care system has become overwhelmed with children who have increasingly complex social, emotional, and medical problems in an atmosphere of limited federal funding and resources. Since the passage of PL 96-272, child welfare agencies have been found to have harmed children through inadequate

selecting, licensing, and training of foster parents.[52] In 1987, the House Select Committee on Children, Youth, and Families identified underfunding of programs, inadequate federal guidelines, and poor accountability by state and local child welfare agencies as persistent problems in the system.[54]

National Trends in Foster Care

The foster care system in the United States is facing increasing numbers of children in an atmosphere of diminishing resources. Nationally, in 1980, the number of children in foster care was approximately 302,000.[55] That number dropped to 267,000 in 1982 and has increased to approximately 280,000 in 1986, the last year for which data are available.[54] An informal ten-state survey by the House of Representatives Select Committee on Children, Youth and Families survey estimated that 340,300 children were in foster care at any point in 1988, representing a 23% increase since 1985.

Estimating the number of children in foster care is difficult primarily because of variations in the accuracy of case reporting from state to state. However, based on the current trend, the House of Representatives Select Committee on Children, Youth and Families projects 553,600 children will be in foster care by 1995.[55] Though estimates are lower, the Center for the Study of Social Policy in Washington D. C. also predicts an increase in the number of children in foster care: 395,000 children will be in foster care by 1995 and over 500,000 children will be in foster care by the year 2000.[36]

The primary reason given for the increase in the number of children in foster care is more children are entering foster care than

are leaving foster care. Data from the Select Committee's ten-state survey indicated that the number of children entering foster care each year increased by 27%, but number of children leaving care in 1988 was only 4% higher than in 1985.[55] There are multiple reasons given for the increase in the number of children in foster care.[55,56] A recent congressional report lists child abuse and neglect, substance abuse, homelessness, and poverty as some of the reasons for the increase in foster care placements.[55] In addition, Representative George Miller, D-California, chairman of the Select Committee on Children, Youth and Families attributes a large part of the problem to budget cuts in social service programs imposed by the Reagan administration.[58]

As the number of children entering foster care increases, the number of foster families is decreasing.[55] Although they are caring for children with increasingly severe medical and emotional problems, foster parents have not been given the resources--financial or social--to care for these children. Foster parents cite persistent problems of poor reimbursement, inadequate or no medical care for children, poor communication with social workers, and exclusion from the decision-making process concerning the children in their care as reasons for their dissatisfaction with the system.[55,59] In addition, foster parents frequently do not receive specialized training or respite support to care for children with complex medical or emotional needs.

California Trends in Foster Care

California has 20% of the nation's children in foster care, but only 10% of the country's population, and influences the national trend of increasing children in foster care.[55] As of December 1988, 64,090 children in California were in foster care. This is 2 1/2 times the number of children in foster care in 1979 and represents an increase of 14% from 1987 and a 28% increase from 1986.[56] The majority of California children in foster care are 6 to 19 years of age, but an increasing number of children entering the system are less than two years of age--partly a reflection of the crack epidemic. Approximately 6.5% of children in foster care were less than 2 years of age in 1979; this number had climbed to 10% by 1988.[56]

As is true on a national level, more California children are entering foster care than leaving foster care. The number of children in foster care increased by 28% from 1986 to 1988. In addition, the average stay in foster care increased 30%, from 15 months in 1986 to 20 months in 1988.[56]

Children enter foster care in California for the same reasons children enter foster care nationally. Jim Brown, Chief of adoptions for the California Department of Social Services, attributes the large number of children in foster care both to tough child abuse reporting laws and drug abuse.[58]

The number of drug-exposed children entering foster care is having a profound effect on the foster care system in California.[56] Los Angeles County reports a 1100% increase in the number of drug-exposed children entering foster care between 1981 and 1987. In Alameda County, 68% of children placed in foster care during a four

month period in 1987 came from families with a history of drug abuse. Contra Costa County reports 56% of children in foster care are there because of parental drug use.[57]

As is true on the national level, foster parents are increasingly difficult to recruit. In California, between 1986 and 1988 the number of foster children increased by 28%, but the number of foster homes increased by only 11%.[56] Foster parent dissatisfaction in California mirrors concerns expressed on a national level--poor reimbursement coupled with inadequate training and social support.

Some attempts have been made in California to improve foster care. Senate Bill 14 was passed in 1982 and like PL 96-272 was an attempt to reduce the amount of time children spent in out-of-home care. SB 14 had four major goals: (1) to prevent the unnecessary placement of children into foster homes by providing support for families in crisis; (2) to reunite foster children with birth parents whenever possible; (3) to place foster children in adoptive homes when reunification is not possible; and (4) to provide stable foster homes for children who remain in foster care.[59] An evaluation in 1985 revealed that SB 14 did help decrease the number of new foster cases as well as increase the incidence of foster children reuniting with their parents; however, these improvements have eroded under the continued increase in child abuse.[59] In addition, it was also found that few programs had been implemented to support and assist families in crisis and help prevent separation of parents from their children.

The foster care system is in crisis. The number of children entering the system is greater than the number of children leaving

the system. Underfunding, disorganized services, children with increasingly complex social and medical needs, and a lack of qualified foster parents are some of the problems facing the system as it prepares to care for children with HIV infection.

The Impact of AIDS/HIV on the Foster Care System

The need for child welfare agencies to find foster care placements for HIV-infected children is unquestioned. HIV infection in children is continuing to increase and is still "on the initial segment of a curve which will rise rapidly in the next five years".[54] Thus, AIDS and HIV infection will place new strains upon an already strained system.

In what ways are HIV-infected children likely to enter the foster system? Over 72% of pediatric HIV is related to intravenous drug use.[14] Many of these children enter the foster care system because of parental (usually maternal) drug abuse and therefore HIV infection is discovered after the child enters the system--one reason evaluation for HIV risk factors is so compelling. Drug abuse can result in child neglect and abuse, but is also worrisome because of the increased risk of HIV infection. In 1988, over 40% of children receiving HIV-related health care in the Children's Hospital AIDS Program of Newark, New Jersey, were known to the state welfare agency before their diagnoses.[60]

The Children's Hospital AIDS Program in New Jersey identified three groups of HIV-positive infants and children who require placement into foster care homes.[61] The first and largest group of children is composed of well HIV-positive infants abandoned at

birth--usually because of maternal drug abuse. As previously stated, the true HIV status of these children may not be known until they are fifteen months of age. These children are clinically well, but their seropositive status makes them difficult to place.

The second group includes HIV-infected infants and children who are sick and whose parents are unable to care for them. The parents of these children, for various reasons, may not be able to handle the responsibility of caring for a sick child. Often the mothers of these children are also sick with AIDS. In addition, drug abuse in the home makes the environment unsafe for the child.

The third group includes infants and children whose parents have died of AIDS. This group is the fastest growing. These infants and children may be healthy or sick, but the mother or father's diagnosis at death makes them difficult to place in foster care. Also included in this group are children without HIV infection who are orphaned or abandoned by parents with AIDS.

The Impact of Drug Abuse

From the above discussion it is obvious that drug use, HIV, and pediatric HIV are closely related. How bad is the problem? During 1988, an estimated 375,000 infants were born drug-exposed in the United States.[55,57] A conservative estimate for California predicts 17,000-31,000 drug-exposed infants were born in California during the same period.[57] A recent Select Committee survey reported a three-to-fourfold increase in perinatal drug exposure between 1985 and 1988. Given that over 80% of seropositive children acquire HIV

perinatally, these figures predict an alarming increase in the number of HIV-infected children in the next few years.

The Number of HIV-Infected Children in Foster Care

The percentage of HIV-infected children in foster care is not known. A recent federal report estimates between 16.5% and 21.9% of HIV-infected children are currently in foster care.[54] Pediatric AIDS centers nationwide estimate 20-40% of HIV infected children are currently in foster care.[62]

Obtaining accurate estimates of the absolute number of known HIV-infected children in foster care is difficult because of variations in the accuracy of case reporting. One study estimates that approximately 979 HIV-infected children were in foster care in July of 1989 in the United States.[54] This figure is obviously influenced by the accuracy of the individual states' case-finding and reporting methods and is probably an underestimate. Assuming 7,000-18,000 HIV-infected children, this same study estimates that 1,750- 4,500 HIV-infected children will be in foster care by 1992.[54]

California

In May of 1989, California had 8% or 78 of the estimated 979 HIV-infected children in foster care.[54] Using the above estimate for the total number of HIV-infected children in foster care by 1992, one can estimate that between 140 and 360 HIV-infected children will be in foster care in California in 1992. Given the dramatic increase in drug-exposed infants in California, this number is probably an underestimate.

As has already been mentioned, the number of drug-exposed infants in California has increased dramatically.[36,57] There has been a shift in drug exposure from injectable drugs such as heroin and amphetamines to drugs such as crack cocaine, that can be inhaled or smoked. Does use of non-injectable cocaine increase a woman's chance of HIV exposure and the chance of HIV exposure to her unborn child? Several recent studies have shown a connection between crack cocaine use and an increase in risk of HIV infection, primarily due to an increase in unsafe sexual practices.[62a] More research is necessary to precisely define the risk of HIV in cocaine-exposed infants. However, given that most urban hospitals in California report 10-20% of all births show evidence of drug-exposure and as many as 60% of drug-exposed infants are placed into foster care, an increase in HIV-infected infants may be anticipated.

As the demographics of the epidemic shifts in California, more children are likely to enter foster care because they are orphaned of abandoned by parents with AIDS.

Summary: Preparing to Care for HIV-Infected Children

California, like the rest of the country, will have to prepare to care for HIV-infected children. Until recently, the total number of HIV-infected children has been small and most child welfare agencies have been able to place these children. As one child welfare worker said, "Quite honestly, the placement of HIV-infected children is the least of our foster care problems at the present time".[54] However, as one author points out, the impact of HIV-infected

children has the potential to move the system from one that is manageable to one that is not.[54]

Child welfare agencies will have to identify HIV-infected children as they enter the system in order to adequately plan for their care. In addition to educating child welfare workers and foster families, agencies will need to recruit and train a sufficient number of foster parents willing and able to care for children with complex social and medical needs. Identification of HIV-positive children is a necessary part of planning for the future care of these children. HIV-risk assessment and testing, if necessary, will help agencies be prepared to plan for the future. The next chapter will give an introduction to HIV testing and screening of foster children.

CHAPTER IV: AN INTRODUCTION TO HIV TESTING AND SCREENING

History of the HIV Antibody Test: Controversy From the Beginning

The Food and Drug Administration (FDA) licensed the first test kits to screen blood products for antibodies to HIV in March of 1985. The test was originally licensed as a way to protect the nation's blood supply from contamination by the virus, but other uses for the test were quickly proposed--and feared. Thus, the HIV antibody test created both an opportunity and an ethical dilemma: who would be tested and for what reasons?

A year before the test was available, gay men questioned whether the test would be used as a way to discriminate against them. Paul Popham, president of Gay Men's Health Crisis in New York City, wondered what health insurance carriers would do once the test was available. In 1984, the typical AIDS patient needed $100,000 in medical care. Popham stated, "If the insurance industry can find relief from these enormous expenditures, it will."[63] Other gay leaders worried about job discrimination. The gay paper the *New York Native* wrote a story predicting that people with positive antibody tests might be placed in quarantine camps.[63]

The first controversy surrounding the antibody test thus became one of confidentiality. How would people be protected from the negative social consequences of a positive test result? James Curran of the CDC did little to help allay fears in the gay community

when he wrote a memo in late July of 1984 to all state and territorial epidemiologists asking whether authorities should keep a registry of everyone whose blood donations proved to be infected with HIV once the blood test was available.[63] Similar registries were kept of people infected with hepatitis B and syphilis. Adding HIV to the list would prevent infected persons from donating blood, but others worried that such a list would jeopardize gays in the twenty-five states where gay sexual acts remained illegal.[63]

The licensing of the HIV antibody test hit a snag in early 1985. Both gay groups and the American Public Health Association objected to the release of the test unless alternative test sites were established where people could learn of their antibody status and be assured of confidentiality. The issue was finally settled after Dr. Mervyn Silverman made a public announcement on January 31, 1985 objecting to the release of the test without the funding of alternative test sites. Within hours of his statement, $12 million of federal money was made available to establish these sites.[63]

Gay groups were still concerned that the HIV antibody test would be used as a way to detect sexual orientation. The National Gay Task Force and the Lambda Legal Defense and Education Fund filed a petition in federal court to stay the licensing of the test. Eager to release the test, the government agreed to label each test with the warning, "It is inappropriate to use this test as a screen for AIDS or as a screen for members at risk for AIDS in the general population."[63]

Thus, in March of 1985 the HIV antibody test was licensed and the controversy shifted to personal concerns about whether or not to

be tested and fears that mandatory screening programs would implemented.

