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A Report on Infants and Children with HIV Infection in Foster Care

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Office of the Assistant Secretary for Planning and Evaluation

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A REPORT ON INFANTS AND CHILDREN WITH HIV INFECTION IN FOSTER CARE

Macro Systems, Inc.

November 14, 1989

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INTRODUCTION TO PARTS I AND II

The Omnibus Reconciliation Act (OBRA) of 1987, P.L 100-203, sec. 9138, requires the Secretary to provide information on the following:

1. the total number of infants and children in the United States who have been diagnosed as having acquired immune deficiency syndrome and who have been placed in foster care; and

2. the problems encountered by social service agencies in placing infants and children with such syndrome in foster care; and

3. the potential increase (over the five-year period beginning on the date of the enactment of this Act) in the number of infants and children with such syndrome who will require foster care.

The statute defines an infant or child with acquired immune deficiency syndrome as including those who are infected with the virus associated with such syndrome. In addition, the report is to "make recommendations to the Congress with respect to improving the care of infants and children with acquired immune deficiency syndrome who lack ongoing parental involvement and support."

In response to OBRA, the Department engaged in two studies which are included in this report as part I and part II. The first is a telephone survey of all 50 states, the District of Columbia, and Puerto Rico. This survey provides information on the following questions:

- How many infants and children tested seropositive with the Human Immunodeficiency Virus (HIV) are there in foster care?
- How many HIV-seropositive boarder babies are there in hospitals awaiting foster care placements?
- What is the distribution of HIV-seropositive children in foster care across the country?
- What percentage of all HIV-infected children get placed in foster care?

The results of this survey provide information that addresses the first requirement of the OBRA, a count of HIV-infected children in foster care. For purposes of the survey of child welfare agencies, children who tested positive for the virus but who may later seroconvert are included. A description of the telephone survey and its findings is Part I of the attached document.

The second study was conducted under contract with Macro Systems, Inc., to assess policy and practice with regard to a number of issues bearing on pediatric AIDS and the child welfare system. The report from Macro Systems, Inc., is Part II of the attached document. It contains case studies conducted in seven local jurisdictions with

a high incidence of pediatric AIDS: New York, New York; Newark, New Jersey; Miami, Florida; Chicago, Illinois; Boston, Massachusetts; Los Angeles, California; State of Connecticut. Among the issues investigated are boarder babies, recruitment and retention of foster parents, enrollment of foster care children in experimental trials, services and training, testing for HIV. Findings from these case studies, contained in Part II of this report, provide information pertinent to the second requirement of OBRA, a discussion of problems faced by social services agencies that are addressing the effects of this disease.

The Macro study also provides an estimate of the number of HIV-infected children who may be in foster care by the year 1992 (Part II), as per the third requirement of OBRA. It should be noted that this is a very soft estimate, given the weak data available to make such estimates.

Part II of the report contains recommendations on actions which, it is believed, would improve the care of HIV-infected children in need of foster care.

[Part II does not contain the appendices to the report submitted by Macro Systems, Inc., to the Office of the Assistant Secretary for Planning and Evaluation (ASPE). The appendices include summary reports of site visits, as well as other background material. The full Macro Systems report is available from ASPE, Room 410E, 200 Independence Avenue, S.W., Washington, D.C. 20201, (202)245-1805)]

Summary of Key Findings

The telephone survey of 50 states and the District of Columbia, reported in part I of this report, found that:

- At the time of the survey, there were 806 infants and children, who tested positive for HIV, placed in foster care in the United States. In addition, 19 HIV-seropositive children in Puerto Rico were in foster care.
- Over time, a total of 979 HIV-seropositive children had been placed in foster care.
- The pattern of placement of HIV-seropositive children in foster care across the country is similar to that of pediatric AIDS cases reported to CDC. There are several exceptions to this pattern, primarily in some southern states, where fewer infected children than expected have been placed in foster care.
- It is estimated that between 16 and 22 percent of all HIV-infected children in the country get placed in foster care. It should be noted, however, that since estimates of the number of HIV-infected children in the country are still very weak, these percentages are not very well based. Also, these estimates may be inflated because there was no way to identify those positive children in foster care who might later seroconvert.

The study by Macro Systems, reported in Part II of this report, found that:

- It is estimated that by the year 1992, there will be approximately 1750 to 4500 HIV-infected infants and children placed in foster care. Given the numbers already in care, it may be that the number in 1992 will be nearer to the high end of this range.
- Foster care agencies need to establish written policies to formalize the successful practices that have been developed.
- All sites visited have been able to recruit adequate numbers of foster parents for HIV-infected children, but their ability to retain families and recruit new families for the growing number of HIV-infected children will depend on continued concentrated recruitment efforts and the provision of adequate support for these families.
- Most children who are HIV-seropositive are minority children and tend to come from poor families. They and their families tend to be underserved generally, a fact that is exaccerbated by this disease. With regard to foster care, the recruitment of homes is complicated by the greater burdens faced by the communities from which these children come.
- Interviewees expressed concern about how long the present foster care homes can continue before becoming overwhelmed with the added care needs and the emotional burden of dealing with death and dying.
- All foster care agencies handling HIV-infected children for placement need a clearly defined training program and expanded support services for foster parents.
- Extended family members will be used to a greater degree as the epidemic progresses, and they need financial and ancillary support to care for HIV-infected children.
- Congregate care homes should be reserved to provide services and meet needs that foster family homes cannot meet.
- The potential benefits to the foster care system and child's health provide compelling reasons to test all at-risk children in foster care.
- State and local child welfare agencies should develop stems to manage the participation of children in foster care in special medical treatment and experimental trials. Currently, few HIV-infected children in foster care are enrolled in these protocols.
- Most sites were not experiencing boarder baby problems with HIV-infected children, but expressed great concern about the potential of this problem to worsen as the epidemic in children increases.
- The problem of the HIV-infected adolescent concerns child welfare agencies, but now is low in the priorities for action. There is a need to determine the number of HIV-infected adolescents and examine their special problems and potential solutions.

PART I: ESTIMATES OF THE NUMBER OF HIV-SEROPOSITIVE INFANTS AND CHILDREN IN FOSTER CARE

The importance of foster care in responding to the pediatric AIDS epidemic has long been recognized. Many children who are infected can not stay with their families, either because they are abandoned in hospitals at birth or because their family has deteriorated so far -- due to illness, drugs, poverty -- that proper care is not possible. While a good deal has been written about providing foster care to these children, including difficulties in recruiting foster care parents and the need for services, there has not been information about how many HIV-seropositive children are actually placed in foster care. While there is ancedotal information that foster care agencies have experienced a good deal of stress responding to the new demands of this disease, the size of that burden and how it is distributed across the country has not been known.

This paper reports the findings of an informal survey of the fifty states and Puerto Rico designed to find out just how many identified HIV-seropositive children have been placed in foster care or are in hospitals awaiting foster care placement (i.e. boarder babies). This is the first time that data from an fifty states have been reported.

THE DATA

Estimates were obtained from each of the 50 states, the District of Columbia, and Puerto Rico. Staff of the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, spoke with supervisors of state foster care programs, of county programs in states with county administered child welfare programs, and, in Florida, with supervisors in state agency district offices. In states with county administered systems, only selected counties were contacted based on the likelihood that cases of HIV infection in children would be found.

Data were collected mainly in March and early April of 1989. Data from California and Florida were collected in July 1989 to coordinate information collection with that undertaken by Macro Systems for the companion study (Part II of this report).

Data were obtained from child welfare program officials with responsibility for HIV-seropositive children. In some cases, these officials drew on formal information systems that track such children but more typically, they relied on their own personal knowledge and that of others. Estimates of current cases are likely to more precise than are estimates of cumulative cases because the latter often depend on the memory of staff.

For this study, the term "HIV-seropositive children" refers to children who are identified as having tested positive for HIV. This includes both symptomatic and asymptomatic children, as well as children who may at a later time seroconvert to HIV negative. This is a greater number than the number of pediatric AIDS cases reported to CDC since those cases represent only children with full-blown AIDS. The degree of illness was not asked because child welfare agencies generally do not have such information. The key factor for child welfare agency operation is the positive test result. It must be stressed that children in foster care are not routinely tested for HIV; therefore it is possible that there are unidentified HIV-seropositive children in foster care.

"Foster care placement" refers to those children in placement under the supervision of a public children welfare agency and for whom a board and care rate is paid. Typically foster care means placement in a licensed home or facility. Numbers do include children placed with relatives who have been certified or licensed as foster parents and receive a foster care board and care payment. Not included are children placed with relatives in unlicensed informal care, with no board and care rate paid, and children with their own families but supervised by the agency.

"Boarder babies" are those HIV-seropositive children in hospitals identified by foster care officials as awaiting action by their agency. Children held in hospitals beyond the time of medical necessity for reasons other than the unavailability of a foster care placement would not be known to the child welfare agency and, hence, would not be counted.

This study asked only about boarder babies who tested sero-positive. Estimates of boarder babies who do not carry the antibody were not made. It is primarily non-HIV-seropositive children, usually drug exposed during pregnancy, who are the boarder babies in hospitals.

FINDINGS

Number of HIV-seropositive Children in Foster Care, Nationally

The following total number of children, tested positive for HIV, have been placed in foster care in the 50 states and the District of Columbia:

Current	804
Cumulative	979

These numbers indicate that about 80 percent of all HIV-seropositive children who have been in foster care were in placement at the time of the survey.

In addition, Puerto Rico reported that 19 HIV-seropositive children were placed currently and 25 cumulatively in foster care.

Distribution by States

Table 1 shows the numbers of HIV-seropositive children in foster care for all states. Most of the HIV-seropositive children in foster care are in a limited number of states, those with the highest rates of pediatric AIDS cases reported to CDC. Three states have 52.7 percent of HIV placements: New York, New Jersey, Florida. Fifty-three percent of AIDS cases among children are in the same three states.

TABLE 1. Number of HIV-Seropositive Children in Foster Care, by States

	Current		Cumulative	
	No.	%	No.	%
New York	271	33.7	301	30.7
New Jersey	89	11.1	95	9.7
Florida	83	10.3	121	12.4
Maryland	60	7.5	60	6.1
California	50	6.2	78	8.0
Connecticut	43	5.3	60	6.1
Massachusetts	38	4.7	48	4.9
Illinois	32	4.0	45	4.6
Georgia	18	2.2	18	1.8
Dist. of Columbia	16	2.0	26	2.7
Pennsylvania	16	2.0	19	1.9
Michigan	15	1.9	17	1.7
North Carolina	12	1.5	12	1.2
South Carolina	12	1.5	13	1.3
Colorado	8	1.0	9	0.9
Delaware	6	0.7	6	0.6
Washington	5	0.6	6	0.6
Arizona	4	0.5	4	0.4
Ohio	4	0.5	6	0.6
Rhode Island	4	0.5	5	0.5
Louisiana	3	0.4	5	0.5
Virginia	3	0.4	5	0.5
Minnesota	2	0.2	2	0.2
Nebraska	2	0.2	2	0.2
Nevada	2	0.2	3	0.3
Kansas	1	0.1	1	0.1
Kentucky	1	0.1	1	0.1
Missouri	1	0.1	2	0.2
Tennessee	1	0.1	1	0.1
Texas	1	0.1	2	0.2
Utah	1	0.1	1	0.1

TABLE 1. (*continued*)				
	Current		Cumulative	
	No.	%	No.	%
Alabama	0	0.0	0	0.0
Alaska	0	0.0	0	0.0
Arkansas	0	0.0	0	0.0
Hawaii	0	0.0	0	0.0
Idaho	0	0.0	0	0.0
Indiana	0	0.0	1	0.1
Iowa	0	0.0	0	0.0
Maine	0	0.0	0	0.0
Mississippi	0	0.0	0	0.0
Montana	0	0.0	0	0.0
North Dakota	0	0.0	0	0.0
New Hampshire	0	0.0	0	0.0
New Mexico	0	0.0	3	0.3
Oklahoma	0	0.0	0	0.0
Oregon	0	0.0	0	0.0
South Dakota	0	0.0	0	0.0
Vermont	0	0.0	0	0.0
West Virginia	0	0.0	1	0.1
Wisconsin	0	0.0	0	0.0
Wyoming	0	0.0	0	0.0
U.S. Total	804	100.0	979	100.0
Puerto Rico	19		25	

While there is a concentration of placements in the Eastern states most identified with pediatric AIDS, the epidemic is spreading across the country. Fourteen states have had more than 10 HIV-seropositive children in foster care. Foster care agencies across the country are facing this disease and developing approaches to deal with its special demands.