In the remainder of the chapter, the difficulty in using the HIV antibody test for screening and diagnostic purposes will be reviewed and arguments for and against HIV antibody testing and screening of foster children will be presented.

Screening vs Testing for HIV Antibodies

Screening can be defined as the application of the HIV antibody test to specific populations. Screening programs are designed to either identify members of the population who are seropositive, or to screen tissue products (e.g. blood, sperm, or organs) as a way of protecting the recipients from infection.[66] Testing is defined as the application of the HIV antibody test to individuals on a case-by-case basis.[64-66] A person is usually tested when she wants to know her HIV status for personal or clinical reasons. Testing and screening are important concepts, but they do not fully define the social circumstances in which the HIV antibody test may be implemented.

There is a spectrum of application of the test involving increasing coercion--from no coercion, as in patient-initiated HIV antibody testing to complete coercion, such as occurs with universal screening of whole populations. There are three types of testing or screening we can examine along this spectrum: voluntary testing, routine testing, and mandatory screening.

Voluntary testing involves no coercion because the person has specifically requested the test without it being suggested by a health care provider. Voluntary testing may be obtained from a health care

provider or at alternative test sites where both the person and the test result remain confidential. In addition, pre-and-post test counseling is done to inform the person of the consequences of the test.

Routine testing refers to situations where a health care provider offers the HIV antibody test to patients at high risk of contracting AIDS. Pre-and-post test counseling is also done to inform the person of the consequences of the test and informed consent is usually required. The person or person's guardian may refuse the test, but there may be some pressure on the person to take the test because a physician or other health care provider is suggesting it. Several groups, including such disparate groups as The American College of Physicians and the San Francisco AIDS Foundation, now recommend routine testing for persons at high risk of contracting HIV. Some of the reasons given for recommending the test include: testing for diagnostic purposes in persons undergoing medical evaluation with selected clinical signs and symptoms consistent with HIV infection and as an aid in therapeutic and management decisions.[67]

Mandatory screening for HIV antibodies is required under certain circumstances and may not be declined. It is usually specified by law or regulation.[64-66] Mandatory screening also has within it a spectrum of increasing coercion. At one end of the spectrum is mandatory screening of blood or sperm. To avoid being tested in this group is relatively easy--simply do not donate blood or sperm.

The next level of coercion involves the mandatory screening of selected, well-defined populations such as newborns, prisoners, or

persons getting married.[67] These groups can be small or large, high or low-risk for HIV infection. Two key points can be made about these groups: (1) it is harder to avoid being tested if you are in any of the above groups and (2) this is the major way that mandatory or coercive application of the HIV antibody test is done in the United States.

At the far end of the spectrum is the universal application of the HIV antibody test to an entire population without any selection or definition of risk. This is the most coercive application of the test and is very difficult to avoid. HIV antibody testing in Cuba is an example of universal application of this test. Universal screening has been debated in the United States, but has generally been rejected by the public health community as, among other things, too costly--the time, money, and health manpower would be better utilized in developing health education and counseling programs.[66,68-70] There are currently no plans to adopt a universal screening program in the United States.

For the purposes of this paper, I will focus the discussion on the three types of testing/screening which have been proposed or which may be applicable to the case of foster children: voluntary testing, mandatory screening, and routine testing.

HIV Testing/Screening of Foster Children

Voluntary Testing of Foster Children

Voluntary HIV testing is generally a good idea, but it doesn't work well in the foster care setting. Since the child is seldom in a

position to request the test or receive informed consent, someone has to act as an agent for the child. The child's biological parents may not be willing or able to request the test and may not have the best interests of the child in mind--either because they are absent or abusive parents or because of their own fears of a positive HIV antibody result. The foster parents may act as an agent for the child, but may request the test more for themselves --out of fear of contagion--than for the child. Thus, voluntary testing of children who enter foster care may result in either under-or-over testing of children.

Mandatory HIV Screening of Foster Children

In this paper I will argue that mandatory HIV screening is excessively restrictive and potentially harmful. However, the argument in favor of mandatory screening of foster children is usually based upon the idea of identifying and protecting both the foster child and the foster family. Because many foster children have a parent at risk of HIV-infection, this population of children is already identified as being at risk.[57] A mandatory screening program would identify those children who are HIV-positive and allow child welfare agencies to direct them toward appropriate medical treatment. Zidovudine (AZT) is now approved for use in children and other experimental therapies are becoming available for children.[71]

Mandatory screening programs would also protect those persons the foster child may come into close contact with--the foster family. Though the possibility of transmission of HIV in the foster

care setting is remote, the CDC suggests that it is theoretically possible for transmission to occur--especially with HIV-infected children who lack control of their body secretions.[72] Though good infection control techniques should always be employed, common sense suggests that foster parents would be more vigorous in exercising care when handling stool or blood if they were aware of the child's HIV status. Thus, a mandatory screening program would identify HIV-infected foster children and ensure they have access to adequate medical care as well as protect foster families from the potential of infection with HIV.

Identifying and protecting foster children and foster families are important goals. However, I will argue that a mandatory screening policy is unnecessary to achieve these goals. Mandatory screening of all children who enter the foster care system involves some of the same problems that other mandatory screening programs face: casting too wide a net. Testing the whole foster care population will yield a relatively larger percentage of false positives than screening higher risk groups. In populations where HIV antibody prevalence is very low, a repeatedly reactive ELISA test has poor predictive value and false-positive ELISA reactions will predominate.[11] For example, in a population with a seroprevalence of less than 0.5%, at least 50% of repeatedly reactive ELISA tests will represent false-positive results. In populations with a higher rate of seroprevalence (say 20%), only 2% will be false positives.[67] As mentioned in chapter I, the Western blot test is used to confirm a reactive ELISA test, but the test must be done under optimal laboratory conditions to achieve

maximal results. In addition, HIV antibodies may take several months-to-over one year to appear after infection. Thus, testing would have to be repeated periodically to be accurate.

Because of the stigma associated with HIV infection and the potential loss of civil rights, the price of a false positive is high. Without guarantees of confidentiality and enforced penalties for unauthorized disclosure, mandatory screening may lead to discrimination. Identifying a foster child as HIV-infected also identifies the biological mother as HIV-infected. In this way, mandatory screening of a foster child leads to unconsented testing of the mother.[73]

Finally, mass screenings for HIV have not been shown to be cost-effective. The State of Maryland estimated that it would cost approximately $840,000 to test the cord blood of 70,000 live births. It was estimated that such testing would reveal up to 115 HIV-infected infants. The cost of identifying each HIV-positive infant would have been $7,700 per child.[64] Mandatory screenings of other low-risk populations have also not been shown to be cost-effective. Pre-marital screening has been estimated to cost between $40,000-$100,000 to identify each HIV-positive case.[70,73]

Routine Testing of Foster Children

As previously mentioned, routine testing is directed at high-risk populations and is generally regarded as an important component of AIDS education and prevention. The Public Health Service states that "priorities for public health counseling and testing should be based upon providing ready access to persons

who are most likely to be infected or who practice high-risk behaviors, thereby helping to reduce further spread of infection."[74] Because many foster children come from populations at higher risk for HIV infection (e.g. drug-exposed) or an unknown risk of HIV infection, evaluating foster children for routine HIV testing--on a case-by-case basis--is consistent with the goals of the Public Health Service.

The goals of mandatory screening--identification and protection--can be achieved while preserving confidentiality and controlling costs by adopting the third testing alternative: routine testing. Routine testing allows for informed consent--especially important when the biological family is involved. Counseling provides a mechanism for education which is still the most effective way to decrease the incidence of HIV infection. Routine testing should ensure confidentiality which is so crucial because discrimination is still very much a risk with unauthorized disclosure. Routine testing also decreases costs--the only children tested are those who fit specific, well-defined criteria.

There is widespread support for employing a routine testing rather than mandatory screening strategy in the foster child population. The Child Welfare League of America states that "The decision to test should be made on a case-by-case basis, based on medical necessity. Testing should always be voluntary and with the informed consent of the child or person legally entitled to give informed consent for the child."[75]

The American Academy of Pediatrics states "The widespread testing of all infants and children awaiting adoption or foster

placement is not warranted, given the variability of prevalence of AIDS infection in childbearing women. However, in populations that have high seroprevalence among women of childbearing age, foster and adoptive parents should have access to information about antibody status. Access to this information may improve the ability of agencies to place. . .high-risk infants and children who prove to be uninfected."[49]

The CDC is also supportive of this position. In 1985 they recommended that adoption and foster care agencies should consider adding HTLV/LAV (sic) screening to their routine medical evaluations of children at increased risk of infection before placement in foster or adoptive homes. At that time, the CDC made their recommendation, " . . .since these parents must make decisions regarding the medical care of the child and must consider the possible social and psychological effects on their families."[72]

In a federal study of infants and children with HIV infection in foster care, it was recommended that all child welfare agencies should develop HIV antibody testing policies for all *at-risk* children currently in placement or entering the system for placement--both to ensure the child proper access to medical treatment and to allow the agency to plan adequately for services, staff, and other resources.[54]

Risk Assessment

Adopting a routine HIV antibody testing policy means that some foster children will be tested and some will not. How do we decide who will be tested? The answer lies in careful assessment of

foster children for risk of HIV infection. It needs to be made clear that universal risk assessment is not testing, but rather a mechanism to identify those children and families who might benefit from HIV antibody testing.

As a child welfare agency develops policies, the idea of who is at risk needs to be firmly established. "Risk" is often reduced to the simplest of terms when we define who is "at risk" for becoming infected with HIV. In fact, not everyone in the usual risk categories is of equal risk. A person who received a blood transfusion in San Francisco in 1981 is at much greater risk of contracting HIV than someone who received a blood transfusion in Fargo, North Dakota in 1981. A child whose mother smokes crack cocaine, but does not inject IV drugs may be at equal or greater risk than a child whose mother is an IV heroin user if the mother frequently exchanges sex for crack. It is important to be aware that child welfare agencies, when defining policies related to risk assessment for HIV infection, may be tempted to reduce the concept of risk to its simplest of terms. Child welfare agencies will need to accurately define who is at risk according to local definitions of "risk". In addition, the definition of risk must be constantly assessed as certain behaviors or groups become "at risk".

Generally, a child is identified as possibly being at risk for HIV infection if he or she falls into one or more of the following categories:

--Mother has AIDS or tests positive for antibodies to HIV
--Mother is suspected or known Intravenous/Intramuscular drug user

--Mother is suspected or known to use crack cocaine
--Mother is the sexual partner of a suspected or known IV drug user
--Mother has sexual partner(s) who are gay or bisexual men
--Mother has multiple sexual partners or exchanges sex for drugs or money
--Mother received blood products between 1978 and 1985 (child born after mother received blood products)
--Mother is the sexual partner of a person who received blood products between 1978 and 1985 (child born after partner received blood products)
--Mother involved in the exchange of blood products (e.g. tattooing or ear piercing with shared needles; ritualistic exchange of blood)
--Child or child's parents immigrated from parts of the world with high seroprevalence rates since 1975
--Child was victim of a sexual assault by a person known to be infected with HIV
--Child was victim of a sexual assault by a person who was identified as being at risk for developing HIV infection (serostatus unknown)
--Child was victim of a sexual assault by a person with unknown risk factors for developing HIV infection
--Child has symptoms consistent with HIV infection
--Child or adolescent is sexually active
--Child received blood products between 1978 and 1985
--Child was abandoned (i.e. medical & social history unknown)

Summary

In this chapter, I have argued that a routine rather than a voluntary or mandatory HIV antibody testing policy is appropriate for foster children. A routine testing policy has an agreed-upon set of risk criteria and provides child welfare agencies with a fair way to identify and protect foster children as well as protect foster parents. In addition, a routine testing policy helps to protect civil rights, reduces costs, avoids false positive test results, and still accomplishes

the goal of identifying and protecting HIV-infected children. Clearly, risk assessment is a key tool in implementing this strategy. The next chapter will examine the specific social, medical, and legal reasons that a routine HIV testing policy for foster children is necessary.