The pattern of placement usually follows the pattern of reported AIDS cases, but it does not always do so. Table 2 lists 20 states with 10 or more cases reported to CDC. States are ranked both by the number of HIV-seropositive children placed in foster care and by the number of AIDS cases reported to CDC. (A "(T)" after the foster care rank indicates a tie with other states having the same number of placements.) Several states with relatively high numbers of reported AIDS cases do not have many children in foster care: Texas, Virginia, Ohio, Louisiana, Alabama, Tennessee. Five of six of these states are in the South.

Some states have more HIV-seropositive children in foster care then they do full blown AIDS cases: Connecticut, Illinois, Maryland, Massachusetts, the District of Columbia.

TABLE 2. Ranking by Number of HIV Seropostive Children in Foster Care and by Number of Reported Pediatric AIDS Cases (May 1989)

	Foster Care	Rank	CDC AIDS	Rank
New York	301	1	476	1
Florida	121	2	200	2
New Jersey	95	3	192	3
California	78	4	126	4
Texas	2	15 (T)	51	5
Pennsylvania	19	10	45	6
Connecticut	60	5	37	7
Illinois	45	6	35	8
Maryland	60	8	36	9
Massachusetts	48	7	33	10
Georgia	18	11	30	11
Virginia	5	19 (T)	22	12
Ohio	6	16 (T)	20	13
Dist. of Columbia	26	9	19	14
North Carolina	12	12	18	15
Louisiana	5	19 (T)	15	16
Michigan	17	12	19	17
Alabama	0	35 (T)	13	18
South Carolina	13	13	14	19
Tennessee	1	29 (T)	10	20
U.S. Total	979		1506	

Distribution Within Selected States

Foster care is administered in some states by counties. In a few others, notably Florida, the local district offices of the state agency have a good deal of latitude in administering foster care. In both situations, it was necessary to talk to local officials to obtain placement numbers. This process afforded a picture of the distribution of placements within the states, a picture that was not obtained from state administered programs.

The spread of foster care placements of HIV-seropositive children within some states was broader than expected. Table 3 presents data for the state of Florida, broken out by district offices. In Florida, only about 25 percent of HIV placements have been made by the Dade district office of the state agency. Three other districts have more

than 10 placements. However, Miami, which is in Dade County, accounts for about 50 percent of AIDS cases reported from the state.

TABLE 3. Number of HIV-Seropositive Children in Foster Care, Florida by State Dept. of HRS District Offices	
Dade (Miami)	21
Broward (Ft. Lauderdale)	15
Tampa	15
Palm Beach (W. Palm Beach)	13
Ft. Meyers	7
Gainesville	7
Jacksonville	3
St. Petersburg	2
Total	83

In California, table 4, the distribution of HIV placements is concentrated in Los Angeles County, with 25 current and 50 cumulative placements, 50 and 64 percent of state totals respectively. This concentration is higher than represented by the pediatric AIDS cases reported to CDC, where Los Angeles represents about 43 percent of California's cases.

TABLE 4. Number of HIV-Seropositive Children in Foster Care, California by Selected Counties		
	Current	**Cumulative**
Los Angeles	25	50
Orange	7	10
San Francisco	6	9
San Diego	4	4
Alameda	2	2
Contra Costa	2	2
Santa Clara	2	2
Sacramento	2	2
Total	50	78

New York State reports that 92 percent of HIV-seropositive children placed in foster care are in New York City. This follows the pattern of pediatric AIDS, where 90 percent of cases reported to CDC are in New York City.

Types of Foster Care Placements

Child welfare officials were asked whether HIV-seropositive children were placed in foster family homes or in group homes. The specific numbers are not reported because the information was not precise. However, it appears that an overwhelming number of HIV-seropositive children are placed in family homes rather than group

homes. The estimate is that nationally over 95 percent of these children are in family homes.

Boarder Babies

There are very few HIV-seropositive boarder babies in hospitals awaiting foster care placements, according to child welfare agencies across the country. Only two state foster care agencies reported that they had HIV-seropositive children currently in hospitals for whom placement had been requested and had not yet been found. New York State reported 6 HIV-seropositive children and Washington, D.C. reported 4 children in hospitals awaiting placement, a total of 10 children. No other state or local agency reported being aware of HIV-seropositive boarder babies for whom they had been asked to find a foster home. States generally do not maintain data on how many boarder babies they have had over time.

In the course of discussions with child welfare agencies, a number indicated that they did have drug exposed children, not identified as HIV-seropositive, in hospitals for whom placement had not yet been found. Information was not collected on how many of these children there are.

Many foster care agency officials believe, however, that they certainly could be facing a significant increase in HIV-seropositive boarder babies as the number of HIV-seropositive infants grows.

Foster Care Placement Rates

The proportion of all HIV-seropositive children placed in foster care is unknown. This study provides a numerator needed to make an estimate: 979 children. It should be pointed out again that this is a very soft number. Since states do not know how many children will seroconvert, the figure refers to seropositive children, not HIV-infected. Also, the figure does not include children who may be seropositive but have not been tested.

To calculate the proportion of all HIV-seropositive children in foster care, a good denominator is needed. CDC staff indicates that the number of HIV-infected children can only be estimated. The rule of thumb that they use to estimate the number of HIV-infected children not meeting the CDC case definition for AIDS is two to three times the number of reported AIDS cases.[1] Since the reported number of cases through April 1989, about the time foster care data was collected, was about 1500 cases, the national total of HIV-infected children would have been estimated to be between 4500 and 6000. Using these figures as the denominator, the rate of foster care placement among all HIV-infected children is between 16.5 percent and 21.9 percent nationally.

[1] Personal communication from Martha Rogers, CDC.

Using state foster care placement data of HIV-seropositive children and state AIDS cases reported to CDC, placement rates for selected states have been calculated. These percentages are presented in table 5.

Maryland and Connecticut have the highest rates of placement of HIV-seropositive children in foster care. Massachusetts and the District of Columbia follow. The states with the highest incidence of pediatric AIDS, and it follows the highest prevalence of HIV among children -- New York, New Jersey, Florida, California -- tend to have a foster care rate of between 15 and 20 percent. A number of southern states have very low rates of placing HIV-seropositive children in foster care.

TABLE 5. Estimated Percentage of HIV-Seropositive Children in Foster Care for States with Highest CDC Pediatric AIDS Case Reports

	Estimated Range	
	From	To
New York	15.8	21.1
Florida	15.1	20.2
New Jersey	12.4	16.5
California	15.5	20.6
Texas	1.0	1.3
Pennsylvania	10.6	14.1
Connecticut	40.5	54.1
Illinois	32.1	42.9
Maryland	41.7	55.6
Massachusetts	36.4	48.5
Georgia	15.0	20.0
Virginia	5.7	7.6
Dist. of Columbia	34.2	45.6
Ohio	7.5	10.0
North Carolina	16.7	22.2
Louisiana	8.3	11.1
Michigan	22.4	29.8
Alabama	0.0	0.0
South Carolina	23.2	31.0
Tennessee	2.5	3.3

DISCUSSION

Boarder Babies

The data on boarder babies presented here may be problematic for some. Ten HIV-seropositive boarder babies for the nation would seem totally wrong to many

hospital personnel who often indicate that they have much higher numbers of boarder babies. However, the fact that only two child welfare agencies, New York State and the District of Columbia, report awareness of any HIV-seropositive children boarder babies awaiting their action is a significant finding. HIV-seropositive children whom hospitals consider to be boarder babies are not always officially referred to the child welfare agency for placement, for a variety of reasons. This may account for the discrepancy between information coming from hospitals and the numbers reported here. The attached Macro Systems study discusses this issue.

In addition, there are probably fewer HIV-seropositive boarder babies than is commonly believed. Most of the states have made significant strides in reducing this problem over the last few years.

In the course of discussions with child welfare agency officials it was clear that many agencies are aware of babies in hospitals awaiting placement who are not HIV-seropositive. Most of these children are drug exposed and abandoned by mothers who are addicts. This population of boarder babies is a much bigger problem now for hospitals and agencies than are HIV-seropositive children. The issues surrounding the placement of drug exposed children in foster care are complex and are significantly different from those regarding HIV-seropositive children. These issues require a good deal of further investigation and policy discussion.

Foster Care

The figures reported here are the first Federal government estimates of the number of identified HIV-seropositive children in foster care. They allow a basis for estimating the burden for care of pediatric AIDS children that is being born by foster care programs across the country. The current number of 804 HIV-seropositive children in foster care is a better estimate than is the cumulative one of 979 children because of the limitations of state data. The numbers were collected mainly in April and May, 1989. A follow-up survey would be needed to track the rate of growth of such placements over time.

The rhetoric about pediatric AIDS can sometimes make it seem that most infected children are in foster care or that very few of them are. The foster care placement rates of HIV-seropositive children calculated here provide estimates that suggest that, particularly in high AIDS areas, about 15 to 20 percent of such children are in foster care. These estimated rates are very rough ones, only a first step in a process. A much better denominator is needed: the number of HIV-infected children in this country. There will be better estimates in the future as new epidemiological data become available.

The data on foster care placements show a pattern of wide variability in the numbers of estimated HIV-seropostive children in foster care. The 15 to 20 percent rates represent only a general pattern and do not necessarily apply in particular localities.

Foster care placements of HIV-seropostive children, as one would expect, follow the pattern of pediatric AIDS in this country. States with the most cases of pediatric AIDS generally have the most cases of seropostive children in foster care. There are exceptions, most notably Texas and some other southern states. The study provides no good explanation for why HIV-seropositive children in those states do not find their way into foster care. Someone other than the state is providing care for these children.

The pattern of foster care placements in Florida was a surprise. It was expected that most of the placements would be in the Miami area. Instead, only 25 percent o placements was in this area with the balance spread across the state. In California, the pattern suggests that the concentration is mainly in Los Angeles County. Although other sections of the state have high incidences of AIDS among adults, the pediatric problem for child welfare is not yet manifest there to a significant degree. In New York, the overwhelming number of placements are in New York City, as expected.

The numbers of HIV-seropositive children in foster care are still quite low, even in high incidence states. While infected children are only a very small share of all children in foster care, they represent a significant burden in terms of costs, difficulties in recruiting placements, services needed, and the extra time required of staff. In addition, some HIV-seropositive children have non-infected siblings who also are victimized by the disease and require foster care placements (the number is unknow). HIV infection and AIDS are slowly spreading across the country, doing their share to stress an already overburdened child welfare system.

PART II: INFANTS AND CHILDREN WITH HIV INFECTION IN FOSTER CARE

Lela N. Baughman, M.S.W.
Cynthia Holmes Morgan, M.S.W.
Stephen Margolis, Ph.D.
Martin Kotler

Macro Systems, Inc.
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Martin Kotler
Stephen Margolis
Lela Baughman
Cynthia Holmes Morgan

EXECUTIVE SUMMARY

The epidemic of acquired immune deficiency syndrome (AIDS) in children has placed new demands on the already overburdened foster care systems in the United States. As of June 1, 1989, there were 1,632 reported cases of AIDS in children under the age of 13, and estimates of the total number of children carrying the human immunodeficiency virus (HIV) range from 3,000 to 20,000. The HIV/AIDS epidemic is in its early stages of development, and the number of children with AIDS are on the initial

segment of a curve which will rise rapidly during the next five years. In 1986, the last year for which there are national data on foster care, approximately 280,000 children were in foster care. As the number of children in foster care has increased, there has been a concomitant reduction in the number of licensed foster care homes and increased difficulty in recruiting foster families.