CHAPTER V: INDICATIONS FOR THE ROUTINE HIV TESTING OF FOSTER CHILDREN

Reducing risks, medical or otherwise, to children with HIV infection and their foster families should be the primary goal in all AIDS policy developed by child welfare agencies. Routine HIV testing of children at risk for HIV infection allows the agency to make informed decisions about the future of the child--both medical decisions and placement decisions. There are also potential legal risks to child welfare agencies if they do not test high-risk children for HIV antibodies as well as risks in not informing potential foster (or adoptive) parents of a child's possible HIV status. In this chapter, medical, social, and legal indications for the routine HIV testing of foster children at high risk for HIV infection will be presented.

Medical Indications for Routine HIV Antibody Testing

Early identification of HIV infection in children helps child welfare agencies obtain appropriate medical care for HIV-infected children. The primary reason for doing a careful risk assessment and administering an HIV antibody test, if necessary, is to identify children as HIV-infected (or potentially HIV-infected) and thus give them access to a medical system that can keep them as healthy and active as possible.

It was hard to justify administering the HIV-antibody test when little was available to the recipients other than potential discrimination. Until recently, the medical management of HIV infection in children has been limited to supportive care (e.g.

nutrition, antibiotics, immune globulin).[13] Within the last year, however, the anti-viral medicine zidovudine (AZT) has been approved for use in children by the FDA--over two years after it was approved for use in adults.[71] Zidovudine has the potential to add months to years to the life of HIV-infected children. In addition, clinical drug trials are including children more than in previous years.

Without adequate risk assessment, failure to administer the HIV-antibody test to high risk foster children may occur. This denies foster children access to treatment options as they become available--which is both unnecessary and unconscionable. Child welfare agencies have a duty to provide quality medical care to HIV-infected foster children and this is only possible if those children have been identified through careful risk assessment and HIV-antibody testing.

Novello, et al, in *The Final Report of the United States Department of Health and Human Service's Secretary's Work Group on Pediatric Human Immunodeficiency Virus Infection and Disease* recommend the establishment of a dialogue between the research and child welfare communities to facilitate the entry of foster children into investigational drug treatment programs. In addition, they recommend that states reevaluate their current policies to ensure court-dependent children's participation in appropriate clinical trials and treatment.[29]

In addition to information about the availability of current therapies and clinical trials, child welfare agencies need to have a basic understanding of the natural history of HIV infection.

Children who are HIV-infected or who have AIDS require complicated medical management. In addition to a primary care provider, these children may be seen by a number of medical specialists. Child welfare agencies do not make medical management decisions, but it is crucial that agencies have enough knowledge to case-manage the care of HIV-infected children in foster care.[76]

Because HIV-infected children require complex medical management, each HIV-positive child entering foster care should have a comprehensive health evaluation within 30 days of placement. The assessment should include: a review of the parent's medical history, including HIV risk factors; a review of the child's past medical history, including mental health information; a complete history and physical exam with special emphasis on identifying HIV-related signs and symptoms; and a complete neurologic examination and evaluation of developmental milestones--this is especially important for children with HIV infection because neurologic involvement occurs in approximately 50% of children with HIV infection.[77]

Children with HIV infection can develop life-threatening illnesses very suddenly. Children with known HIV infection must be closely watched for signs and symptoms of disease progression. Child welfare agencies and foster parents must also be aware that the HIV status of asymptomatic children under the age of eighteen months is uncertain and these children also require close monitoring for signs and symptoms of infection.

Children with AIDS are, by definition, immune suppressed. Children with HIV infection may also be immune suppressed without having a diagnosis of AIDS. Therefore, all children with HIV infection have a greater risk of acquiring infections especially in foster homes with other young children.[78] These children are at a greater risk of suffering severe complications from childhood infections such as measles, chickenpox, and cytomegalovirus. Immune suppressed children need to be followed more closely for signs and symptoms of infections so they can be given prompt and aggressive therapy. Several clinical profiles of the HIV-infected child are commonly seen and should serve as warning signs that a child needs immediate medical attention. (Appendix B)

Children who are immune suppressed are also thought to be at risk for acquiring disease from the immunization of live vaccines, such as measles, mumps, rubella (MMR) and oral polio.[49,79] Inactivated vaccines are not usually considered a risk to immune deficient children. The current Centers for Disease Control recommendations for routine immunizations of HIV-infected children (as of April 1988) are listed in Appendix C.[79]

Risk of Transmission of HIV in the Foster Care Setting

The possibility of transmission of HIV in the foster care setting is controversial. To date, none of the identified cases of HIV infection in the United States has been proven to be transmitted through casual or usual household contact.[80] There is only one well-documented case of infant to mother transmission. In that case, a mother caring for her transfusion-infected child did become HIV-

infected after prolonged and unprotected exposure to blood, secretions, and stool. In one anecdotal case, a sibling of an HIV positive child is reported to have become HIV positive after receiving a bite from the infected child. This case was reported in a brief letter that did not mention the nature of the bite nor the investigation of the family.[80]

Studies of the risk of transmission of HIV between healthy younger children and HIV-infected children who lack control of their body secretions are very limited.[72,80] The CDC suggests that it is theoretically possible for transmission to occur between these children. However, they emphasize that any theoretical transmission that would occur would most likely involve exposure of open skin lesions or mucous membranes to blood or other body fluids of an infected person. To date, the CDC has not documented any cases attributable to transmission within schools, day care, or nursery school settings.[72,80]

There have been several studies of household contacts of HIV-infected patients and the risk of transmission.[80] In these studies over 700 household members have been tested and no evidence of household transmission has been found. Most of these studies involved families of adults or older infected children. None of the studies looked at pre-school aged children who are more likely to drool, bite, or be incontinent.

Rodgers et al. evaluated the household contacts of 25 mostly pre-school aged children--24 children with transfusion-acquired HIV infection and one foster child with perinatally acquired infection. In this study, Rodgers et al. tested 89 household members of the 25

children (12 household members refused to participate; all 25 mothers agreed to be tested). Both adult and child contacts shared items likely to be contaminated with HIV--toys, combs, eating utensils, toothbrushes, etc. Close physical contact, such as hugging, bathing, sleeping, and kissing, was common. Biting was reported by 11 households--all bites were minor and did not break the skin. The 89 household members were exposed to an infected child for a median of 15.5 months (with a range of 2 to 71 months). In this study, all 89 participating household members were HIV seronegative--ELISA samples were confirmed by Western blot analysis.[80]

The Rodgers and other studies indicate that the risk of transmission of HIV from infected adults and children to their household contacts is extremely low. The Rodgers study looked at pre-school children--a group well known to drool, mouth objects, and occasionally lose control of their bowels and bladders. This study is especially relevant to child welfare agencies because HIV-infected foster children are likely to be pre-school aged.[14,29] The risk of transmission between infected foster children and others, therefore, appears to be more theoretical than actual. However, because transmission of HIV from one infected person to another can occur with prolonged and unprotected exposure to blood, foster families still need to be trained in proper infection control techniques to further minimize the risk of transmission.

Foster Placement Considerations

Another indication for HIV antibody testing of high-risk foster children is to allow child welfare agencies to make the proper placement decisions for these children. Children who are at high risk for HIV but test antibody negative will be easier to place. As mentioned in Chapter III, an increasing number of children are being orphaned by parents who are dying or have died of AIDS. These children are not infected with HIV, but may be difficult to adopt or place in foster care because of unwarranted fears about AIDS. A negative antibody test for this group of children will help alleviate the fears of potential foster of adoptive parents; in this way, placement in foster or adoptive homes will be made easier.

Children who are identified as HIV-infected or who have AIDS will need to be placed with foster families who have received specialized AIDS education and training. As mentioned in the previous section, these children may require specialized medical care including frequent physician and hospital visits, and frequent monitoring for signs and symptoms of progression of HIV disease. Children affected by HIV disease have special psychosocial needs; foster parents need to be prepared to help these children confront the death of a biological parent as well as the child's own illness and death.

Various groups, including the Child Welfare League of America and the American Academy of Pediatrics, have recommended that child welfare agencies have written policies outlining the training of foster parents.[49,75] The Child Welfare League of America states:

An agency serving the HIV-infected child and his/her family has a responsibility to establish program procedures which:

> Provide the affected child/family with a nuturing environment that ensures optimal social and intellectual development;
> Protect from the risk of transmission the caretaker(s) and other clients who may be directly affected;
> Protect the susceptible HIV-infected child from infections; and
> Inform and educate the caregivers, other children, and their families about HIV infection--its prevention and its management.[75]

HIV antibody testing of high risk children also allows agencies to obtain accurate data about the number of HIV-infected children in foster care. With accurate and up-to-date information, child welfare agencies can plan services for HIV-infected children--including the recruitment and training of specialized foster parents.

Risks to the Child Welfare agency

In this section, the possible basis of liability for placing children with HIV infection or AIDS in foster homes will be examined. One area of potential AIDS-related litigation is liability related to transmission--as discussed above, the risk of transmission between casual household contacts is extremely remote--nevertheless, the possibility of transmission between family members does exist. Given the remote possibility of HIV transmission between a foster child infected with the virus and potential foster family members, does a child welfare agency have a

duty to warn or inform foster parents of the child's potential (or actual) risk of having HIV?

In Tarasoff v. Regents of the University of California (551 p. 2nd, 334) a psychologist failed to warn a third party that his client had the intent to kill this third party. The client did, in fact, kill this person. The California Supreme Court made two essential points in the Tarasoff ruling. First, the health care professional's responsibility extends to a third party when there is a clear and specific threat to that party. Second, the health care professional's liability is related to his/her ability to do something about warning the third party of the danger.[64]

Given the Tarasoff ruling, it can be argued that child welfare agencies have a duty to inform potential foster parents of the (possible) HIV status of a child. Though the threat to the foster family is remote, the possibility of transmission theoretically exists. A parent who is unaware of the child's HIV status could contaminate an open sore with the virus; cases of HIV seroconversion have been reported in health care workers with open lesions. Unless the parents are aware of the child's HIV status, it is unlikely they will practice the strict infection control techniques necessary to reduce the risk of HIV transmission.

Testing a child at high risk for acquiring HIV infection and reporting those results to the foster family is within the ability of most social service agencies. In California, HIV-antibody testing can only be carried out with the informed consent of the child's parent, legal guardian, or by court order. In California, an adolescent (age 12 or older) may sign his or her own consent. In the case of children

under the age of 12, consent must be sought from the birth parents. If the birth parents are not available or refuse testing (when risk factors indicate a need for HIV testing), an attempt should be made to obtain a court order. If the court refuses to override the birth parents' refusal for testing, the child welfare agency may wish to inform foster parents of the child's risk status.

Reporting HIV test results to the foster family involves breaching the child's confidentiality (and right to privacy). The unique situation of foster care placement overrides a provider's responsibility to maintain privacy in order to protect both the child and the foster family. Foster parents cannot provide proper medical care to the child or take the proper infection control precautions if they are unaware of the child's risk of infection.[81] The AMA, in January of 1987, declared that "[confidentiality] rights are absolute until they infringe in a material way upon the safety of another person or persons."[82] Similar exceptions to absolute confidentiality are found in the Ethical Principles of Psychologists, the Social Worker's Code of Ethics, the International Council of Nurses Code for Nurses, and the guidelines of the American Psychiatric Association.[82]

In California, HIV test results may be disclosed to health care providers, but this does not include social service agencies.[83] Thus, the consent form for HIV testing should include the parties to whom the results may be disclosed and should specifically include other persons who need to know the child's HIV status including the foster family and social workers.

Due to the absence of cases involving HIV testing of foster children, this section will examine cases that pertain to the rights of

adoptive or foster parents when medical information was withheld, misrepresented, or not determined by adoptive or child welfare agencies.

In Meracle v. Children's Service Society of Wisconsin (421 N.W. 2d 856), Quentin and Nancy Meracle sued an adoptive agency for emotional distress and financial damages when their adopted child was found to have Huntington's Disease, a fatal genetic disorder. The Meracles had specifically requested a healthy child from Children's Service Society. The Meracles were told by an employee of the agency that Erin, a twenty-four-month-old girl, had a paternal grandmother who had died of Huntington's Disease. However, the Meracles were assured that Erin's father had tested negative for the disease and Erin was therefore not at risk of contracting the disease. In fact, the agency had misinformed the Meracles about Erin's risk of contracting Huntington's disease. The Court of Appeals, overruling a lower court, held that the Meracles claim for damages and medical expenses against the adoption agency was valid.

Children's Service Society argued that even if the Meracles cause of action was valid, "public policy" requires that the action be dismissed. Public policy will preclude recovery despite a complete and direct claim of causation between conduct and harm when: (excerpts)

> 4. . . . allowance of recovery would place too unreasonable a burden on the negligent tort-feasor; or
>
> 5. . . . allowance of recovery would be too likely to open the way for fraudulent claims;

The Court of Appeals ruled, in fact, that public policy did not prohibit the adoptive parents' suit for damages and medical expenses against the adoption agency.

In Vaughn v. North Carolina Department of Human Resources (252 S.E. 2d 797), Linda Vaughn filed a claim against the Department of Human Resources in North Carolina, under the Tort Claims Act, alleging that a foster child was negligently placed in her home by the county department of social services. In this case, Ms. Vaughn had informed the agency she was attempting to become pregnant. After informing the agency of this fact, a foster child who was a known carrier of CMV was placed in her home. Ms. Vaughn subsequently became pregnant; she became infected with CMV and, on the advice of her physician had an abortion.

The Supreme Court ruled that the directors of the agency were liable for the failure of the agency employees to warn Ms. Vaughn of the known health problems of the foster child. In addition, the Court stated that control over the manner in which this task is to be accomplished is vested in the state. The Court also noted that the selection of a suitable home is one of the keys to successful placement of children in need of foster care.

In Burr vs. Stark County Board of Commissioners (491 N.E. 2nd. 1101), adoptive parents brought fraud action based on wrongful adoption against the Stark County welfare department. In this case, the county welfare agency told the adoptive parents that the infant in question was healthy when tests had indicated that the child had a low level of intelligence and was at risk for Huntington's disease. In addition, the Burrs were told that the mother was an unwed 18 year

old when, in fact, the mother was a mental patient. The Burrs testified that they would never have considered adoption of the child if the medical history had been revealed to them.

In deciding for the Burrs, the Supreme Court of Ohio commented that "in no way do we imply that adoption agencies are guarantors of their placements. Such a view would be tantamount to imposing untenable contract of insurance that each child adopted would mature to be healthy and happy." The Court stated that just as natural parents must weigh the risks of parenting, adoptive parents have the same right to make decisions about adopting a child in an intelligent manner.

In Michael J. v. Los Angeles County Department of Adoptions (247 Cal. Reporter. 504) Mary Trout, Michael J.'s mother, alleged that prior to placement, the County failed to determine the medical condition of the adoptee and made misrepresentations of complete health. Michael was diagnosed 10 years after placement with Sturge-Weber Syndrome, a congenital degenerative nerve disorder. Appellants sought damages for emotional distress and medical expenses.

In deciding for Michael J., the Court of Appeals, stated, "...we are not imposing on the agency a duty to predict the future health of a prospective adoptee. However, there must be a good faith disclosure of material facts concerning existing or past conditions of the child's health. The County *was not without the means or resources with which to investigate the total medical condition* of an obviously blemished child." (emphasis mine)

In this case, the County moved for summary judgement on the grounds that Section 818. 8 of the Government Code ("A public entity was not liable for an injury caused by misrepresentation by an employee. . whether or not such misrepresentation be negligent or intentional.") and Section 822.2 ("A public employee acting in the scope of his (sic) employment is not liable for an injury caused by his misrepresentation . . .unless he is guilty of actual fraud, corruption or actual malice.").

The Court ruled that "Public Policy cannot extend or condone concealment or intentional misrepresentation which misleads prospective. . .parents about the unusual calamity they are assuming." The Court also stressed "As keepers of the conscience of the community, we cannot countenance conduct which would allow persons who desire entrance into the emotional realm of parenting to be unprotected from schemes or tactics designed to discharge societal burdens onto the unsuspecting or unwary."

Summary

In each of the above cases, the agency misrepresented an ill or potentially ill child as healthy. A child welfare agency that fails to identify (via risk assessment or HIV antibody testing) a child at high risk of HIV infection is misrepresenting the health status of that child to the foster family. Most public child welfare agencies do not willfully neglect to do risk assessment on children as they enter foster care. It is often matter of lack of information about the necessity to do risk assessment (and the follow-up testing if indicated). However, failure to do a proper health assessment,

including HIV risk assessment, might be considered negligence on the agency's part.

The establishment of written protocols on HIV-risk assessment and HIV testing will help child welfare agencies identify children infected (or potentially infected) with HIV and ensure that they will have access to the proper health care and foster family placement. In addition, foster parents will be able to make informed decisions to care for HIV-infected children. Foster parents desiring to care for these children can then receive the training and support necessary to allow them to do the best job possible.

In the next chapter, HIV testing protocols from social service agencies in six San Francisco Bay Area counties will be examined.

CHAPTER VI: A COUNTY-BY-COUNTY EVALUATION OF CHILD WELFARE PROTOCOLS FOR HIV RISK ASSESSMENT AND TESTING OF FOSTER CHILDREN

The previous chapters of this paper have laid a foundation for the evaluation of child welfare agency policy regarding HIV testing of children in foster care. This chapter will examine the current HIV testing protocols of six San Francisco Bay Area county (public) child welfare agencies. By carefully examining the HIV testing protocol of each county, the reader will be in a better position to compare the current protocol to the regional protocol developed by representatives from all six counties and discussed in the next chapter.

Federal and State Support for HIV Testing Policy Development

As mentioned in Chapter III, numerous professional associations have published guidelines supporting the routine testing of foster children for HIV.[49,72,75] In addition, there has been both federal and state support for the development of testing policies for foster children.[54,84] A recent Department of Health and Human Services study had the following recommendations:

> All child welfare agencies placing foster care children should develop HIV antibody testing policies for children who are currently in placement or entering the system for placement. The policies should include, at a minimum, the following elements and all policies should be developed with the assistance of medical care and/or public health providers within the context of applicable state laws:

(1) specification of at-risk criteria
(2) the medical necessity (justification) for testing and a mechanism to review all testing requests
(3) informed consent mechanism
(4) pre- and post-test counseling requirements
(5) confidentiality provisions
(6) specification of individuals who may receive the test results[54]

After a brief discussion of the State of California's HIV testing recommendations, the above guidelines will serve as a useful framework for assessing the HIV testing protocols of the six counties--San Francisco, Alameda, Contra Costa, San Mateo, Marin, and Sonoma--to be evaluated in this chapter.

California

In June of 1988, the California Department of Social Services (CDSS) issued All-County Letter (ACL) 88-59 concurring with the CDC's recommendation that foster placement agencies consider adding HIV-antibody screening to routine medical evaluation of children at increased risk for HIV infection--as long as the child's physician determines that HIV screening is medically indicated.[84] The state recommendation was considered consistent with CDSS regulations for Child Welfare Services (CWS) and Community Care Licensing (CCL) which require that "foster parents, group home operators or licensees be provided with information including, but not limited to the medical history and a history of infectious or contagious diseases of the child to be placed".[84]

The June 1988 DSS memo established some initial guidelines for adoption and foster agencies to follow in planning HIV antibody testing policy. These guidelines included information about who may give consent for testing of court-dependent minors (including adolescents), preliminary procedures to follow for HIV risk assessment and mandatory notification of HIV status to potential adoptive and foster parents. An additional memo in September of 1988 clarified that the HIV status of asymptomatic children under the age of six months is indeterminate, and that these children may require repeat testing.[85]

HIV Testing Protocol Policy Development in The San Francisco Bay Area

Of the six counties evaluated in this paper none had a written HIV testing policy before 1987 (Table 3). The reason for this is fairly simple: the number of known HIV-infected children in foster care was small. The three counties with the highest incidence of pediatric AIDS (San Francisco, Alameda, and Contra Costa) reported an estimated 13 HIV-infected children had been placed in foster care through mid-1989 (all three counties combined).[54] Of course, this only reflects the known cases of HIV infection; the number of children reported to be at risk (primarily drug-exposed) is much greater. Nonetheless, for the six counties listed above, the most compelling reason to develop a HIV testing protocol was a fear that the Bay Area would soon be overwhelmed by HIV-infected children. Reports of "boarder babies" and the lack of foster homes for infants with HIV disease on the East Coast concerned social service agencies

enough to begin to develop a written HIV policy--not just for testing, but for other issues as well.[86-88]

In this section, I will evaluate the current HIV testing protocols of six Bay Area counties using the six guidelines listed by the Department of Health and Human Services in the first part of this chapter. In the next chapter, I will look at an inter-county effort, organized by the Child Welfare and AIDS Project of the University of California at Berkeley, to develop a regional HIV testing protocol. It will become apparent that Solano county was involved in this protocol work group. However, Solano county does not have an original HIV testing policy (the county uses the state memorandum ACL 88-59 as guide) and as a result, Solano county was excluded from the following discussion.

TABLE 3 DATE OF FIRST POLICY & REVISIONS

COUNTY	DATE OF FIRST POLICY	DATE OF REVISION
SAN FRANCISCO	6/87	3/88; 8/89; 10/89
ALAMEDA	11/88	4/89
SONOMA	10/87	N/A
MARIN	DRAFT: 2/90	N/A
CONTRA COSTA	5/87	DRAFT: 5/89
SAN MATEO	12/89	N/A

(1) Specification of At-Risk Criteria--Risk Assessment

All six counties have HIV Testing protocols that outline criteria to help child welfare workers (CWW) identify infants, children, and/or adolescents at risk for HIV infection. Table 4 lists twenty criteria culled from all six protocols: the wording is the author's interpretation of the criteria and may not exactly match what is

written in the protocol. No county protocol lists all twenty criteria, but San Francisco, with one of the more recent protocols (October 1989) lists sixteen of the criteria. Sonoma county, with the oldest protocol (October 1987) lists only four circumstances that place a child at risk. All six counties list "mother with AIDS or tests positive for antibodies to HIV" and "mother is suspected or known intravenous/intramuscular drug user" as criteria for risk assessment. Most (5 out of 6) list some criteria based on the mother's sexual partners (drug use or bisexual male partners) and another 4 out of 6 list "sexual partner of hemophiliac" as a specific risk criterion.

Why do the counties differ so much in the type and number of criteria used? One possible explanation is experience: those counties with the most experience with foster children at risk for HIV infection have the most criteria. For example, Alameda county revised its HIV-risk criteria to reflect the increase in cocaine-exposed children. Counties, such as Sonoma, with little experience caring for HIV-affected foster children have little real experience to guide policy decision-making. Other counties, such as San Mateo and Contra Costa, might have more complete criteria because they have used other HIV testing protocols as a model. Another possible explanation is that the risk criteria may actually differ from county-to-county. The following is discussion of each county's specific risk criteria.

San Francisco County

San Francisco county has revised its protocol at least three times. This may explain why the San Francisco county HIV testing

protocol lists 16 out of the 20 risk criteria in Table 4. The protocol lists separate risk factors for the mother, children under 12 years, and adolescents. Risk factors applied to the mother include known HIV-positive status as well as IV drug use, sexual contact with individuals considered to be high risk (sexual contact with recipients of blood products or hemophiliacs are not listed), and receiving blood products or tissue from unscreened donors (unscreened implies received blood products between 1978 and 1985). San Francisco is the only county to list previous perinatally HIV-infected children as a risk factor. Neither multiple sexual partners nor exchanging sex for money or drugs, were included as risk criteria for mothers.

Criteria, as applied to infants and children under 12 years of age, include: a positive screen for drugs commonly abused by IV (cocaine, opiates, and amphetamines), receiving blood products or tissue from unscreened donors, history of sexual abuse, symptoms of HIV disease, and no available history.

An adolescent (age 12 or over) was considered to be at risk for HIV infection if there was a history of IV drug use, sexual contact with persons at risk for HIV infections, and/or a history of receiving blood products or tissue from unscreened donors.

Alameda County

Only Alameda county has a specific checklist attached to the protocol--complete with instructions for when and how the form is to be completed (the checklist is to be completed on both children entering and on children already in foster care). Alameda county lists

seven categories of risk criteria and gives the CWW the option to apply all of the criteria to the parent(s), partners of the parent(s), or the child. The criteria include: positive HIV test, diagnosis of AIDS/ARC, recipient of blood products, child has symptoms consistent with HIV disease, participation in potentially unsafe blood exchange (e.g. tattooing or ear piercing with shared needles), sexual contact with member of high risk group, and history of drug use.

Alameda county revised its protocol in April of 1989 specifically to expand some of the risk criteria associated with drug use.[83] The 1988 HIV testing protocol only mentioned intravenous drug use; the revised protocol was expanded to include intramuscular drug use. In addition, the revised protocol mentions some specific drugs--heroin, PCP, cocaine, and amphetamines--associated with an increased risk of HIV infection.

The Alameda county risk assessment checklist does not mention sexual abuse of the child or multiple sexual partners as risk categories. In addition, infants or infants born to mothers with positive drug screens are not mentioned as risk categories. The protocol also does not make distinctions between age groups at risk; specifically the protocol fails to mention adolescents as a separate risk group.