Little is known about how the areas most severely affected by the AIDS epidemic are dealing with the children who are HIV-infected and foster care. This study was designed to define the specific problems related to providing foster care for children with HIV infection. Its major purpose is to respond to the statutory requirements contained in the Budget Reconciliation Act of 1987, requiring a report to Congress on the number of children with HIV infection in foster care, problems faced by the foster care system in placing these children, and an estimation of the number of children who will require foster care by 1992.

A major element of the project was to conduct site visits to areas with a high incidence of AIDS in children to learn how organizations have grappled with the issues of providing foster care for HIV-infected children. The study focus was on children in need of foster care. While some issues related to needs of intact families in which one or more members were HIV-infected, the scope of the project did not permit in-depth examination of these issues, nor were we able to explore thoroughly the issues related to HIV-infected adolescents in foster care.

The project methodology included conducting a literature review, preparing a background document to define relevant issues, conducting site visits to seven areas with a high incidence of pediatric AIDS and producing a report that included a series of issues and related recommendations. The cities chosen for site visits were Los Angeles, California; Hartford, Connecticut; Miami, Florida; Chicago Illinois; Boston, Massachusetts; Newark, New Jersey; and New York, New York.

Approximately 800 HIV-infected children nationally were in foster care placement as of June 1989. The seven sites visited served 545 HIV-infected children in foster care, or 68 percent of the total. The site discussions confirmed the oft-made statements that the foster care system is under severe stress or in crisis. As the foster care system continues to respond to such concerns as growing caseloads, staff shortages, fewer foster family homes, stationary or decreasing budgets, and a large influx of young children who are medically fragile or have medical complications into the system, complex issues will be raised and creative solutions will be required. The foster care delivery systems that have struggled with recruitment, placement, and care issues related to HIV-infected children have underlined some specific concerns and approaches to resolve some of these broad concerns. The key issues which were discussed during this study include an examination of these issues:

- To what extent are state/local agencies developing systems that can be sustained over time?

- Are states able to recruit and retain adequate numbers of foster parents for HIV-infected children?
- What role do extended family members have in providing foster care and what are the implications for HIV-infected children?
- What are the gaps in services provided to children and foster parents?
- Are congregate care living arrangements for HIV-infected children used appropriately?
- Should there be HIV antibody testing of all at-risk children in foster care?
- Are HIV-infected children in foster care enrolled in experimental drug trials?
- What is the boarder baby problem, how serious is it, and what is its relationship to the HIV epidemic?
- What are the issues surrounding HIV-infected adolescents?

Conclusions from our site visits related to the issues outlined above are the following:

- Foster care agencies need to establish written policies to formalize the successful practices that have been developed.
- All sites visited have been able to recruit adequate numbers of foster parents for HIV-infected children, but their ability to retain families and recruit new families for the growing number of HIV-infected children will depend on continued concentrated recruitment efforts and the provision of adequate support for these families.
- Interviewees expressed concern about how long the present foster care homes can continue before becoming overwhelmed with the added care needs and the emotional burden of dealing with death and dying;
- All foster care agencies handling HIV-infected children for placement need a clearly defined training program and expanded support services for foster parents.
- Extended family members will be used to a greater degree as the epidemic progresses, and they need financial and ancillary support to care for HIV-infected children.
- Congregate care homes should be reserved to provide services and meet needs that foster family homes cannot meet.
- The potential benefits to the foster care system and the child's health provide compelling reasons to test all at-risk children in foster care;
- State and local child welfare agencies should develop systems to manage the participation of children in foster care in special medical treatment and experimental trials. Currently, few HIV-infected children in foster care are enrolled in these protocols.
- Most sites were not experiencing boarder baby problems, but expressed great concern about the potential for this problem to worsen as the epidemic in children increases.
- The problem of the HIV-infected adolescent concerns child welfare agencies, but now is low in the priorities for action. There is a need to determine the number of

HIV-infected adolescents and examine their special problems and potential solutions.

This study revealed that as child welfare agencies continue with limited funding to serve even greater numbers of children and families, pressure for resources for recruitment, training, support services, and reimbursement for the placement of HIV-infected children in foster care will continue to test the limits of the foster care system's ability to respond and survive.

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I. BACKGROUND

Description of the Problem

The epidemic of acquired immune deficiency syndrome (AIDS) in children has placed new demands on the already overburdened foster care systems within the United States. As of June 1, 1989, there were 1,632 reported cases of AIDS in children under the age of thirteen (CDC, 1989, #1) and estimates of the total number of children carrying the human immunodeficiency virus (HIV) range from 3,000 to 20,000 (CDC, 1989, #2). Initially, the epidemic was felt most acutely by New York, New Jersey, and Florida; these three states accounted for 64 percent of reported AIDS cases in children through 1986. By 1989 these states accounted for only 55 percent of reported AIDS cases, as other states began to experience larger caseloads of children with AIDS and began dealing with issues related to the delivery of health care and social services. The HIV/AIDS epidemic is in its early stages of development and the number of children with AIDS will rise rapidly during the next five years.

Seventy two percent of children with HIV infection acquire the virus through perinatal transmission related to intravenous drug abuse (CDC, 1989, #2). These children often come from an impoverished, disadvantaged environment, and many are already candidates for foster care because of parental abuse or neglect. Other HIV-infected children have a significant chance of entering the foster care system as their parents become disabled or die from the effects of AIDS.

Foster care is a state and/or county administered child welfare service designed to provide full-time substitute care for children outside of their parental homes. Foster care can be provided in foster family homes, group care homes, or institutions. Typically, it is intended as a temporary arrangement until the child can return home or until an adoptive placement is found. Children can enter the foster care system through voluntary placement by the parent who is unable to meet the needs of their offspring or by state removal of the child because of neglect and/or abuse.

Federal funding for foster care is available through Title IV-E of the Social Security Act, specifically for children from families eligible for Aid to Families with Dependent Children (AFDC). States may receive matching Federal Title IV-E (Social Security Act) funds for the maintenance of children in foster care placement. Additional federal funding is available to states through Title IV-B (Social Security Act), which provides funds for services and incentives for the implementation of statewide foster care inventories, information systems, and case management plans which include six month reviews.

In 1986, there were approximately 280,000 children in foster care, of whom approximately 109,000 were in AFDC-funded foster care (Task Force, 1989). Since then, case loads have been increasing in part due to the increased incidence of reported child abuse and neglect, the rapidly rising incidence of drug abuse among women, and the increased number of homeless persons. Furthermore, as the number

of children in foster care has increased, there has been a reduction in the number of licensed foster care homes and increased difficulty in recruiting foster families. Factors commonly cited as contributing to this shortage include low reimbursement rates, insufficient support services, increased number of single parent families, increased numbers of women in the work force, and increasing numbers of children with special medical or emotional needs who require specialized foster parent attention.

Oversight reviews in recent years from Congress and criticism from the national media have pointed out certain problems in the nation's child welfare system in general and the foster care system specifically. In 1987, the House Select Committee on Children identified such persistent problems as under-funding of programs, inadequate federal guidelines, and poor accountability by state and local child welfare agencies for the quality of their child care programs. The appearance of children with HIV infection and AIDS in need of foster care services has added further strains on the child welfare system. The Department of Health and Human Services Work Group on Pediatric HIV Infection and Disease released its final report June 26, 1989. Three of the thirteen recommendations for immediate action relate to the foster care system.

Purpose and Scope of the Project

Little is known about how the jurisdictions most severely affected by the AIDS epidemic are coping with HIV-infected children and foster care. To address this, the current study will define the specific problems related to providing foster care for children with HIV infection. The study will respond to statutory requirements contained in the Budget Reconciliation Act of 1987 (Public Law 100-203). Under this act, the Secretary of the Department of Health and Human Services was asked to report to Congress on the number of children with HIV infection in foster care and on the problems faced by the foster care system in placing these children and to estimate the number of children who will require foster care by 1992.

This study, conducted for the Assistant Secretary for Planning and Evaluation (ASPE), examines a number of issues related to foster care in general and issues related to the unique situation of children with HIV/AIDS in foster care specifically. The focus of this project was on site visits to areas with a high incidence of AIDS in children to learn about approaches to providing foster care for HIV-infected children. While there was some discussion of issues related to needs of intact families in which one or more members were HIV-infected, the scope of the project did not permit in-depth exploration of these issues nor were we able to explore extensively the issues related to HIV-infected adolescents in foster care.

Methodology

The project methodology had three components: conducting a literature review, preparing a background document to define the relevant issues, and conducting site visits to seven areas with a high incidence of AIDS in children.

The literature review included abstracts of papers presented at the Fourth and Fifth International AIDS Conferences held in Stockholm, Sweden, and Montreal, Canada, respectively, and published papers in child welfare, medical, and public health journals. The literature review was not intended to be exhaustive, but rather to provide an overview of the salient cross-cutting issues. A bibliography of these materials is included in Appendix A.

The background issues document summarized important information about issues, barriers, and responses related to children with HIV infection within the child welfare system.

The cities chosen for site visit were Los Angeles, California; Hartford, Connecticut; Miami, Florida; Chicago, Illinois; Boston, Massachusetts; Newark, New Jersey; and New York, New York. The purpose of the site visits was to explore the experiences and responses of different foster care systems in providing services to HIV-infected infants and children. We attempted to arrange interviews with a cross-section of people who deal with HIV-infected children including state and local child welfare officials, local public foster care officials, staff from private foster care placement agencies, foster parents and/or association representatives and hospital social work staff. In some instances a large group introductory meeting preceded individual interviews. A list of the people interviewed at each site appears in Appendix B.

Based on the information gleaned from the literature review and issues document, we designed a discussion guide to elicit pertinent information on the topic. We focused on various points in the guide for discussion, and depending on the person's area of expertise, explored relevant tangential issues that surfaced during the discussions. The discussion guide appears in Appendix C.

Each site visit was summarized and reviewed by the key contacts within each organization visited. Site visit summaries appear in Appendix D.

This report compiles the information gathered during each of the site visits and focuses on identifying broad issues that cut across sites and have national relevance. We addressed the following policy questions:

- To what extent is HIV infection contributing to the crisis in foster care?
- To what extent are state/local agencies developing systems that can be sustained over time?
- Are states able to recruit and retain adequate numbers of foster parents for HIV-infected children?
- What role do extended family members have in providing foster care and what are the implications for HIV-infected children?
- What are the gaps in services provided children and foster parents?
- Are congregate care living arrangements for HIV children being used appropriately?
- Should there be HIV antibody testing of all at risk children in foster care?

- What is the "boarder baby" problem, how serious is it, and what is its relation to the HIV epidemic?
- What are the issues surrounding HIV-infected adolescents?
- What are the barriers to the enrollment of HIV-infected children in experimental drug trials (investigational drug treatment programs)?

Section III of this report presents an in-depth discussion of each of these issues with recommendations for further action.

II. MAGNITUDE OF THE PROBLEM PROJECTED BY 1992

Two years after AIDS was recognized in the adult population, the public health community came to accept a diagnosis of AIDS in infants and children. Initially, the diagnoses of the few reported cases of AIDS in infants were questioned. Some cited its potential confusion with rare congenital immune deficiency diseases, and there was a lack of appreciation of the risk of HIV infection among the pregnant women. However, the phenomenon of pediatric AIDS cases and HIV infection is now widely known, and the numbers are increasing. As of June 1, 1989, AIDS had been reported in 1,632 children under the age of thirteen and in approximately 400 adolescents, aged thirteen to nineteen. Thus, approximately 2,000 cases of AIDS have been reported in infants, children, and adolescents since the epidemic began (CDC, 1989, #2). The risk factor for 79 percent of the reported cases of AIDS in children is a mother who has or is at risk for HIV infection either through IV drug use or sexual contact with an IV drug user. These women are the fastest growing risk group among reported AIDS cases (CDC, 1989, #1). Approximately 40 percent of all of the reported cases of AIDS in children were reported during the one-year period June 1988 through May 1989, attesting to the rapid growth of the epidemic in this population.

The number of children with AIDS represents only the tip of the iceberg. To assess fully the impact of this epidemic on the foster care system, the total number of children with HIV infection -- including those who are asymptomatic, symptomatic, and who have ARC or AIDS -- must be included.

A recent Government Accounting Office (GAO) report presents an analysis of the AIDS case reporting assumptions and its altered approach to estimating AIDS cases. This chapter uses some of those assumptions to estimate the number of HIV-infected children that can be expected by 1992 to describe the potential impact on the foster care system.

Previous Projections

The Public Health Service estimated that for every child with AIDS reported to the Centers for Disease Control (CDC), "another two to ten are infected with HIV." Moreover, "by 1991, there will be at least 10,000 to 20,000 HIV-infected children in the United States," according to reports at the Second Public Health Service AIDS

Prevention and Control Conference (Report, 1988). The same report estimated a total of 270,000 AIDS cases overall by 1991, and 365,000 cases by the end of 1992.

The General Accounting Office has identified and reviewed 13 national forecasts of total adult and pediatric AIDS cases for 1991. Overall, the ranges were 84,000 - 750,000 cases by 1991. When limiting the forecasts to those made in 1988, the "best" projections narrow from about 120,000 to 320,000. For all published forecasts the "best" estimate was from 120,000 to 400,000 cases of AIDS through the end of 1991. The GAO presents a range of 300,000 - 480,000 cumulative cases through 1991. The primary GAO criticism of the other forecasts relates to the under-counting of heterosexuals. Unpublished CDC analyses show an increasing number of cases stemming from heterosexual contact with drug-using partners. Some forecasts have assumed no expansion of the epidemic in the heterosexual population. However, the GAO contends that "the true proportion of heterosexual cases may be somewhat higher than the often quoted 4 percent, that the ability to track trends in certain heterosexual risk groups has been limited, and that the accuracy, of some forecasts has been affected" (General Accounting Office, 1989). The continual and dramatic increases in HIV infection rate among IV drug users guarantees the continued infection of heterosexuals, specifically women.

The projected number of HIV-infected children by the year 1992 can be calculated by using widely accepted assumptions and estimates for such factors as the number of HIV-infected cases in relation to reported AIDS cases, the proportion of all cases that are women, birth rates, and perinatal transmission rates. Table 1 displays these estimates, sources, and assumptions.

At present, 79 percent of children with AIDS, and probably the same percentage of children with HIV, have a mother who is in an at-risk category. The remainder of the children with AIDS acquired the virus through blood transfusion/tissue transplant (cumulative number = 189) or via blood factor administered for the treatment of hemophilia (cumulative number = 94). These latter two groups will contribute less and less to the total number of HIV-infected children during the next four years. Thus, the assumption is that the source of most cases of HIV/AIDS in children will be mothers at-risk for HIV/AIDS.

Number of HIV/AIDS Children in the Foster Care System

Data to estimate accurately the projected number of HIV-infected children in foster care by 1992 are non-existent. However, current experiences of those dealing with HIV-infected children provide some base for estimating the future impact.

As of June 1989, approximately 1,000 known HIV-infected children were in foster care. This number -- influenced by individual states' accuracy in reporting, the accuracy of their information and tracking systems and the extent to which they have conducted case-finding efforts -- most likely is an underestimate. Several hospitals visited across sites reported that 25 percent of their pediatric HIV-infected patients are in foster care.

Thus by 1992, a total of 1,750-4,500 HIV-infected children in foster care can be expected. This represents at least a doubling, and as much as a five fold increase of the known cases today.

Table 1 describes a method for calculating the projected magnitude of HIV-infected infants and children in foster care by 1992. The method uses the total number of AIDS cases by 1992 (300,000-480,000) and the assumption that 10 percent of AIDS cases as of 1988 were in women and that 10 HIV infections exist for each reported AIDS case. Thus, the number of women of childbearing age who will have AIDS or be HIV-infected by 1992 will be 330,000-520,000. Since the birth rate is approximately 7 percent, it is estimated that 22,000-35,000 deliveries of HIV-infected infants will occur by 1992. Thirty to fifty percent will remain infected; CDC feels 30 percent is closer to reality. Given our assumption that approximately 25 percent will be in foster care, we derive a range of 1,750-4,500 HIV-infected children in foster care by 1992. ASPE's companion study has counted approximately 1,000 HIV-infected children in foster care cumulatively, suggesting that the number of such children is likely to be near the higher end of our projected range.

A number of factors indicate that the impact of HIV-infected children on the foster care system will be severe. These factors include an increase in mothers with HIV infection/AIDS who will die and leave children without a parent; increasing numbers of women/mothers using crack and the concomitant lack of capacity to act as a responsible parent; increased poverty and homelessness, making it more difficult for extended families to care for their family members; and the use of new and experimental therapeutic agents to extend the lives of children with AIDS.

TABLE 1. Projected Magnitude of HIV-Infected Infants and Children in Foster Care, 1992

	1992 Estimate	Assumption/Source
Total AIDS cases	300,000 - 480,000	GAO (1989)
Number of women of childbearing age with AIDS	30,000 - 48,000	10 percent of all AIDS cases have been women since 1988 (CDC surveillance data)
Number of HIV-infected women of childbearing age	300,000 - 480,000	10 HIV cases for every reported AIDS case (Report, 2nd PHS AIDS Conference, 1988)
Cumulative AIDS and HIV-infected women of childbearing age	330,000 - 520,000	AIDS & HIV cases combined
Number of AIDS/HIV-infected women giving birth	22,000 - 35,000	7 percent of all women (Ory, 1983)
Number of children born HIV infected (and who will remain infected)	7,000 - 18,000	30-50 percent of children born to AIDS/HIV-infected women (Report, 1988)
Number of HIV-infected children in foster care	1,750 - 4,500	25 percent of total infected (site visits)

III. DISCUSSION OF ISSUES, STUDY FINDINGS, AND RECOMMENDATIONS

Introduction

Through site visits to 7 state and local foster care delivery systems, the study team discussed the foster care system and the relationship of HIV-infected children to that system with approximately 90 individuals who provide foster or medical care to HIV-infected/AIDS children. Interviewees included state agency directors, foster parents, caseworkers, attorneys serving as guardians (or representing dependent children in court), nurses and social workers (within both a foster care and hospital setting), physicians, and private foster family agency directors and service delivery staff. All respondents had, at some level, confronted one of the many issues -- testing, participation in clinical trials, placement, recruitment, increasing caseloads -- surrounding HIV-infected children in foster care.

Concern about the impact of HIV-infected children on the crisis in foster care.

For the past several years, many individuals have expressed concern about the foster care system, particularly about systems serving large communities. The large number of children the system must serve, the potential for multiple foster home placements, and the need to find a permanent placment for foster children are only a few of the issues that have surfaced.

National concern about the foster care system as a whole has been expressed by various audience forums such as Congressional hearings, television, newspapers, and legal suits. The following items reveal the scope of concern.

- A Los Angeles Times editorial (July 1986), entitled "Official Child Neglect" uses the beating and subsequent death of a foster child to discuss the low reimbursement rates for foster parents and to highlight a recent gubernatorial veto of budget increases for health and social service spending

- A Congressional hearing of the Select Committee on Children, Youth and Families, House of Representatives (April 1987) addressed "Continuing is in Foster Care: Issues and Problems."

  Representative George Miller, Chairman of this Select Committee in his opening statements at the hearing summarized many of the key issues within the foster care system:
  - the number of children in foster care is again increasing
  - homeless families are often forced to place their children in foster care because shelters are rarely set up to accommodate them
  - children born to drug dependent parents have begun to enter the foster care system as their parents are too ill or unprepared to properly care for them

- many abused and neglected children continue to be placed in foster homes indefinitely
- children of drug-dependent parents too often are relegated to hospital wards rather than caring homes

- ABC News Closeup on August 30, 1988, broadcast a special television show entitled "Crimes against children - the failure of foster care."

- The New York Times on April 11, 1989, featured a story on "Disabled foster-care youth kept in New York hospitals."

- A Congressional Hearing of the House of Representatives Ways and Means Committee, Human Resources Subcommittee (June 1989), focused on proposals to improve the child welfare and foster care programs. Testimony specific to foster parent training and recruitment was highlighted

- In June 1989 a class action suit was filed in the U.S. District Court by the American Civil Liberties Union on behalf of District of Columbia's foster care children. The suit states that the child welfare system jeopardizes the health and safety of children and keeps them in foster care longer than the national average

Varied sources are beginning to express an interest and concern related to the impact of pediatric AIDS on the foster care delivery system:

- Department of Health and Human Services, Secretary's Work Group on Pediatric HIV Infection and Disease. The final report, released in 1989, made 13 recommendations, 3 of which were specific to foster care for HIV-infected children

- Congressional Hearing, House of Representatives Governmental Operations Committee, Human Resources and Intergovernmental Relations Subcommittee, February 1989. The hearing addressed the role of government on pediatric AIDS. The issue of foster care was raised throughout the 2-day hearing.

- American Academy of Pediatrics, Task Force on Pediatric AIDS. The Task Force published an article in Pediatrics (Vol. #83, No. 4, April 1989) entitled "Infants and Children with Acquired Immunodeficiency Syndrome: Placement in Adoption and Foster Care."

- Fifth International AIDS Conference - Poster Sessions, Montreal, Canada, June 1989. Several posters focused on foster care, including: "The HIV-infected child in the foster family"; "Providing comprehensive services for developmentally disabled children with AIDS -- services and issues"; and "Who speaks for the abandoned child born with HIV? A foster parent and adoptive parent respond."

Study Findings

The 90 individuals at the 7 sites articulated both the successes and problems within the foster care system and the impact of HIV-infected children on that system. A sample of comments from respondents summarizes some of these views.

- The majority said their system had experienced an increase in the number of children who require foster care placement.

- Staff commented about the inability to fill vacant social/caseworker positions as state budget offices had imposed a freeze and expressed concerns about turnover in staff. One caseworker stated, "I find in the 12 months I have been in this office, a large majority of the staff have left." Another made a similar observation, "I have been with this organization for a year, and I am the senior person in terms of length of time with the organization."

- Foster parent recruitment and retention was another issue highlighted by site respondents. All officials alluded to a decrease in the number of available licensed foster homes. Respondents at one site stated they had lost more than 100 foster homes in the past year.

- Although HIV-infected children do have an impact on the foster care system overall, they currently do not present a tremendous burden on the foster care delivery system. One respondent stated, "Quite honestly, the placement of HIV-infected children is the least of our foster care problems at the present time."

- Complexity of needs of children requiring placement is increasing. One respondent stated, "The number of medically fragile infants requiring placement in foster care has skyrocketed in the past several years." Another said "Our children are becoming more and more difficult to place. They require specialized placements as they have a multitude of problems."

- Children requiring placement not only have complex needs, but also may not have support from their natural families. One program respondent said, "We find that fewer and fewer natural parents make any contact with the young children we have in our care. The children are literally being abandoned."

- Multiple priorities affect the foster care delivery systems. One worker told the study team that while many cases require special attention, the worker could not devote the time to those cases because departmental policies and priorities dictated the worker's case priorities and functions.

These comments reflect severe stresses and strains on the system and begin to highlight the multiple issues surrounding the foster care system and its attempt to serve HIV-infected children. The comments also parallel concerns of Congress, the media, and the judiciary about the foster care system.

Site respondents were able to discuss system improvements and -- at the same time -- express reservation about the continued success of their foster care delivery system. Several systems were handling their caseloads adequately, but were aware of forecasts of continued growth in infant and child foster care caseloads. This continued caseload growth and the complex needs of children that make up the increasing caseload were the primary issues highlighted by child welfare officials during the study team visits.