TABLE 4: Risk Criteria by County (Current Protocol or Draft ONLY)

Specific Risk Criteria	SF	ALA	CC	SM	MAR	SON
Mother has given birth to previous perinatally HIV-infected child	YES	NO	NO	NO	NO	NO
Mother has AIDS or tests positive for antibodies to HIV	YES	YES	YES[2]	YES	YES	YES
Mother is suspected or known Intramuscular/IVDU	YES	YES	YES[2]	YES[3]	YES	YES
Mother is suspected or known to use cocaine	YES	YES	YES[2]	YES[3]	NO	NO
Mother is the sexual partner of a suspected or known IV drug user	YES	YES	YES[2]	YES[3]	YES	NO
Mother has sexual partner(s) who are gay or bisexual men	YES	YES	YES[2]	YES[3]	YES	NO
Mother has multiple sexual partners or exchanges sex for drugs or money	NO	NO	YES[2]	NO	YES	NO
Mother received blood products between 1978 and 1985	YES	YES	YES	NO	YES	NO
Mother is sexual partner of hemophiliac	YES	YES	YES[2]	YES[3]	NO	NO
Mother is the sexual partner of a person who received blood products between 1978 and 1985	NO	YES	NO	NO	NO	NO
Mother involved in the exchange of blood products (e.g. tattooing or ear piercing with shared needles; ritualistic exchange of blood)	NO	YES	YES[2]	NO	NO	NO
Child or adolescent was victim of a sexual abuse by person unknown or at risk of HIV infection	YES	NO	YES	YES	YES	YES
Child has symptoms consistent with HIV infection	YES	YES	YES	YES	YES	NO
Child or adolescent received blood products between 1978 and 1985	YES	YES	NO	YES	YES	YES
Child was abandoned	YES	NO	YES	YES[3]	YES	NO
Infant born with positive hepatitis screen	NO	NO	YES	NO	NO	NO
Infant born with a positive drug screen	YES	NO	NO	YES	NO	NO
Infants born to a mother with a positive drug screen	YES	NO	NO	YES	NO	NO
Adolescent is sexually active with person at risk for HIV	YES	YES[1]	NO	YES[4]	YES	NO
Adolescent (over 12 years) uses IV drugs	YES	YES	NO	YES[4]	YES	NO

SF=San Francisco; ALA=Alameda; SON=Sonoma; MAR=Marin; SM=San Mateo; CC=Contra Costa

1=Adolescents are not mentioned specifically, but does have column on checklist for "child admits to having had sexual contact with an individual" at risk for HIV

2=Criterion is for infants and children under age 3 ONLY

3=Criterion is for infants age 0-2 ONLY

4=Includes children up to age 12 in a similar, but separate category

Contra Costa County

Contra Costa county has revised it's 1987 policy and greatly expanded the risk assessment category. The current protocol lists 13 out of the 20 risk criteria in Table 4. In revising the policy, Contra Costa county looked at other HIV testing protocols to broaden the risk criteria.[84] The draft protocol separates risk criteria by age: infants and children under age three, children three years of age and older, and children of all ages. Infants under the age of three are considered at risk for HIV infection if the child is an abandoned infant (under fifteen months) or has parents suspected of being HIV-infected. In addition, risk criteria for children under the age of three include having parents who are known or suspected to engage in high risk behavior--defined as history of multiple sexual partners (including prostitution), IV/IM drug use (heroin, PCP, crack cocaine, and amphetamines), or unsafe exchange of blood (e.g. tattooing or ear piercing with shared needles). Children with parents who have sexual contact with high risk individuals (e.g. IV drug users, bisexual men, hemophiliacs, persons with HIV disease) are also considered at risk for HIV. Contra Costa is the only county to list a positive hepatitis B screen at the infant's birth as a risk factor. Surprisingly, Contra Costa does not list a positive drug screen (infant or mother's) as a risk factor for HIV.

Children over the age of 3 years are considered at risk of HIV if they have a significant history of sexual abuse. In addition, children with developmental or neurological delays who display aggressive behavior or lack the ability to control body secretions are also

considered at risk of HIV--presumably because of an apparent risk to others.

Children of any age are considered at risk for HIV if the mother received many unscreened blood products or if the child was the victim of sexual abuse by a male who may be HIV positive or an IV drug user. Children with symptoms of HIV disease are also considered at risk of HIV infection.

Receiving unscreened blood was not listed as a risk factor for children of any age. In addition, there is no special mention of adolescents as a separate group.

San Mateo

San Mateo, with 14 out of the 20 criteria listed in Table 4, outlines risk criteria based on age groups: infants, children, and adolescents. Children under the age of five are considered at risk if they have a parent known to have HIV infection. San Mateo is the only county to use age five as a cutoff for parental HIV infection as a risk factor.

Infants are defined as up to age two years and are considered at risk for HIV infection if they are abandoned, have symptoms consistent with HIV or if the infant or the mother has a positive drug screen at the infant's birth. In addition, any infant born with a father who has hemophilia or is in a high risk group (defined as bisexual or IV drug use) is at risk.

Children up to age 12 are at risk of HIV in San Mateo county if the child has been sexually abused by someone defined as high-risk (HIV infected, drug user, homo-or-bisexual or hemophiliac). Children

with a history of receiving unscreened blood products are also considered at risk. San Mateo county is the only county to specifically list multiple sexual partners and drug use by children under the age of 12 as risk factors. (The Alameda county protocol has a place to check drug use and unsafe sexual practice, but it isn't clear if this is meant specifically for children.) Multiple sexual partners or exchanging sex for money or drugs are not included as risk criteria for mothers. In addition, children who have mothers with a history of receiving unscreened blood products are not listed as at risk for HIV infection.

Adolescents in San Mateo county are considered at risk for HIV infection for all the same reasons as children up to age 12, except that having a parent with HIV infection is not a risk category for the older group of children.

Marin County

Marin County does not have an approved HIV testing policy in effect. This evaluation is based on an unapproved draft prepared by the Marin county Department of Health and Human Services. Marin County has 12 out of the 20 risk criteria listed in Table 4 and lists separate risk factors for the mother, children under 12 years, and adolescents. Four criteria are listed for the mother and include: positive HIV antibody test; suspected or known drug use (route or type of drugs not specified); recipient of unscreened blood transfusion; and participation in high risk sexual practices (e.g. sexual partner of IV drug user or bisexual man, but not sexual partner of hemophiliac blood product recipient). In addition, Marin lists both

multiple partners and prostitution as risk factors for HIV infection in mothers.

Children in Marin county are considered at risk for HIV infection if they have received unscreened blood products or if they are hemophiliacs born before 1985. Sexually abused or abandoned children are considered at risk because the history of the abuser or parents is likely to be unknown. Children with symptoms consistent with HIV disease are also placed in the high risk category. Infants born with or born to mothers with positive drug screens are not considered high-risk children.

Risk factors for adolescents are well defined in Marin county. Risk factors include unsafe sexual practices (e.g. multiple partners or partner of IV drug user) and IV drug use by the adolescent. A history of receiving blood products or of having hemophilia is included; so is having symptoms consistent with HIV infection. Marin is one of only two counties (the other being San Mateo) to list sexual abuse as a specific risk factor for adolescents.

Sonoma County

Sonoma county's HIV testing protocol is the oldest of the six counties and has not yet been revised. Perhaps it is not surprising that only four of the criteria in Table 4 are listed--two of the criteria apply to the mother and two apply to the child. Risk factors are listed for the mother of an infant under the age of one year and include known HIV infection and known IV drug use. There is no consideration of heterosexual transmission factors and there is an

assumption implicit in the protocol that HIV-infected infants over the age of one year do not need risk assessment.

Sexual abuse by an HIV-infected person or known IV drug abuser as well as a history of receiving unscreened blood products are the only risk factors listed for children. Adolescents are not considered separately as a group.

The Sonoma county protocol has several major deficiencies when it comes to defining mothers and children at risk for HIV infection--including failure to separately consider most major heterosexual transmission risk factors and failure to consider most children over the age of one year as having the potential to be at risk for HIV.

Discussion

The above review of county testing criteria reveals a wide variation in both the number and type of risk criteria listed in the six county protocols. While all consider the mother's HIV-status and drug use as risk criteria, there is less consensus about adolescents as a group or heterosexual risk factors (e.g. multiple sexual partners or sexual partners of blood or blood products recipients). The majority of counties also consider children who are victims of sexual abuse or who have symptoms consistent with HIV disease as specific risk categories.

Infants born with positive drug screens are considered to be at risk for HIV infection in only two counties--San Francisco and San Mateo. Yet this is the exact group of children considered to be at the greatest risk of becoming infected. While failing to consider a

positive drug screen as a specific risk factor, Contra Costa county does consider infants born with a positive hepatitis B screen to be at risk--presumably because this is an indirect and less intrusive way to identify drug-exposed infants and maternal IV drug use.

There is little consensus among the counties as to an appropriate age when the child's parental risk factors are no longer considered relevant. San Mateo county uses age five as a cutoff while San Francisco uses age twelve. Given that one of the first cases of pediatric AIDS was reported retrospectively in the Bay Area in 1978, it is entirely possible for a child over the age of five to be HIV-infected.[1] Therefore, age categories should be as broad as possible when defining parental risk factors for HIV.

(2) The Medical Necessity (Justification) for HIV Testing and Mechanisms to Review Testing Requests

An accurate and complete risk assessment is the first step toward identifying HIV-positive children--and obtaining appropriate medical care for these children. The second step is to obtain the HIV antibody test. As argued in Chapter IV, most children who undergo an appropriate risk assessment will not receive the test. Since the main argument for administering the test is a medical one, it is important for the request to be evaluated as being medically necessary. Deciding what is medical necessity is usually done by a physician and all but Sonoma county have described some mechanism for obtaining medical approval for HIV testing requests. Few counties have a mechanism to review the relevancy of the testing request beyond the initial physician's approval. Some

counties also review the physician's approval before allowing social services to obtain informed consent for testing--either from the biological parents or the court.

San Francisco County

Of all the counties, San Francisco has the most comprehensive procedure for deciding if an HIV antibody test is warranted. In San Francisco, the child's physician must document in writing the medical justification for obtaining an HIV test. The documentation consists of a form listing the risk criteria developed by San Francisco--the physician circles the criteria that apply and signs the form. The completed form and the child's medical history are sent to the Perinatal AIDS Coordinator (a physician) who reviews the document from the child's physician plus any additional documents from the child's social worker. If the Perinatal AIDS Coordinator agrees that the child should be tested, a recommendation (signed by the Perinatal AIDS Coordinator) is sent back to the Department of Social Service worker. The DSS worker can then begin the procedure for obtaining informed consent.

Alameda County

In the introduction of the HIV testing protocol, it is stated "early medical intervention can add to the length and quality of life of HIV positive children. Therefore, children who are high risk of being HIV positive. . .will be considered for HIV testing." HIV testing is pursued under two circumstances: (1) the child's physician recommends testing following medical evaluation or (2) the CWW

determines that the child is high risk after completing the risk assessment checklist. In both cases, a recommendation for testing must be signed by a physician before informed consent or a court order can be obtained.

Contra Costa County

Contra Costa county social services will proceed with obtaining informed consent when two conditions have been satisfied: (1) foster children meet one of the risk criteria listed in the protocol and (2) a physician agrees that there is a medical basis for the test.

San Mateo County

In San Mateo county, foster children who are defined as being at risk for HIV infection based upon the risk criteria listed in the protocol are to be screened for exposure to HIV. If the child is in a medical setting (not defined), medical personnel must agree to performing the test. While no specific mechanism for reviewing the decision to test is specified, the protocol does say that the final decision to seek consent for testing rests with DSS in consultation with the Department's physician.

Marin County

In the draft HIV testing protocol for Marin county, risk assessment is described as being done with a primary care physician. The protocol states that "An HIV antibody test must be performed if it is determined by the child's doctor that the child is at risk for HIV

antibodies". A mechanism for reviewing the physician's decision is not described.

Sonoma County

Sonoma county's current protocol does not describe any mechanism for determining the medical necessity of HIV testing or reviewing testing requests if the child clearly fits the definition of risk as defined in the protocol. However, if someone suggests that the child be tested and s/he does not clearly fit the definition of risk (this will most likely be the case) AND a court order will be required to obtain the test, a special Case Review Committee may meet to decide if the test is indicated. The Committee consists of a public health officer (a physician) and a pediatrician with knowledge of HIV disease. If the two physicians sign a recommendation for testing, the court will then order the test.