Although foster care placement of HIV-infected children was not considered the most pressing problem, study respondents recognized that the impact of these children on the system, as with the impact of any subgroup, has the potential to move the system from one that is manageable to one that is not.

Systems of Care for HIV-Infected Children in Foster Care.

Approximately 800 HIV-infected children nationally were in foster care placement as of June 1989, according to ASPE. The 7 sites visited by the study team represented 545 HIV-infected children in foster care, or 68 percent of the total number of HIV-infected children in care. Whereas many sites did consider HIV-infected children their most difficult-to-place population, they said that the influx of HIV-seropositive children provided an opportunity to develop systems of care and models of service delivery that could be used for other children with complex and special needs.

In developing a system of care for HIV-infected children, child welfare agencies were exploring and developing new policies, system linkages, and concepts. Some programs and policies were unique to the care of HIV-infected children, and others, while generalized to all foster care children, were developed because of the influx of HIV-seropositive children into the foster care system.

The entrance of HIV-infected children into the foster care system has raised some unique issues for child welfare officials. As an example, some of these children have been placed in foster care because they are sick and their parent(s) can no longer care for them. In other cases, the parent(s) may be in the final stages of AIDS and dying. These situations, not generally typical within the foster care system, have become more common with AIDS.

Another issue raised by the influx of HIV-infected children is that of access to experimental drug trials and other treatments. This is becoming a major concern because of the medical care requirements of HIV infection and AIDS. Although this particular issue is important to address for all children in foster care, it had not been part of the formal mechanisms or policies in many child welfare agencies. Furthermore, confidentiality, long a cornerstone of the child welfare system, has now become even more important for staff and prospective foster parents as they work with HIV-infected children.

Fiscal concerns related to HIV-infected children are also an issue. With the severe demands on child welfare agencies and tight state and Federal budgets, child welfare agencies have had to find and develop new resources to continue to provide needed services and to develop new ones. Particularly in the area of recruitment and training of new foster parents, agencies have increasingly relied on nontraditional funding sources to achieve program goals.

Foster care payment mechanisms have also been affected by the influx of HIV-infected children into the foster care delivery system. All states visited by the study team had established higher monthly payment rates for foster parents who care for HIV-infected children. Although respondents did not necessarily view HIV-infected children from a "cost" perspective, these increased payment rates have had an impact on budgetary limitations.

As child welfare officials continue to serve even greater numbers of children and families, the increase in resources required for recruitment, training, support services, and reimbursement for the placement of HIV-infected children in foster care will continue to test the limits of the foster care system's ability to respond and survive.

Conclusions

National forums and site discussions confirm that the foster care system is under severe stress or in crisis. As the foster care system continues to respond to growing caseloads, staff shortages, fewer foster family homes, tight budgets, and a large influx of children with special medical needs, many resulting from drugs, complex issues will be raised and creative solutions will be required. The foster care delivery systems that have struggled with managing HIV-infected children have developed creative approaches to recruitment, placement, and care. This report will discuss several HIV-specific issues. The issues will be presented in the context of the opportunities they offer for system change and will focus on the aspects of the foster care delivery system that stil require attention.

The next section synthesizes the common concerns raised across sites. Within the context of each issue, or innovative practices and findings and, where appropriate, recommendations are described. This chapter examines the following issues:

- To what extent are states/local agencies developing systems that can be sustained over time?
- Are states able to recruit and retain adequate numbers of foster parents for HIV-infected children?
- What are the gaps in services provided to children and foster parents?
- What role do extended family members have in providing foster care and what are the implications for HIV-infected children?
- Are congregate care living arrangements for HIV-infected children used appropriately?
- Should there be HIV antibody testing of all at-risk children in foster care?

- Are HIV-infected children in foster care enrolled in experimental drug trials?
- What is the boarder baby problem, how serious is it and what is its relationship to the HIV epidemic?
- What are the issues surrounding HIV-infected adolescents?

1. To what extent are states/local agencies developing systems that can be sustained over time?

Importance of Issue

The ability of state and local foster care systems to continue to respond to the growing number of HIV-infected children in need of foster care is a critical issue. Their ability to respond is influenced by the system's early response to the issues and the capability of sustaining those responses over time. While small caseloads of HIV-infected children may have been successfully treated as unique situations and handled through informal arrangements, the persistence of the HIV epidemic and the increasing caseloads speak to the need for systematic approaches to dealing with policies and issues of foster care placement for this population. Formalized policies help ensure uniformity in how cases are handled and in the quality of care provided.

Establishing such policies and procedures is a complex task, given the evolving knowledge base about HIV infection and treatment as well as the changing community attitudes and level of knowledge and the concomitant need to remain flexible and adaptable to these changes.

The degree to which responses and responsibility are a part of the broader foster care system and guided by formalized and written policies and procedures indicates the system's ability to be sustained over time. The HIV epidemic has posed some new issues and problems that span a broad array of health and social service needs. To meet these needs the foster care system must collaborate closely with health and medical service systems and other social service systems. The strength of the linkages between these systems affects the foster care system's ability to respond on a long-term basis.

Coordination between the various levels within the foster care system is also required. This challenge encompasses clear delineation of state and local responsibilities, as well as linkages between policy-making staff, field staff, caseworkers, private agencies involved in placement and other services, and foster parents.

Study Findings

Child welfare and foster care agency staff indicated that the unique medical and social aspects of HIV infection and AIDS and the unique needs of HIV-infected children have required special responses. The responses of the seven different sites vary and have been shaped by the foster care system already in place, the medical and community groups in the area, and by dedicated individuals who have taken on the interests of this abandoned population with compassion and relentless efforts to coax sometimes inflexible systems and policies into humane and effective responses. Following is a description of the systems that have been developed among the seven sites in response to providing foster care for HIV-infected children.

Responsibility for-HIV-Infected Children in Need of Foster Care

Several sites have assigned responsibility for HIV-infected children to units handling medically fragile or medically involved children. It is not uncommon for these units to have lower staff-to-child caseloads and to have some special provisions and reimbursement mechanisms in place. One site has created a separate unit dedicated to handling all HIV-infected children and related policy issues. Several other sites have designated one person to serve as the contact and coordinator of all HIV/AIDS related issues within the broader foster care system. In one case, a special review board has been established to review all foster care placements of HIV-infected children.

Policies and Procedures for Placement of HIV-infected Children

The seven sites are at various stages of developing and implementing written policies and procedures regarding HIV testing and foster care placement of HIV-infected children.

The comprehensiveness of the policies varies across sites. One site had broad policy provisions in place, but specific issues were handled at the caseworker level. These provisions are currently under revision. Most sites were operating under draft policies or were in the process of developing policies, and one site operated under very broad guidelines promulgated by the state but had no specific written policies nor seemed to be in the process of establishing policies. Sites that had draft policies or were developing policies relied primarily on intra-departmental staff or task forces. Massachusetts established a review board composed of a broad array of experts including public health officials, medical practitioners, field staff, foster parents, and lawyers. This board developed policies based on experience from case-by-case reviews. While all sites had some form of policies, many sites had not been broadly disseminating these policies; many persons from outside the foster care systems reported that field staff were uninformed about the policies.

Use of Private Foster Care Agencies

The seven sites vary in the degree to which they rely on private foster care agencies to place HIV-infected children into foster care homes. One area uses private agencies exclusively, while several others handle all placements within the state/local system. Other areas handle some of the placements themselves and contract with private agencies to provide additional placements.

Linkages between Organizations and Divisions within Organizations

Formal linkages with other agencies and community services and within the foster care system itself were achieved to different degrees among the seven sites visited. Sites that tended to rely on one person to handle all HIV related issues tended also to have more informal linkages. The lead individuals seemed to be responsible for formulating the linkages. Whereas the linkages were far reaching and impressive, they appeared to be dependent upon individuals rather than the organizations they represented.

Sites that had formulated task forces or review boards with broad representation had more formalized linkages that could be traced back to organizational commitments rather than the dedication or interest of a specific individual. While the linkage may have been initiated by one individual, organizational commitment was followed by a formal appointment to the task force or review board. These sites also drew from a broader representation of organizations in their policy-setting process.

The ability to link foster families caring for HIV-infected children with special services and reimbursements depends on the caseworker's knowledge of those services. In many cases, sites have established such specialized service systems that they are not widely known among all levels of the foster care system as a whole. A child who is identified as HIV-antibody positive before becoming a ward of the state can be easily linked into the specialized services; however, children who are not found to be HIV-antibody positive until after placement may not be so easily linked with needed services. Several sites recognized the need to broaden the base of knowledge about HIV transmission and the special services and systems among agency staff and private foster care agencies providing services.

Conclusions

The foster care system responses and practices at each of the sites visited exemplified different strengths. It is important that practices that have been put into place to deal effectively with the issues facing foster care for Infected children outlast the individuals who have been responsible for formulating the practices. Often, practices evolve through one person's ability to manipulate the various systems into responding to individual cases. The HIV/AIDS epidemic has prompted the development of unique approaches that may have application to the foster care system as a whole -- several persons said they felt their responses could serve as a model for handling medically fragile children -- yet, often, such practices are known to only a few persons in the system. As the caseloads grow and as children who are infected begin to exhibit symptoms, more persons within the system will face issues posed by HIV/AIDS and will need to be informed of the practices and services available to deal with the issues.

Recommendations

Recommendation 1.1

Foster care agencies should establish written policies to formalize the successful practices that have been developed. Some of the elements that should be addressed include:

- **Facts about HIV transmission**
- **Universal precautions/hygiene practices**
- **HIV-antibody testing**
- **Training for staff at all levels as well as contracting agencies**
- **General HIV/AIDS training for all foster parents**
- **Specialized training for foster parents of HIV-infected children**
- **Intake procedures to establish appropriate linkages/identification of special agencies/staff who handle HIV/AIDS and community resources.**
- **Placement procedures and considerations.**
  - **shelter/emergency care**
  - **placement options and priorities**
  - **number of children per home**
- **Recruitment policies and procedures**
- **Medical procedures**
- **Research protocols**
- **Support services (e.g., respite care, day care, babysitting, in-home services, transportation, counseling)**
- **Reimbursement rates**
- **Adoption**
- **Record keeping/information management**

Recommendation 1.2

The policy setting process should incorporate input from a variety of health and social service agencies, relevant community service agencies, and legal representatives.

Recommendation 1.3

A mechanism to ensure continued input and guidance from the various agencies and community groups such as an advisory board or task force should be established.

Recommendation 1.4

Policies and procedures should be disseminated to all persons involved in providing foster care services and to agencies and organizations with which such services are linked.

2. Are states able to recruit and retain adequate numbers of foster parents for HIV-infected children?

Importance of Issue

Concern has been raised about the ability of state and local foster care systems to recruit and retain adequate numbers of foster parents for HIV-infected children. Shortages in foster parents could have unfortunate consequences such as an increase in the number of hospital boarders, overcrowding of children in a home, pressure to certify unqualified homes, and increased numbers of children floating among temporary placement situations.

HIV-infected children have special needs and require more care and commitment than most foster children. They require additional health precaution measures, frequent hospital visits, and additional care due to developmental delays. Foster families who care for these children face the possibility of stigmatization from family and friends and the emotional drain of watching the child's health deteriorate and possible death. Reported shortages of foster parents in general make more acute the challenge of recruiting foster parents for this specialized population. These shortages are attributed to increased numbers of single parent families, the increased participation of women in the work force, insufficient reimbursement rates and support services, foster parent dissatisfaction with the system, and the increasing numbers of children in need of foster care.

Study Findings

All sites visited have been able to recruit sufficient numbers of foster parents or arrange other foster placements. Most sites indicated that they are barely keeping ahead of the demand and rarely have families waiting for a child. Site visit interviewees also expressed concern that as the caseloads grow, the need for foster family homes for HIV-infected children may exceed the number of homes available. Several sites reported decreases in the number of available foster homes in general over the past few years. If enough homes cannot be recruited, areas with a high incidence of HIV-infected babies may be faced with a boarder baby problem or forced to turn to other alternatives such as group homes, which are considered a less optimal form of care.

All sites have undertaken concentrated efforts to recruit specialized foster homes. These efforts have been similar across sites and have included targeting special populations from outside the pool of regular foster parents, providing education to address fears and describe the facts of transmission, and providing enhanced reimbursement rates and additional support services.

Recruitment Methods

Almost all the sites visited indicated that their recruitment efforts have been outside of the pool of traditional foster parents. Many target people with a health care

background -- often home health aides. Some of the first foster parents to take HIV-infected children were nurses from hospital units where HIV boarder babies were languishing.

Several sites identified networking and word-of-mouth as the most successful recruitment methods; however, this approach has been tempered by the need to maintain the confidentiality of a child's HIV status. Many foster parents who currently care for an HIV-infected child discretly shared this information with friends whom they feel may be potential foster parents for other HIV-infected children, and they have been successful in recruiting people in this manner. Some sites have indicated a reluctance to allow these parents to speak publicly about their, experiences for fear of breach of confidentiality and potential for discrimination.

Although all sites identified cultural matching and placement within a child's natural jurisdiction as priorities for foster care in general, it was clear that, for HIV-infected children, these two issues have a lower priority than finding a specialized home for the child. While some areas have been successful in matching some HIV-infected children with families of the same cultural/ethnic background, others have had difficulty in recruiting black and Hispanic families and have placed children of those racial groups in Caucasian families. Placement across jurisdictions and even in other states has also occurred.

Most sites limit the number of HIV-infected children to a home to one or two, although many exceptions to this were cited. Some sites allowed as many as six HIV-infected children in a home that was considered exceptionally qualified to care for the children.

Education

At all sites, successful recruitment included efforts to allay people's fears about acquiring HIV infection and correct misconceptions about how HIV can be transmitted. As a recruitment tool, several sites recently have developed videos on the facts of HIV transmission and the need for foster parents. Several sites also have included universal infection control precautions in their standard training sessions for all foster parents.

In addition to the standard training, all sites provide specific training on HIV-infection for foster parents who take HIV-infected children. Formats for this HIV-specific training vary from group training to one-on-one training specifically focused on the particular needs of one child. Some sites provide training in the individual's home during a home visit, and others require, in addition, training in the hospital before the child's discharge.

Enhanced Reimbursement Rates and Support Services

All sites provide enhanced reimbursement rates for families who accept HIV-infected children. The regular foster care rates among the seven sites ranged from

$240-$600 per child per month and are usually based on age. Two sites have intermediate rate categories for special needs which range from $500 to $900 per month. Rates for families taking HIV-infected children either fall into exceptional rate categories that cover all exceptional needs children or categories that have been created specifically for HIV-infected children. These rates ranged from $950 to $2,450 monthly. Only one site reimbursed at $2,450, and that rate included everything with no supplemental allowances. The other six sites averaged $1,150 to $1,200 per month, and many supplement those rates with clothing allowances, special equipment or supplies, and, occasionally, additional services such as babysitting, in-home assistance, and respite care.

Most interviewees felt that the enhanced reimbursement rates were necessary to compensate the families for the additional care needed by HIV-infected children and played a major role in attracting potential foster families. Several persons said that the enhanced rates allowed them to recruit specialized and highly qualified homes. Some maintained that the higher rates permit foster parents to quit their jobs and provide care as a full-time job, thus professionalizing the role of foster parenting.

Conclusions

Although all sites visited have been able to recruit adequate numbers of foster parents for HIV-infected children, their ability to retain the families recruited and to recruit families for the growing number of children in need of foster care will depend on continued concentrated recruitment efforts and provision of adequate support for those families.

The specialized and targeted recruitment efforts, enhanced reimbursement rates, and additional training and education provided have created a highly specialized group of foster care homes for HIV-infected children. Interviewees expressed concern about how long these homes can continue to take HIV-infected children before becoming overwhelmed with the added care needs and the emotional burden of dealing with ill and dying children. Efforts have been made to provide additional support services; however, there is still an expressed need for more services.

Another issue revolves around the conflicting goals of keeping sibling groups together and providing specialized care for children who are HIV-infected. An HIV-infected child may be one of several siblings, all of whom need foster care but not all of whom are HIV-infected. Most sites use specialized homes strictly for HIV-infected children, which necessitates splitting up the sibling group. Several site interviewees stated that circumstances often make it difficult or impossible to keep sibling groups together among the foster care population in general.

A related concern centers on the infant who initially tests positive, is placed in a specialized home, but after 18 months seroconverts to negative. Many sites seek permanent placement, and, in some cases, the current foster family decides to adopt the child. If an adoptive placement is not immediately available, some sites have a

policy of moving the child into a regular foster home to free space in the specialized home for another child who is HIV-positive and needs the specialized care. One site indicated that the current foster family may keep the child and continue to receive the enhanced reimbursement rate for up to a year or, in some cases, up to two years after the child serconverts to negative.

Recommendations

Recommendation 2.1

State and local foster care placement agencies should develop policies for recruiting and retaining foster parents for HIV-infected children. Such policies should include provisions for:

- **Increased payment structures to encourage the development of specialized, highly skilled homes.**
- **Active recruitment measures backed by staff support and resources.**
- **Sibling groups.**
- **Children who seroconvert to negative.**
- **Support services aimed at retaining families who have been recruited.**

Recommendation 2.2

State and local foster care placement agencies should actively plan for and implement vigorous recruitment efforts for foster parents to care for HIV-infected children.

Recommendation 2.3

State and local foster care placement agencies should give consideration to the development of a cadre of highly skilled, well trained, professional foster parents.

3. What are the gaps in services provided for children and foster parents?

Importance of Issue

Services for foster parents and children are important to support families and supplement the initial training and agency staff support. Services should provide key elements to help recruit new foster parents and retain current foster parents.

Services provided for foster parents and children typically fall within two broad categories training and supportive services. Training usually occurs before a child is placed in a foster family home and also at various times afterwards, usually in the form of specialized workshops, in-service training, continuing education, or forums for updates on specific topics.

Supportive services are broad in nature and are intended as supplements to the basic board and care reimbursement and caseworker services. Supportive services range from fiscal support for such items as baby-sitting and transportation to support groups, respite care, counseling, and other services.

Training for foster parents has been identified as a need within the foster care system for several years, and the development of several training curricula have been supported at the Federal level. States also have developed and mandated both pre-service and in-service training. However, systematic training efforts have not been uniform, and many states still have unmet training needs.

Supportive services for foster parents and children vary widely across states. While some states offer several support elements, others offer only one or two. Several support services recently have been identified as essential services within the foster care system, particularly when foster parents are caring for a child who has HIV infection or other complex medical needs. Mary Lee Allen, Director of Child Welfare and Mental Health for the Children's Defense Fund, recently testified to this need before the Subcommittee on Human Resources, Committee on Ways and Means, in the U.S. House of Representatives. Ms. Allen stated,

> "We, also suggest that consideration be given to extending Federal financial assistance for other critical supports to foster parents. Specifically, we recommend that funds for respite care be made available to foster parents caring for children with special needs.... Foster parents caring for troubled children, such as youths with serious emotional problems, or drug addicted infants and children with HIV-infection or AIDS, need some relief from the full time responsibilities they have assumed...."
>
> Source: Written testimony, Mary Lee Allen, Children's Defense Fund, June 1, 1989, pages 4 and 5.

Study Findings

Training

Foster parents caring for HIV-infected children receive the general foster parent training (pre-service or other training curriculum) with additional training specific to HIV infection and AIDS. All study sites had implemented some level of a specialized training component focused on the care of HIV-infected children. All the agencies visited found it necessary to seek nontraditional funding sources to develop the needed training elements or a comprehensive training program. Across sites, the development of specialized training programs was funded through public and private grants from a variety of sources, including the Robert Wood Johnson Foundation, Health Resources and Services Administration (HRSA), Office of Human Development Services (OHDS), and private organizations, such as Aetna Life Insurance. Block grants and entitlement programs were not used for new training initiatives.

Study sites varied in their methods of providing specialized training for the care of HIV-infected children. Several utilized the pre-training or foster parent curricula both to recruit specialized foster homes and to train prospective families about HIV infection and AIDS. Other sites provided a specialized training session focused on HIV/AIDS.

Many of the sites worked cooperatively with the local hospitals for training related to HIV/AIDS and medical aspects of care. Some hospitals provided general courses for foster parents who care for HIV-infected children; others provided one-on-one training specific to the medical condition(s) of the foster child.

The level of in-service training sessions for foster parents caring for HIV-infected children was difficult to determine across all sites. Some sites had requirements and forums for an update, while others used the foster parent support groups as the forum for in-service training. Other sites required in-service training but did not specify topics or sessions for parents caring for HIV-infected children.

The sites had developed some level of specialized training for foster parents caring for HIV-infected children, and all study sites were planning to expand their training efforts. Foster parents and child welfare study respondents indicated that additional training was still needed. When foster parents expressed a need for additional training, they usually felt their training was adequate, but thought that other families could use additional training, particularly on medical care aspects of HIV-infected children. The majority of the foster parents interviewed had previous experience in a medical or health care setting, which may be why they were comfortable with their training.

Training topics that the respondents plan to develop or expand include death and dying and aspects of medical care for HIV-infected children. Several sites, such as Los Angeles and Chicago, will develop expanded training programs within the next two

years through recently implemented demonstration grants (HRSA and OHDS, respectively).

Support Services

The study sites varied in the number and type of support services provided to foster parents who care for HIV-infected children. Several sites provided transportation services, support groups, counseling, or 24-hour phone support. The services offered varied across sites, and even varied within each jurisdiction in cases where multiple agencies were involved with placing HIV-infected children in foster care. The study team observed differences in the support services offered within the same service delivery area, particularly when public and private agencies were compared. Foster families were eligible for the support services that were offered by the agency of placement.

The study respondents listed several types of support services needed in their particular area. These services included:

- respite care
- 24-hour support hotline
- babysitting
- transportation
- in-home health assistance
- psychological support (counseling)
- additional foster parent support groups
- need for a foster parent resource center
- support in dealing with death and dying

The most frequently requested need across sites was respite care. Respondents were almost unanimous in articulating the critical need for a formalized respite care system. Although one or two sites had provided some respite services to foster parents, officials stated that these systems were not formalized or, in some cases, were only available through collaborative efforts (and funding) with other agencies. Several sites said that the major reason delaying implementation was funding, either monthly payments to parents or actual respite care funding. Further exploration and clarification of funding would be required before developing a formal respite care service.

As sites have developed alternative funding sources for recruitment and training of foster parents to care for HIV-infected children, support services have been targeted for development. The study respondents indicated that the ability to recruit and retain the needed number of foster parents in the future would be contingent on the available support services and systems available to the prospective foster parents. Several sites with demonstration or research grants have identified one or more support services for development during the grant period.

Conclusions

The agencies visited generally bad some level of specialized training and support services for foster parents who care for HIV-infected children. In most cases, the services and training were developed through the assistance of outside funding and grants. The type of training available to parents and the number of support services developed within each locale was not uniform across or even within sites. In some cases, the support services may not have been available to all parents caring for an HIV-infected child if multiple agencies were placing children.

Although sites were providing training in cooperation with local hospitals and health care providers, a formal training curricula for foster parents caring for HIV-infected children often was not available. To further develop comprehensive training models for foster parents caring for HIV-infected children agencies need to develop training plans that specify the type of training, frequency, topic areas, agency responsible for training delivery, and other training-related information.

Study findings related to support services provides documentation that two key support services are essential for foster parents caring for HIV-infected children:

- support groups for foster parents caring for HIV-infected children, and
- respite care services.

In communities where strong, developed support groups were established, foster parents indicated that these were very helpful in providing a forum for sharing ideas, information, and concerns and resolving problems. Additionally, child welfare officials and foster parents thought the support groups were particularly helpful because the group provided a safe forum where common issues could be shared without breaching the child's privacy.