Discussion

All of the protocols suggest or state that medical review or approval for testing is appropriate. Having a mechanism in place to review referrals is important to prevent unnecessary HIV testing--as such, it provides a system of checks and balances. San Francisco has the most comprehensive policy and this may be explained by the numerous revisions of the HIV testing protocol. Many of the counties may have internal mechanisms for reviewing testing requests, but with the exception of San Francisco these are not clearly described in the current protocols.

(3) Informed Consent Mechanism

California state law requires that informed consent be obtained before administering the HIV antibody test to foster children. Therefore, it is not surprising that all six counties state the procedure for obtaining consent. The six counties agree on the following items: (1) written parental consent should be obtained whenever possible; (2) when parental consent is not obtainable and HIV testing is indicated, a court order must be obtained; and (3) adolescents (over 12) may give their own consent.

There is some variance in the protocols; some counties specifically state which parties, such as CWW or foster parents, may not give consent for testing. One county requires court approval for ALL testing done on foster children regardless of whether parental consent has been obtained. The following discussion will focus only on variances from the above in each county's protocol.

San Francisco County

If parental consent is unobtainable, the CWW must prepare an affidavit stating the reasons why consent was not obtained. In seeking a court order, three items must be submitted to the court: (1) a physician's letter justifying the need for testing (2) the perinatal AIDS coordinator's recommendation for testing and (3) an affidavit of failure to obtain parental consent.

Alameda County

Alameda county requires juvenile court approval for all foster children regardless of whether the parent or minor has given

consent. In addition, both the parent and the child must consent if the child is over 12 years of age. The Alameda county protocol, like San Francisco, requires documentation of the reasons parental consent was not obtained.

The Alameda county protocol states that a court hearing must be requested when either the parent or the child (over age 12) refuses to give consent for testing.

Contra Costa County

Contra Costa county specifically states that neither the social worker nor the foster parent has the authority to give consent for testing. The protocol mentions that the court may give consent when a child over 12 refuses to be tested. Unlike the San Francisco and Alameda county protocols, there is no mention of documenting a failed attempt to obtain parental consent.

San Mateo County

The San Mateo county protocol states that the CWW must document efforts to locate the parents and/or obtain consent. If the worker cannot obtain consent, an attempt must be made to notify the parents of the date and time of the court authorization for testing.

Marin County

Marin, like Contra Costa county, mentions that HIV antibody test results in infants (under 18 months) can be indeterminate and may need to be repeated. The Marin protocol does not require written documentation of an effort to locate parents.

Sonoma County

The Sonoma county protocol includes the basic information listed in the beginning of this section.

Discussion

Because the state law requires that informed consent be obtained before administering the HIV antibody test, all six counties include the basic procedural steps the CWW must take to obtain consent for testing although some are more careful to include the biological parents. In the next section, it will become obvious that not all counties clearly describe a mechanism for obtaining truly informed consent.

(4) Pre- and Post-Test Counseling Requirements

Informed consent implies that the person(s) understands why the HIV test is being recommended, the risks and benefits of the test, and especially, the implications of the test results--both positive and negative. The HIV antibody test can have many different meanings to many different people--each person will respond to having the test performed in an individual way. A positive HIV antibody test is frequently considered a death sentence. Careful counseling at the time the consent is obtained is an excellent opportunity to educate parents (and sometimes children) about treatment options and the changing nature of HIV disease. Parents who are approached to sign the child's consent will frequently be at risk for HIV infection themselves--thus, it is especially important that well-informed people do pre-test

counseling when obtaining consent. In addition, pre-and post-test counseling can be an important way to educate people about safe sex and other risk-reduction behavior.

Unfortunately, not all of the counties describe pre- and post-test counseling procedures in the protocols. Some of the protocols include information sheets for the child and/or parent and some of the protocols state that counseling is to be done by the social worker.

San Francisco County

The San Francisco county protocol does not specifically mention who does pre- and post-test counseling, but the consent form does say "I have been given both written and verbal explanation of why the test is important, and what the test can and cannot tell. I understand the benefits and risks of the test." An information sheet is given to the parent explaining the significance of both a positive and negative test and an information number (San Francisco AIDS Foundation). In addition, the parent is warned to exercise care in disclosing HIV tests results to "unnecessary" people.

Alameda County

Alameda county has one of the most comprehensive protocols when it comes to describing pre- and post-test counseling requirements. The protocol specifically states that the CWW is to provide pre- and post-test counseling to the parent, guardian, caretakers, and the child when appropriate. The protocol states that

the CWW worker is to conduct the counseling session in person. The CWW is cautioned to have a non-judgmental approach when counseling parents and/or children and to be prepared for anger, grief and denial. The protocol encourages CWWs to be aware of any feelings they may have about AIDS and those high-risk behaviors which may result in HIV infection.

The Alameda county protocol carefully outlines what must be covered during the session. Highlights from the counseling section of the protocol include: evaluating support systems for the child, parent, and caretakers; educating biological parents and adolescents about high-risk behavior; discussing how to reduce transmission of HIV to others; explaining the (possible) need to re-test children under the age of two; and referring parents to community resources for additional information. The Alameda county protocol also provides an information sheet for the parents with the same information as the San Francisco information sheet--including a note of caution about unnecessary disclosure of test results.

Contra Costa County

The Contra Costa county protocol is modeled after the Alameda protocol and also has one of the most detailed and comprehensive approaches to pre- and post-test counseling. The protocol has all the information included in the Alameda county section above and the reader is referred to the above section for detail.

San Mateo County

The San Mateo county protocol states that the San Mateo County Health AIDS Project staff will provide "specialized resources to the foster parent, as well as counseling services to the natural parent when appropriate". In addition, foster parents are expected to participate in HIV training when caring HIV-positive children. The protocol does not include an information sheet for the natural or foster parents.

Marin County

The Marin County protocol does not specifically mention pre- and post-test counseling. After consent has been obtained for HIV testing, children under twelve are referred to CSS for diagnostic testing. Children over the age of twelve are referred to an anonymous test site. The consent form mentions that test results will be used to assist social services in planning foster placement--there is no mention of medical risks or benefits to the child.

Sonoma County

Pre- and post-test counseling is briefly mentioned in the Sonoma county protocol. The child's parent or legal guardian is to be given an information sheet about the "significance and ramifications" of both positive and negative test results, but the protocol does not mention who should give the information to the parent. In another section of the protocol it is suggested that the child's parents should have access to information and counseling about the significance of the test results, but does not say who should do the counseling. The

foster parents fare a little better--they are to be given information and counseling regarding the child's test results by a physician or a "public health person or physician doing this work".

Discussion

Pre-and post-test counseling are an essential part of any informed consent procedure for HIV antibody testing. Only the Alameda and Contra Costa counties protocols comprehensively address the issue of counseling. Complete understanding of the implications of the HIV antibody test are necessary for the parents, caretakers, and when appropriate, the child. Given the legal mandate, written consent is obtained, but it isn't at all clear that consent is truly informed. Child welfare workers conducting pre- and post-test counseling must be completely informed about the implications of positive and negative test results.

(5) Confidentiality Provisions

The HIV antibody test is not like other medical tests--a positive test can result in discrimination and isolation. State law requires that HIV test results remain confidential. Therefore, it is essential that all foster care agencies keep HIV related information in a separate section of the case file--and instruct the CWW on the correct procedure to follow when doing so.

San Francisco County

The San Francisco county protocol does not specify how documentation of tests results is to be handled. The information

sheet for parents states that HIV test results must remain confidential, but the protocol contains no specific guidelines to help CWW workers assure confidentiality.

Alameda County

The Alameda county protocol clearly and carefully states the process for "receiving and handling test results". The protocol includes mention of the state law requiring confidentiality of medical documents (including HIV tests results) relating to an AIDS diagnosis. In addition, the protocol clearly states that HIV information is to be kept in a separate file from the child's case record and directs the CWW to the secretary who handles the confidential file.

Contra Costa County

The Contra Costa county protocol clearly outlines confidentiality and record keeping procedures. The protocol explains the state law requirements on confidentiality. The CWW is also told that documentation regarding the child's HIV test results are to be kept in a separate file, but does not specifically mention where the file is to be kept.

San Mateo County

The San Mateo county protocol, like Alameda county's, gives the CWW specific instructions for documenting HIV test results. Documents are kept in a separate folder and are to be sent to the Program Deputy of Children's Services where the records will be kept in a locked cabinet. There is no specific mention of state law

requirements for confidentiality, but the protocol states that "regulation requires that all documents related to the child's medical condition" are confidential.

Marin County

The Marin county protocol mentions that the diagnosis of "HIV antibodies in a child can evoke fear and suspicion in others", but does not mention the legal imperative for confidentiality. The protocol also neglects to guide the CWW on how and where HIV test results are to be kept.

Sonoma County

The Sonoma county protocol states that "the test result will be kept confidential for the child's best interest". The protocol gives a list of people who may have access to the test results (covered more thoroughly in the next section) and cautions that providing the test results to anyone else is a violation of state law. The Dependent Unit Superintendent is designated as the person who will keep the HIV antibody test results in a separate locked file.

Discussion

The protocols for Alameda, San Mateo, and Sonoma counties give the CWW the most guidance for keeping HIV test results confidential. In addition to clearly mentioning state law requirements concerning confidentiality of records, these counties tell the CWW exactly where these records should be kept. Because of the potential repercussions of unauthorized disclosure of HIV test

results, it is imperative that child welfare agencies clearly spell-out the exact procedure CWW must follow to maintain confidentiality.

(6) Specification of Individuals Who May Receive the Test Results

Disclosure of HIV test results (i.e. who may receive the test results other than the person being tested) is a key component of any comprehensive HIV testing protocol. HIV test results may be disclosed without written consent to the third party who signed the consent for the child. In addition, health care providers may receive HIV test results for the purpose of diagnosis, care, and/or treatment.[83] Any other disclosure of HIV test results requires specific written authorization. The HIV testing consent form should specify who will receive test results--this usually includes the foster family and the CWW.

San Francisco County

The San Francisco county protocol does not instruct CWWs regarding disclosure of HIV test results. There is no discussion of laws pertaining to disclosure of HIV test results. The informed consent signed by the child's parent allows for disclosure of test results to DSS, the Department of Public Health, and the child's caretakers. The consent form also allows the test results to be placed in the medical record.

Alameda County

The Alameda county protocol states that positive HIV-antibody test results may be disclosed to all caretakers of the child (birth

parents, guardian, relative caretakers, foster parents) and specific providers (physicians and dentists, etc) as approved by the parent/child and the court. The parental consent for testing also authorizes release of test results to the above persons.

Contra Costa County

The Contra Costa county protocol is similar in scope to the Alameda county protocol. The child's biological mother, foster parents, and caretaker relatives may be informed of positive HIV test results. In addition, the Contra Costa county protocol lists the child's social worker and the unit supervisor as people who may receive test results. Disclosure to "alleged" fathers was being referred to county counsel for an opinion before being incorporated into the final HIV testing protocol. Health care providers, such as physicians and dentists, were also to be informed of the child's antibody status.

San Mateo County

The San Mateo county protocol designates the following people on the HIV testing consent form as persons who may receive positive test results: the child's physician, the social worker, the child's caretaker(s), Juvenile court, child's parent/guardian, and the child's attorney, if any. The San Mateo county protocol also specifically mentions the law (199.27 H & S) pertaining to unauthorized disclosure and which persons may receive results of the testing without written authorization.

Marin County

The Marin county protocol lists the social worker, program manager, health care provider(s), psychologist, and foster parents as people who potentially "need to know" the child's HIV antibody status. The informed consent form authorizes both the supervising social worker and foster parents to receive HIV test results.

Sonoma County

The Sonoma County protocol states that the child's private physician, caseworker, Dependent Unit Superintendent, and foster parents should receive HIV test results. In addition, the protocol mentions that "support network persons designated to provide direct care" may also receive test results. In addition, the protocol mentions that children over twelve and the biological parents should have access to test results.

Discussion

Disclosure of HIV antibody test results is generally done on a "need to know" basis. Persons who "need to know" are generally defined as those who are involved in the daily care of the child, such as the foster parents, the social worker managing the case, and the biological parents. Thus, the six counties generally limit disclosure to those persons directly involved in the foster child's care. The more carefully worded protocols, such as Alameda county's, specify who may receive HIV test results in the main body of the protocol document. In addition, the consent for HIV testing lists those persons who will receive test results other than the child or the child's

parents. Because unauthorized disclosure is both illegal and potentially harmful to the child (and the child's parents) it is essential that counties clearly specify who shall receive HIV test information.