All sites highlighted the need for respite care. With the small number of currently available homes for placement of HIV-infected children, many foster families care for more than one child. In some cases, additional children have been placed in a home after a child with AIDS has died. Respite care would allow the foster parents some time away from the child (or children). Respite care could also be used after a death of a child, when other children are in the home. Many agencies are convinced that the time away from care responsibilities contributes to longer term retention of these foster families.

Recommendations

Recommendation 3.1 (Training)

All foster care agencies involved in recruiting foster parents and placing HIV-infected children in those homes should have a clearly defined training program that specifies:

- **type of training the foster parent will receive**
- **intervals for training and updates**
- **topics for training**
- **agency responsible for training**

Training should be developed in collaboration with local health and medical care providers knowledgeable about the care of children with HIV infection and AIDS

Recommendation 3.2 (Support Services)

Support groups for foster families caring for HIV-infected children should be implemented.

Recommendation 3.3 (Support Services)

Respite care should be developed, reimbursed, and made available to foster families providing care to HIV-infected children

4. What role do extended family members have in providing foster care and what are the implications for HIV-infected children?

Importance of Issue

Child welfare personnel at all sites visited stated that the "tended family is the first choice for placement of a child in need of foster care. They think it is more desirable for a child to be with relatives than with strangers. Extended family was defined as a relation up to and including a first cousin; usually it is the grandmother or aunt of the child. These families often require financial support for the care of these children. In the case of an HIV-infected child, the aging grandmother generally is the family member who volunteers to care for the child.

In many cases, extended family caretakers are poor and may be unable to provide optimal care. The physical, financial and emotional strain on the grandmother managing a sick grandchild, and perhaps her own child, demands greater involvement and interaction on the part of child welfare agencies.

Study Findings

Sites took different approaches in licensing and reimbursing family caretakers. A significant percentage of children were placed with extended family members at all sites visited; however, sites varied in the extent of foster care reimbursement offered.

The study team found that the percentage of children in relative placements ranged from 10 percent at one site to as high as 45 percent at another. The licensure requirements for the relative homes varied as well. The requirements were minimal, with no licensing requirements (or subsequent reimbursement), to specified licensure criteria and reimbursement that was used for all other types of foster parents. One site required licensure of extended family members only if the family member was beyond the level of a first cousin. Two sites required licensure for all extended family members serving as a foster parent.

Reimbursement also varied across sites. One study site did not require licensure for reimbursement to extended family foster families; another locale had the option of reimbursement open to extended family members serving as foster parents.

Staff from the medical centers caring for HIV-infected children found that 20 to 40 percent of the children they served were placed with an extended family member. In some cases, the hospital staff had worked out the placement of the child with the relative. In most of these cases, the family members were not being reimbursed for the care they provided.

The desire to use extended family members to care for HIV-infected children has led to many informal and innovative approaches by the social service staffs of major medical centers with large pediatric AIDS clinics. These medical centers can assist the

extended family caretakers, often an aging grandmother, with ancillary services, such as respite care, day care, and transportation, and can assist these relatives in obtaining the necessary foster care licensing and reimbursement.

The concept of utilizing extended family members to care for children who lose their parents is not a new concept and is widely accepted within many communities. However, for many the extended family caretakers financial resources may be inadequate and added support services may be necessary. It is also important that extended family members meet the same criteria for licensing that non-family members must meet. Child welfare agencies must be able to provide support to assist with the caretaker responsibility.

As the AIDS epidemic progresses, more and more children with HIV infection will require alternate caretakers. Their parents will die from AIDS or abandon them. To increase the pool of foster families able to care for HIV-infected children, child welfare organizations should further develop efforts related to licensing, reimbursement, and placement of HIV-infected children with extended family members.

Recommendations

Recommendation 4.1

State child welfare agencies should license and reimburse extended family members as caretakers of HIV-infected children.

Recommendation 4.2

State child welfare agencies should make provisions for supplying ancillary services such as day care, respite care, transportation, and homemakers to extended family caregivers.

5. Are congregate care living arrangements for HIV-infected children used appropriately?

Importance of Issue

Concern has been raised that, because of inadequate foster home recruitment efforts, group homes have been used as an alternative for HIV-infected children who, consequently, will not benefit from the family-like settings they deserve. An underlying concern is that sick and dying children are not afforded the same quality of care as other foster children and are relegated to less optimal forms of care.

It is a generally held value that children who are under the guardianship of the state deserve to live in a family-like setting. Institutionalized or congregate care is considered a less desirable option. Child welfare advocates have worked hard over the past 15 years to keep children out of the less nurturing environment of group care and to provide more foster home care, with the goal of permanent placement through adoption or return to the natural family. Group homes as a placement alternative have not been totally eliminated and are considered appropriate placements under certain circumstances. Children who have special medical needs that cannot always be provided at home may be considered better off in group home situations than in large institutions, and teens with severe behavior problems are sometimes handled better in group home situations than in individual homes. However, HIV infection is not considered a circumstance that requires placement in a group home.

Study Findings

Most HIV-infected children have been placed in foster family homes. Many sites visited also have placed children in congregate care facilities. Several congregate care homes have been established within the last year, which may indicate a trend towards wider acceptance of this option. There is no accounting of the number of congregate care homes in operation, but the numbers appear to be increasing. There are, nevertheless, strongly held attitudes toward congregate care and the role it should play in the continuum of placement options for HIV-infected children.

Characteristics of Congregate Care

The congregate care homes operating in the sites visited varied by type, intended function, and size. All facilities initially were opened to serve as temporary placements until a foster care home could be found. Many were established in response to the problem or potential problem of boarder babies.

Although most of the congregate care homes indicated that their intent was to serve children on a temporary basis (30-90 days), in practice, children often end up staying longer -- sometimes as long as a year.

Only one of the congregate care facilities considered long-term placement an appropriate option. This facility reported that a few of the children there came from "failed" foster home placements.

One congregate care facility was established as a respite care facility for biological parents who intended to bring their child home but, who, for a variety of reasons, found they were unequipped or unable to care for the child. Parents are expected to visit their children at this facility regularly and are encouraged to take the children home for several days a week. This facility was designed to meet the needs of the family. It has been used by the local foster care agency to place children who are medically ready for discharge but for whom foster families are not yet available.

The capacity of the congregate care homes visited ranged from 6-24 beds, and most had 9 or fewer. Most of the sites using congregate care as a placement option for HIV-infected children also use congregate care as a temporary placement for the general foster care population.

As an alternative to congregate care, some sites are using specialized foster home placements in which as many as six HIV-infected children are placed. The number of children is limited only by the size of the home in which they are placed. In terms of size, these homes approximate congregate care living situations; however, the institutionalized element is diminished by the presence of one or two unit "*parents*" and usually a full-time assistant to whom the children relate as opposed to general staff.

Attitudes Toward Congregate Care

A variety of attitudes towards the concept of congregate care for HIV-infected children was expressed during the site visits. Several persons were adamantly opposed to congregate care homes as a placement option and felt that option would not be necessary if adequate efforts were made to recruit foster care homes. According to this perspective, HIV-infected children deserve to have individual attention from one primary person to whom the child could become attached. Others viewed congregate care homes as appropriate for temporary placements, but acknowledged that temporary placements all too easily can extend to long-term placements. The pressure to find a foster home placement is somewhat eased if the child can at least be discharged from the hospital when medically ready.

Persons at sites with specialized foster homes for larger groups of children (six or more) felt that these homes were substantively and philosophically different than congregate care homes since the children are in a family setting with one primary person caring for them.

Some persons interviewed felt that the focus should not be on the type of care but rather on the quality of care provided and felt that, for some children, congregate care was the best option. A few hospital staff members reported that the children they

followed who had been placed in congregate care were thriving and receiving excellent quality care.

Several people identified specialized purposes that congregate care homes could serve. Congregate care homes could be used as a training ground for potential foster parents and help ease them into their responsibilities. These homes also could be used as respite care facilities for foster care parents, although this assumes that some beds would be set aside for this purpose. It was also felt that because of the caliber of the staff and their training, congregate care homes were better equipped to handle the children who were ill and required more medical involvement.

Conclusions

Although respondents at almost all sites said that their congregate care facilities for HIV-infected children were intended for temporary or transitional care while foster homes are being sought, the length of stays reported indicate that many, in fact, are being used as longer-term placements instead. That more facilities are being established may indicate that congregate care is being considered an appropriate placement option for this population. Whereas these facilities may be needed to help avoid the problem of boarder babies in hospitals, congregate care facilities also may serve as a disincentive to foster care agencies to undertake more rigorous recruitment efforts for foster family homes.

Recommendations

Recommendation 5.1

Congregate care homes should be used only to provide services and meet needs that foster family homes cannot meet. If these facilities are to be used for temporary placements, limits should be set, and stringently followed, as to how long a child will be placed there. This approach assumes that sites institute rigorous efforts to recruit foster family homes to keep temporary placements from becoming long-term placements.

Recommendation 5.2

State/local foster care agencies should assess the need for intermediate care (e.g., pediatric skilled nursing facilities) for the severely medically involved HIV-infected child as part of the continuum of care for this population. This type of facility should be used as an option to in-patient hospital care. It should not take the place of foster family homes or be considered an option to placing a child with a family. Many medically involved children can and should be cared for in the home with adequate training and support.

6. Should there be HIV antibody testing of all at-risk children in foster care?

Importance of Issue

The importance of HIV antibody testing for foster children can be viewed from the perspective both of the system and of the child. From a systems standpoint, the testing of children ensures that the number of HIV seropositive children will be known, an adequate number of specialized foster parents can be recruited, the children can be linked with the appropriate services, and agencies can use the data on the HIV-infected children to plan adequately for services, staff, and other resources.

From the perspective of the child, early identification of HIV allows for appropriate medical treatment, placement with a family that has specialized training, and access to treatment regimens that may prevent or delay symptoms.

Many groups, including the American Academy of Pediatrics Task Force on Pediatric AIDS, do not recommend widespread testing of all infants and children awaiting adoption or foster placement. Testing of foster care children in "populations that have high seropositive prevalence among women of childbearing age" is, however, recommended.

For foster care officials to know the number of HIV-infected children in placement and in need of placement, there must be a mechanism for testing. The testing will determine the number of children who are identified as HIV seropositive and, therefore, need to be placed within a specialized foster family home.

Study Findings

All sites were working within the parameters of an HIV antibody testing policy for children who were entering, or were in, the foster care system. Policies for testing the HIV status of children in the foster care system were developed within the context of pertinent state and local laws. As an example, one site stated they were unable to test children at risk because of their state's restrictive HIV antibody testing policies. Conversely, a second site was located in a state where physicians may test for the HIV antibody without informed consent. In this case, the child welfare agency received reports of children who tested HIV-seropositive.

Although the specifics of the policies varied across the sites, key elements of the testing policies included determination of need for testing, consent procedures, and confidentiality provisions.

<u>Determination of Need for HIV Antibody Testing</u>

Medical necessity was identified by all sites as a necessary condition for testing. It is typically documented by a physician or other medical professional. In some cases,

policies stated that the documentation of signs and symptoms could be used to indicate testing for HIV antibodies.

In a few sites, the frequency with which officials documented the need to test children influenced the "practice" of how that policy was followed. As officials became more comfortable with the criteria and procedures for need documentation, the interpretation of the criteria became more flexible. In some cases, additional factors relating to the testing decision were considered.

All sites also used some determination of "risk" as a key determinant for testing. Risk factors could be defined in terms of the parent or child. Common risk factors included the following: known HIV status of the parent; parental death from AIDS; sexual abuse by an HIV-seropositive individual; parental whereabouts unknown, but parent known to be at risk; use of intravenous drugs; and others.