Summary

The focus of this chapter has been a systematic evaluation of HIV testing protocols from six San Francisco Bay Area counties. Some of the county protocols, particularly Alameda county's, have most of the elements suggested by the Department of Health and Human Services at the beginning of this chapter. Other county protocols, notably Sonoma county's, fail to adequately include the basic components of a comprehensive HIV testing policy. Of the six counties evaluated, none has many known HIV-infected foster children in its case load. All of the counties evaluated are anticipating increased case loads (for all the reasons mentioned in this paper), but none of the six has yet felt an impact similar to the East Coast experience.

Three counties--San Francisco, Alameda, and Contra Costa--have the most comprehensive policies. All three of these counties reported that few HIV-infected children were in foster care, but a large number of foster children were drug-exposed and therefore at risk of becoming HIV-infected. Of the six counties, San Francisco, Alameda, and Contra Costa also have the largest number of children in foster care (Table 5) and may feel more compelled to have written protocols regarding HIV-infected foster children. All three counties have revised or are in the process of revising their HIV testing

protocols and this may explain, in part, why the protocols are more complete.

TABLE 5: NUMBER OF CHILDREN IN FOSTER CARE DURING OCTOBER 1989

COUNTY	CHILDREN IN FOSTER CARE
SAN FRANCISCO	1,790
ALAMEDA	2,326
CONTRA COSTA	1,540
SAN MATEO	515
MARIN	106
SONOMA	234

SOURCE : PUBLIC WELFARE IN CALIFORNIA, OCTOBER 1989

Wilhelmina Johnson, program analyst for Contra Costa County Social Service, stated that the driving force behind revising the original protocol was to make it more accessible to social workers.[87] Barbara Droher from Alameda County Social Service, said the HIV testing protocol was revised in her county to expand the list of risk criteria to more accurately reflect children at risk (i.e. drug-exposed).[86]

Sonoma, Marin, and San Mateo counties have not yet revised their HIV testing protocols. The San Mateo county protocol is the most recent (December 1989) and is the most comprehensive of the three. Marin county has had very limited experience with HIV infected foster children and no official policy concerning HIV-infected foster children currently exists. The HIV testing protocol under consideration in Marin county, used in this chapter's evaluation, includes some important points (e.g. risk criteria), but is generally weak overall (especially pre- and post-test counseling and

medical justification for testing/review). The Sonoma county protocol, as previously mentioned, is the oldest of the six protocols. As such, it should not be surprising that it is the weakest of the lot.

HIV testing protocols guide child welfare workers as they care for children in foster care. But even the most comprehensive protocol is ineffective if child welfare workers do not use it or are unaware of the contents of the protocol. In the next chapter we will examine an innovative approach to making HIV testing protocols both comprehensive and useful.

CHAPTER VII: THE DEVELOPMENT OF A REGIONAL STANDARD FOR CHILD WELFARE HIV TESTING POLICY

In the previous chapter, I examined six different HIV testing protocols from child welfare agencies in the San Francisco Bay Area. Developed over the past three years, the protocols vary in both scope and approach. However, all of the protocols are designed to identify HIV-infected children in foster care and direct them toward appropriate health care. In addition, the protocols allow prospective foster parents to make an informed decision to care for an HIV-infected child.

Even the most comprehensive and up-to-date HIV testing protocol is ineffective if it isn't being utilized. An AIDS training needs assessment of 209 child welfare workers (CWWs) in eight Bay Area counties found that there was a gap between HIV testing policy and practice.[89] The 1989 survey, conducted by the Child Welfare and AIDS Project revealed that 32% of CWWs believed their caseloads were at risk for HIV, but only 15% reported that they always do risk assessment. Fifty-one percent reported that they never do risk assessment. Child welfare workers were also not well informed when it came to the legal requirements of informed consent and documentation of HIV test results. Of the CWWs responding, 66% could not correctly identify who may consent for court-dependent children under the age of 13 and 85% could not identify who may consent for HIV testing of adolescents. Fifty-nine percent of CWWs would not document HIV results in a special file.

Workers responding to the the survey expressed a need for guidance and training in several areas--including HIV risk

assessment and testing. A local group, known as the Child Welfare and AIDS Project of the Bay Area is attempting to address these needs by working with local child welfare agencies to evaluate current agency protocol documents and develop a regional standard.

In the first part of this chapter, I will describe the Project's effort to develop comprehensive policy guidelines for children with HIV infection in the child welfare system. Then I will present the recommendations from a protocol work group of the Child Welfare and AIDS Project. In the final part of the chapter I will argue that both the method and the results of this work group could constitute a model for other regions of the country in their efforts to respond to HIV infection within the foster care system.

Toward A Regional HIV Testing Policy

The Child Welfare and AIDS Project of the Bay Area

In this section, I will briefly describe the Child Welfare and AIDS Project of the Bay Area and its effort to develop a regional standard for child welfare protocol and policy. The Child Welfare and AIDS Project of the Bay Area is a three year demonstration project funded in October 1988 by the Children's Bureau, Administration of Children, Youth and Families, Office of Health and Human Services. The Project has as its mission the study of local child welfare services available to families caring for children with HIV disease. After careful evaluation of services, the Project hopes to enhance these services by way of (1) regional planning and coordination of service

delivery; (2) development of model demonstration programs such as a respite care program; and (3) model regional pediatric AIDS education and training programs.

The Project brought together administrators from eight Bay Area counties to facilitate the regional planning and coordination of child welfare services. The eight counties participating in the Regional Planning Group (RPG) include: San Francisco, Alameda, Contra Costa, San Mateo, Marin, Sonoma, Santa Clara, and Solano counties.

Child Welfare and AIDS Project Protocol Work Group

As one part of regional planning and coordination, the Project sought to develop comprehensive child welfare HIV policy guidelines covering seven topics: staff and caregiver training, HIV risk assessment, HIV testing, placement considerations, daycare and school attendance, health care considerations, and support services to caregivers. The development of these policy guidelines was a long process. The staff of the Project first set some goals, reviewed the literature, consulted medical and legal experts, and drafted protocols; then a protocol work group was formed to carry out the final steps.

The goal of the Project was to develop a comprehensive HIV policy that would (1) encourage a uniform standard within the child welfare system regarding HIV-infected children and their families in the Bay Area (a highly interconnected geographic area); and (2) facilitate an efficient use of consultation from medical and legal experts.

Using selected HIV protocol documents from both local and national child welfare agencies as well as recommendations from groups such as the Child Welfare League of America and the American Academy of Pediatrics, the staff developed draft forms of protocol documents covering the seven topics listed above. Each of the seven protocol documents contained a brief overview of the issues to be covered, recommendations on what specific procedural issues should be contained in the policy, and examples of policies which can serve as models.

After developing the draft protocols, the project brought together representatives from seven of the eight Bay Area counties (Santa Clara county chose not to participate) and formed a protocol work group. The work group first met in January of 1990. In addition to child welfare administrators, the group included health care professionals and social workers caring for medically fragile and/or HIV-infected foster children.

The protocol work group met four times between January and April of 1990. As might be expected from the discussion in Chapter VI, representatives from the seven counties brought to the work group varying levels of experience with HIV-infected foster children. Representatives from Solano county had less experience with HIV-infected foster children than representatives from San Francisco, but all members expressed an eagerness to develop a regional consensus regarding the care of children at risk for HIV infection.

A discussion of the development of all seven protocols is beyond the scope of this paper. The remaining discussion will focus on the development of the risk assessment and HIV testing protocols,

which are the issues I have focused on in this paper. These two issues are also arguably the most difficult and crucial of the seven issues looked at, and the proposed guidelines on these topics may therefore prove to be valuable to other regions in the country.

Risk Assessment and HIV Testing Protocol Development

The risk assessment and HIV testing protocols were discussed during the first two meetings of the protocol work group. Members of the group received drafts of the protocol to be discussed in advance and came prepared to discuss it during the two hour meeting. Risk assessment was discussed first. Members of the group identified one important stumbling block in carrying out risk assessment: it has frequently been equated with testing. In other words, doing risk assessment was tantamount to testing. Members expressed a reluctance to label children as being at risk--usually because of the stigma attached to such a label. Thus universal assessment was seldom done. One of the key policy recommendations of the group, therefore, was to state that HIV risk assessment should be a routine part of intake for all children and families coming into the system. In addition, risk assessment should continue until an adequate risk profile is obtained.

A second major obstacle was the lack of a standardized form to assist CWWs in doing risk assessment. As mentioned in Chapter VI, only Alameda county provides its workers with a form for conducting risk assessment. Thus, another recommendation was for the provision of a standardized form, with clear guidelines for use,

for conducting risk assessment. Some counties also expressed a need for special training in taking drug and sexual histories.

Risk assessment, especially of families, is best done in person. However, several members of the group mentioned that a face-to-face interview isn't always possible. In addition, some risk factors, such as a history of drug use or prostitution, may become apparent without personal interviews. Another recommendation of the group was for workers to use a variety of sources for gathering information at the time of risk assessment (e.g. medical records, interviews, etc.).

Given the wide variation in risk criteria identified in Chapter VI, it should not be surprising that much of the discussion centered upon defining risk criteria. A group consensus was reached on a variety of criteria pulled from the various county protocols. A lively discussion centered upon including "multiple sexual partners" as a risk criteria, but ultimately "trading sex for drugs or money" was felt to be inclusive enough.

Other major concerns regarding the HIV testing protocol included informed consent and disclosure laws. Members of the group expressed a need to clearly define informed consent. In addition, the group consensus was that whoever obtained informed consent needed to do pre- and post-test counseling. However, there was a concern that not all CWWs were adequately trained to do counseling. One of the final recommendations states that all CWWs referring clients for testing must be adequately trained in the meaning of test results.

In one and one-half sessions, administrators, physicians, nurses, and members of the academic social welfare community

came together and agreed upon a regional risk assessment and testing policy. The discussions were intelligent, thoughtful, and lively. Malia Ramler, staff member of the Project and participant in the work group, synthesized the ideas and suggestions to produce final draft forms of the protocols. What follows is the current HIV Risk assessment draft protocol:

Risk assessment policy should include:
(1) A clear statement that HIV risk assessment should be a routine part of intake for all children and families coming in the child welfare system.

(2) A standardized form, which clearly defines pediatric criteria for inclusion in high risk groups, (see section III, Testing) and which provides guidelines for the gathering of risk information should be available to CWWs. If necessary, training and guidelines on the gathering of drug histories and sexual histories should be provided.

(3) Risk assessment should begin at the time of a family's entry into the system, and continue until an adequate risk profile is obtained. Information from a variety of sources should be gathered and documented, in a central location in the chart. Sources of information should be noted, and might include: interviews, medical records, physicians or other hospital staff, and police reports.

(4) A consultation team, including medical and legal personnel should be available to any CWW who has questions regarding appropriate follow-up to information gathered in the risk assessment.

Policy on referrals to HIV testing should include:
(1) A statement of confidentiality. In California, any medical information related to HIV or AIDS is confidential under numerous

legal provisions including the Constitutional right-to-privacy, the Confidentiality of Medical Information Act, the physician-patient privilege and others. There are detailed California statutes which govern the confidentiality of HIV test results. California law provides that HIV antibody test results may only be disclosed with the written authorization of the subjects of the test, or of the person providing consent for the test. Minors twelve years and older need to give consent to share this information.

(2) Referral to testing should be determined on a case-by-case basis with information based on careful risk assessment as detailed above.

(3) The CWW or health care provider identifies the child as high risk for infection with HIV if any of the following criteria apply:

I. Mother of the child has any of the following risk factors:
   a. Known to be HIV-positive, to have AIDS/ARC, or to have had previous perinatally HIV-infected children.
   b. Has a positive toxicology screen, a history, or physical evidence of drug abuse (cocaine, opiates, amphetamines, PCP).
   c. Sexual contact with an individual with AIDS, ARC, HIV seropositivity; or sexual contact with an IV drug user, hemophiliac, or bisexual man since January 1, 1978.
   d. Current practice or history (since 1978) of trading sex for drugs or money.
   e. Received blood products (i.e. transfusion, factor concentrates) or tissue or organ transplant from an unscreened donor between January 1, 1978 and June 1, 1985.

II. Child (up to age 12) has any of the following risk factors:
   a. Symptoms of neonatal drug effects or positive screen for drugs (cocaine, opiates, amphetamines, PCP).

b. Received blood products or transplant from an unscreened donor between January 1, 1978 and June 1, 1985.
c. History of sexual abuse
d. Signs and symptoms consistent with HIV-infection or AIDS (e.g. chronic pneumonia, recurrent infections, chronic diarrhea, failure to thrive, developmental delay, or unusual neurologic symptoms). Refer child to physician immediately.
e. No history available i.e. abandoned infant.

III. Adolescent has any of the risk factors listed in I, mother's risk factors, or:
a. history of sexual abuse
b. Signs and symptoms consistent with HIV infection or AIDS

(4) Request for referral to testing, particularly in cases where the court will be asked to consent, should be reviewed/verified by medical personnel. Agencies may handle this in different ways. Some require that the physician verify that the test is medically advised and have the physician sign the request to the court. Another mechanism that has been adopted is that of a multidisciplinary case review board which reviews all cases recommended for testing prior to referral to the courts. Typically these case review boards have medical and legal representation. A board of this nature can be employed for consultation on additional case decision making beyond review of appropriate referral for testing.

(5) In compliance with state law, testing can only be carried out with informed consent of the child's parent or legal guardian, or in the case of an adolescent (12 years of age or older), with the informed consent of the minor. Policy should advise that informed consent requires that the parent, legal guardian, or child understand why the test is being recommended, and the risks, benefits, and implications of obtaining the test, and the meaning and limitations of the test

results. A court may consent to the testing of a court-dependent teen if testing is done in order to render prevention, care, or treatment.

(6) In all cases where the child cannot consent for his or her own test, consent must first be sought from the birth parent. When the birth parents not available, or when risk factors indicate a need for testing and the birth parent will not consent, a court order for consent for testing should be sought. Protocols should include step-by-step instructions for the submission of the request for a court order consenting for testing. In cases where the consent is obtained from the court, an effort should be made to inform the birth parent of the test.

(7) County protocols may want to clarify who may not consent for testing e.g. foster parents, physicians, child welfare workers, etc.

(8) All referral for testing and requests for consent must be accompanied by pre-test counseling to birth parents, substitute caretakers, and when age appropriate, the child. All CWWs referring clients for testing must be adequately trained on the meaning of test results, particularly for infants and young children, have clear guidelines for pre- and post-test counseling, and be aware of community resources for follow-up referral. Informed consent requires that the parent, legal guardian, or child understand why the test is being recommended, the risk, the benefits, the implications of obtaining the test, and the meaning and limitations of the test results.

(9) Referral for the child's testing should be made through the nearest CCS HIV children's program. CCS may cover payment for screening and diagnosis, treatment costs for eligible children, and assistance with medical case management.

(10) If the risk assessment reveals that birth parents are at risk for HIV infection, the CWW should encourage them to consider testing in order to help them care for their own health, and advise them of

community resources for free, anonymous, confidential, and voluntary testing.

(11) HIV test results may be disclosed without written consent to the individual tested, the third party who provided consent for the test, or to the individual's licensed health care providers for the purpose of diagnosis, care, or treatment. Any other disclosure requires specific written authorization and must specify to whom disclosure will be made. Each HIV-infected child should have a court order signed "release of information" document attached to the case folder. Unauthorized disclosure of HIV information may result in civil liability and/or criminal penalties of up to $10,000 fine and one year in jail.

(12) HIV related information should be documented in a special section of the case file, or kept in a locked file. It may be most practical to keep it in the case. If so, it should be kept in a separate envelope that is clearly labeled confidential and has instructions as to who may have access to this information, and the procedures necessary for disclosure to others. Care should also be taken so that this portion of the file is not reproduced or disclosed without specific written authorization of the third party (parent, legal guardian, or the court) who provided consent for the test. Instead, in the case record there should be general information on the child's medical condition and an indication that the child's immune system is suppressed.

Summary

The standardized protocol developed by the work group is just the first step. The second step will be to take it back to the Regional Planning Group (RPG) and lobby the administrators to adopt the protocol as policy. If the protocol is accepted and successfully

implemented, the approach which has been described in this chapter could serve as a model for other regions in the country.

There are numerous strengths of this model of policy development. One of these strengths is that it brought people and ideas together in several different ways. First of all, it brought together people who are usually geographically separate--counties with different levels of experience with HIV infection can share information. Secondly, it brought together people with different training and expertise. People from the academic (university) social welfare community provided the starting point for discussion while social workers who know the real world were able to shape policy that is practical to implement. Health care workers were able to provide a clinical perspective. Thirdly, it also combined the work of the six counties--incorporating the best of each HIV testing policy and facilitating the creation of a uniform, regional policy while saving time and resources. This uniformity could help eliminate any problems in intra-regional transfers of children.

The most important strength of this model of policy development is the production a HIV testing protocol that meets the high standards established by groups such as the Child Welfare League of America and the American Academy of Pediatrics. Having a strong and uniform regional protocol allows child welfare agencies to have the same starting point. Many of the counties involved in the protocol work group have had little experience in working with HIV-affected families. This model illustrates the possibility of being well-prepared if and when the foster care system becomes besieged with children with HIV infection.

There are many strengths to this model of policy development, but how realistic are the goals of the protocol work group given that the foster care system is currently overwhelmed and underfunded? As described in Chapter III, social workers already face unreasonable case loads and HIV-infected children are the least of the problems facing many child welfare agencies. The AIDS training needs assessment conducted by the Project revealed that even in counties with fairly complete testing protocols the CWWs were not adequately utilizing the protocols. The question is: can the gap between written protocols and action be bridged?

One of the answers to this question may lie in adequately training social workers to use the protocols developed in the work group. Though the counties would have to make an initial investment of time and money in training programs, such an investment would be well worth it. A preventative approach to this issue will help the foster care system avoid becoming overwhelmed by HIV-infected children in the near future. The San Francisco Bay Area child welfare community has a chance to avoid a crisis-oriented method of problem solving--it is now up to the county administrators to prepare for the entry of HIV-infected children into the system.

CONCLUSION

The AIDS epidemic became a part of our collective awareness almost ten years ago. During that time, much has been written about the medical and social aspects of HIV disease. In this relatively short period of time we have learned a tremendous amount not only about this one disease but also about ourselves.

In this paper I have reviewed the major findings of current research on the virology, sociology, and epidemiology of pediatric AIDS. We have seen that the numbers of children with HIV disease is still small--but is expected to grow. We have seen that foster children are a special population which includes a disproportionate number of children at risk for HIV infection, and that HIV infection in these children is a potentially difficult problem for foster families and child welfare agencies.

The issue of HIV antibody testing of foster children has been a particularly difficult one. In Chapter IV we saw that HIV testing can be carried out in several kinds of ways, including mandatory screening, routine testing, and voluntary testing programs. In looking at the special needs and circumstances of foster children, I argued that routine testing based on universal risk assessment is the most appropriate method to follow for this group of children.

In Chapter V the specific indications for routine HIV antibody testing were examined. I argued that there are important medical, legal, and ethical reasons to support a routine testing program based on universal risk assessment. Some of the legal cases reviewed illustrate the complex and important issues which such testing

programs will raise: confidentiality concerns must be balanced against the legitimate arguments in favor of testing. In the final analysis, the legal precedents support the concept of routine HIV testing of foster children.

In the final chapters of this paper I closely examined an important contemporary case study, which is illustrative in several ways. Seven counties in the San Francisco Bay Area have developed a uniquely coordinated approach to the issues discussed herein, and as we have seen, such a coordination may provide an important example for other regions of the country to follow. However, we have also seen that there are some problems with this model and numerous obstacles to its successful implementation. One of the main obstacles is that the foster care system is overwhelmed and underfunded. It may not have the endurance to withstand the onslaught. However, this very danger is a strong argument in favoring of following the preventative approach to this issue as opposed to the usual crisis-oriented method of the social welfare system.

It is often said that the AIDS epidemic has been remarkably effective in bringing to light and magnifying previously existing social problems. For example, Bateson and Goldsby comment,

> The AIDS epidemic, as it moves around the planet, is posing new questions about justice and teaching us new ways to think about human learning and human suffering. . . AIDS moves along the fault lines of our society, and becomes a metaphor for understanding that society.[90]

What lessons about our society have we learned from this study? Some of the lessons are all too familiar: those who have not are hardest hit, and our institutions are improperly equipped to respond to the needs of those least fortunate. However, the story of pediatric AIDS and AIDS among foster children is also a story of courage and extraordinary effort on the part of those on the front lines. In spite of the considerable obstacles, many in the social welfare and medical communities have made major strides towards improving our collective response to this crisis. When future generations look back on our response to AIDS, they will judge us in part on how we treated those most disenfranchised and powerless. I hope this paper has helped to point the way towards a response that we can look back on with pride.

APPENDIX A: SUMMARY OF THE CDC CLASSIFICATION OF HIV INFECTION IN CHILDREN UNDER 13 YEARS OF AGE[3]

CLASS P-O INDETERMINATE INFECTION

CLASS P-1 ASYMPTOMATIC INFECTION

SUBCLASS A Normal Immune Function
SUBCLASS B Abnormal Immune Function
SUBCLASS C Immune Function Not Tested

CLASS P-2 SYMPTOMATIC INFECTION

SUBCLASS A Nonspecific Findings
SUBCLASS B Progressive Neurologic Disease
SUBCLASS C Lymphoid Interstitial Pneumonitis
SUBCLASS D Secondary Infectious Disease
Category D-1 Specified secondary infectious diseases listed in the CDC surveillance definition for AIDS
Category D-2 Recurrent serious bacterial infections
Category D-3 Other specified secondary infectious diseases
SUBCLASS E Secondary Cancers
Category E-1 Specified secondary cancers listed in the CDC surveillance definition for AIDS
Category E-2 Other cancers possibly due to HIV infection
SUBCLASS F Other Diseases Possibly Due to HIV Infection

Source: Centers for Disease Control

APPENDIX B: SIGNS & SYMPTOMS OF HIV INFECTION IN CHILDREN

Infants with HIV infection acquired in utero are often small for gestational age. Symptoms frequently appear within the first six months of life, but children may remain asymptomatic for many years.

Several profiles of the HIV-infected child are commonly seen and should serve as a warning sign that the child needs immediate medical attention:

•Nonspecific features of the disease are common and may be present in the absence of more specific syndromes: failure to thrive is seen in 20 to 50% of children with symptomatic HIV infection; diarrhea, acute or chronic, is often observed and may lead to malnutrition and wasting syndrome, hepatomegaly and splenomegaly (enlarged abdominal organs), fever, and weight loss.

•Lymphadenopathy/Parotitis: Enlarged salivary glands and lymph nodes may be seen together or separately. This may be the only symptom the child has or it may be associated with other infections.

•Pulmonary syndromes: pulmonary disease is the most common cause of morbidity and mortality in children with HIV infection and is often the first manifestation of the disease. Common symptoms of pulmonary disease, including *Pneumocystis carinii* (PCP) and *lymphoid interstitial pneumonitis* (LIP), include a progressive cough associated with difficulty in breathing. Other upper respiratory illnesses, including colds, are also common and may develop into serious medical conditions.

•Bacterial infections in children with HIV infection can be recurrent and serious. They can include meningitis, pneumonia, ear infections (otitis media), septicemia, and urinary tract infections.

•Neurologic impairment: Neurologic involvement is seen in 50% of children with HIV infection and up to 90% of children who meet the case definition of AIDS. Neurologic manifestations include developmental delays, weakness, spasticity, blindness, loss of motor skills, or progressive encephalopathy (degenerative disease of the brain).

APPENDIX C: RECOMMENDATIONS FOR ROUTINE IMMUNIZATIONS OF HIV- INFECTED CHILDREN

In children who are HIV-positive the live oral polio vaccine (OPV) is considered contraindicated because of the potential of acquiring disease from the vaccine. Inactivated vaccines are not considered a risk to immune deficient children. The current Centers for Disease Control recommendations for routine immunizations of HIV-infected children (as of April 1988)[79] include:

Vaccine	Asymptomatic	Symptomatic
DTP	Yes	Yes
OPV	No	No
IPV[1]	Yes	Yes
MMR	Yes	Yes
Hemophilus influenzae type B	Yes	Yes
Pneumococcal	No	Yes
Influenza	No	Yes

1. Children who are HIV seropositive, indeterminate status and children who are at high risk but not yet tested should be given IPV rather than OPV.

Other vaccines to be considered include: if child is exposed to varicella/zoster (chicken pox) give VZ immune globulin as soon as possible. If child is exposed to measles give measles immune globulin as soon as possible.

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The New York City Department of Public Health also reports cases of AIDS in children as early as 1978. (City Health Information, a Publication of the NY City Department of Public Health, Volume 5, No. 2. Feb. 19-March 12, 1986.)

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