Consent

Several sites had consent procedures related to HIV antibody testing. The consent for testing may require parental or court consent. At one site, the consent order specified the individuals who were to be informed of the test results. Two sites had developed consent procedures specific to adolescents. Additionally, several sites used a type of "review team" composed of medical and child welfare representatives as a minimal core group to review requests for HIV testing.

Confidentiality

Maintaining confidentiality as it relates to testing and test results was addressed by all sites as they developed and implemented testing policies. The sites viewed confidentiality from the perspective of the agency, community, and child. Disclosure policies, part of the broader concept of confidentiality, were documented by several of the sites. Sites developed disclosure policies around the concept of individuals who have "a need to know" the test results. Sites varied in specifying the individuals who should be informed of HIV test results and the mechanisms for informing them.

Conclusions

The potential benefits to the foster care system and the child's health provide compelling reasons to test all at-risk children in foster care. Such a decision would need to be guided by careful consideration of the complex issues it raises. The key elements to consider when developing a testing policy include:

- state laws related to HIV antibody testing
- adequacy of the confidentiality laws in place -- the need for additional laws/procedures for foster children
- conditions under which a child should be tested

- determination of who can request an HIV antibody test, eg., foster parent, physician, natural parents, or adolescents (and at what age)
- confidentiality
- determination of who has the right to be informed of test results
- the role of pre- and post-test counseling

As agencies explore these elements, they should consider the broad and long-range implications of HIV antibody testing. A policy to test foster children for the HIV antibody implies that there are benefits to testing, that certain individuals have a right to know the test results, and that support services, treatment linkages and specialized foster home placements or a system of care will be available to these children.

As child welfare agencies begin to implement an HIV antibody testing policy for children who are placed in foster care, fiscal issues become important. The fiscal implications of policies and procedures are critical aspects to the delivery of services within the foster care system. Most child welfare agencies have seen dramatic increases in caseloads, staff (caseworker) shortages, and tight budgets. HIV antibody testing of at-risk children may reveal that these systems are serving many more children who are HIV-seropositive who otherwise might not have been identified for a period of time. This awareness will place increased demands on staffing, funding for support services, and foster parent reimbursement dollars.

Recommendations

Recommendation 6.1

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:

- **the medical necessity for testing**
- **specification of at-risk criteria (child or parent at-risk)**
- **informed consent mechanism**
- **mechanism for adolescent informed consent**
- **mechanism to review all testing requests**
- **specification of individuals who may receive the test results**
- **confidentiality provisions**
- **pre- and post-test counseling requirements**

All policies should be developed with the assistance of medical care and/or public health providers within the context of applicable state laws.

Organizations that have developed HIV antibody testing policies encompassing the elements listed above, may wish to review their policies and incorporate additional procedures to strengthen it. In a recent article in Pediatrics, the American Academy of Pediatrics Task Force on Pediatric AIDS, in their discussion of the role of testing within

the foster care and adoption system, recommended incorporating additional procedures within existing testing policies. They suggested that agencies should:

- establish a process that would accomplish, with appropriate consent, pre-placement HIV testing of infants or children
- establish a record-keeping system to contain test results with access to such information strictly limited to those who need to know, but specifically including the informed adoptive or foster care family and the physician responsible for the infant's medical care
- establish a procedure for retesting infants who have positive antibody results on a regular basis

7. Are HIV-infected children in foster care enrolled in experimental drug trials?

Importance of Issue

Many of the children with AIDS and HIV infection are or will become wards or dependents of their foster care systems. Many issues have been raised concerning the participation of these children in pharmacologic treatment protocols, or experimental drug trials. The issues include:

- What are "protocols," "treatments," and "experimental trials?"
- Are HIV-infected children in foster care not participating in treatment protocols and experimental drug trials because they are wards of the state?
- What are the benefits and risks of participating in treatment protocols and experimental drug trials?
- How have different jurisdictions managed the issue of HIV-infected children in foster care participating in treatment protocols and experimental drug trials?

In 1988, the National Institute for Allergy and Infectious Diseases began funding 12 clinical centers to provide drugs to HIV-infected children under scientifically controlled protocols within major medical centers. The primary drug being administered is azidothymidine (AZT). However, this is not the first use of pharmacologic agents in HIV-infected children. Since 1982, immune-enhancing biologics, specifically gamma globulins, have been used to treat HIV-infected symptomatic and asymptomatic children. The National Institutes of Health is expanding the focus of its experimental trials from large medical centers to include local, community-based facilities, including groups of local physicians. New treatments and experimental trials soon will be widely available to many HIV-infected children.

Terminology

Misunderstood terminology often clouds the discussions about HIV-infected children in foster care who are in treatment and experimental drug trials. A "protocol" is an agreed-upon set of procedures and guidelines that defines the use of a biologic or pharmacologic agent. Protocols vary and may refer to a standard treatment or experimental drug.

A "treatment" is a biologic agent or drug which has been shown to be effective for the management of a specific medical problem and is an accepted patient management process for the general medical community. Gamma globulin has been shown to be effective in boosting the immune response of treated patients and is, for example, standard treatment after exposure to hepatitis. Such immune-enhancing agents are being administered to people with HIV infection to help combat the syndrome's underlying immune suppression.

"Experimental trials" are studies that follow scientifically formulated protocols and into which participants enter as subjects. The end point of an experimental trial can be the defining of the toxicity, side effects, and efficacy of the agent under study. All experimental trials must have the approval of a local institutional review board, composed of scientists, ethicists, clergy, and community members. Classically, participants do not know whether they are receiving the agent under study or the placebo. The lethal nature of the AIDS epidemic has led to a modification of the protocols for experimental trials to allow, in some studies, the elimination of the placebo or control group.

There is a level of concern and ambiguity because of the use of agents and drugs in children. For example, although gamma globulin is a standard treatment agent, the appropriate long-term dosage for children with symptomatic or asymptomatic HIV infection is not known, nor is the efficacy in slowing the progression of HIV infection known. Thus, there are "treatment" trials comparing the relationship of different doses of gamma globulin. Some may define this as a "treatment" protocol, whereas others may define this as an "experimental trial."

State Laws

In many states, child protection laws provide mechanisms for consent for standard medical treatment for children in foster care. The laws usually focus on standard medical treatment or practice. At this time there are no standard treatments for HIV-infected children, and although many drugs and agents are under study most state laws proscribe consent procedures for standard treatment and not experimental trials. A recent study by Sacks and Martin (1989) determined how state agencies and pediatric AIDS investigators were dealing with the issue of foster care and clinical trials. Thirty-five of 51 states and territories responded to the survey. They reported a cumulative total of 189,326 children in foster care, approximately 753 HIV-infected children in foster care, and approximately 15 HIV-infected children involved in a clinical trial. Seven states had a policy that allowed participation of their wards or dependent children in clinical trials, and 28 states reported no policy. Most states and local jurisdictions are very sensitive to their guardianship responsibility for their dependents. They are also concerned about the liability issues related to participation in treatment and experimental protocols.

Benefits and Risks

There are benefits and risks to be considered in involving a child in a treatment or experimental protocol. The drugs and biologics administered in these trials are on the cutting edge of AIDS research and medical treatment, and participation in the protocols is required to receive the agents. In addition, the medical centers carrying out the treatment and experimental protocols are also primary AIDS resource centers, with additional funds from Federal, state, and private agencies. Enrollment in a protocol guarantees the availability of many health and social service services and benefits, e.g, respite care, day care, travel allowances, support groups, comprehensive medical care,

case management, and family-focused services. A primary risk of involving HIV-infected children in foster care is the potential toxicity of the administered agent or of children receiving only placebo or non-therapeutic doses of the agent and, thus, receiving little or no benefit from participation. In addition, the schedule related to a child's participation in a protocol can create a significant time and logistical burden for the foster parent. Finally, there is a fear of racial or ethnic stigmatization, namely that these children, who are overwhelmingly from minority communities, will be enrolled in studies and protocols as "guinea pigs" and have no guardianship protection from abuse during the studies.

Study Findings

One state has created an innovative system to protect the rights of children in foster care. Its AIDS Review Board provides a formal forum for establishing linkages between key government agencies and community groups dealing with HIV and foster care issues. The Board composition includes broad representation from social service, public health, community, and nonprofit foster care agencies, as well as legal counsel. (See the Massachusetts site visit summary for a complete listing of the Review Board's constituency.) The appropriate use of HIV antibody testing on children in foster care was the primary impetus for creating the Board, but it now reviews clinical trial protocols to determine if HIV-infected foster children will be approved for participation. The AIDS Review Board has approved both AZT and gamma globulin clinical protocols. Once a protocol is approved,-foster children must be approved on a case-by-case basis to participate (see Massachusetts site visit summary).

Another state visited is typical of the majority of states: at present, it has no policy regarding the participation of foster children in clinical trials, and no foster children are enrolled in treatment or experimental protocols. The state has the authority to provide consent for medical treatment for ordinary and routine care, but a court order is necessary for extraordinary care. The definitions of these categories are often ambiguous.

Another state currently has no clinical trials in progress and has not developed a policy specific to foster children participating in such trials. However, the state has identified the need for an institutional review board that would review treatment and experimental trials, as well as HIV testing and medical resuscitation orders.

Overall, the lack of policies for the participation of HIV-infected foster care children in treatment and experimental protocols has not allowed many of these children access to new and innovative medical management and accompanying ancillary services.

Recommendations

Recommendation 7.1

State and local child welfare agencies should create systems to manage the participation of children in foster care in special medical treatment and

experimental trials. These systems should address the rights of the biologic parent(s), methods of protocol review, ongoing evaluation of the protocols, privacy, methods to safeguard children from potential abuse, guardianship responsibilities, and reduction of liability issues. Ideally, a broad coalition of representatives from AIDS and child welfare organizations should approve protocols and create exemplary approaches for the participation of children in protocols and experimental trials.

8. What is the "boarder baby" problem, how serious is it and what is its relationship to the HIV epidemic?

Importance of Issue

"Boarder-baby" is a term that has been coined to describe the infant or child who remains in the hospital although determined medically ready for discharge. The reasons for boarder babies have included: the parent(s) have abandoned the child and a foster home is not available; the natural parents are available but not prepared to take the child home (e.g., because the parent is incarcerated, homeless, in drug rehabilitation program or hospitalized); and institutional or procedural problems or issues.

When the boarder baby problem was first publicized several years ago, the focus was on the role of HIV infection in creating the problem. The continuing problem of HIV-infected boarder babies has been mentioned by several hospital representatives in New York City. However, Child Welfare agency representatives report very few HIV-infected hospital boarder babies.

An exploratory study of pediatric AIDS issues conducted by ASPE attempted to describe the boarder baby problem (Margolis, 1988). The study determined that, in addition to HIV-infected infants, the boarder baby population included infants with perinatal drug addiction, chronically mentally or physically ill children, and other children with special needs. Further, the problem appeared to be concentrated in New York City. Other areas experienced some problems but to a much lesser degree.

Study Findings

During the site visits the study team concentrated on determining the current number of boarder babies the site had compared to two years ago, the number of HIV-infected boarder babies in relation to the total number, how the site defined "boarder baby," identified reasons for boarders, and future problems expected.

Number of Boarder Babies

Almost all sites visited could only provide estimates of the numbers of boarder babies currently and two years ago. New York has set up a tracking system so was able to provide more concrete numbers. At several sites, interviewees did not concur about the exact number of boarder babies.

In terms of current problems with boarder babies, New York represented the extreme with as many as 158 boarders at one time, 4 of whom were HIV-infected. Other sites reported only three or fewer HIV-infected boarders in the last two years.

Some sites indicated that HIV-infected children are the only boarder babies they have encountered, while other sites indicated that the problem was not isolated to HIV-

infected children but included other special-needs children. In those sites, the majority of boarders were not HIV-infected.

All sites indicated that the boarder baby problem was more acute two years ago than it is now. New York, then reportedly had boarder babies numbering several hundred. The greatest number any other site reported was 14, all of whom were HIV-infected.

Definitions

All sites defined boarder babies similarly: children who are medically ready for discharge but remain in the hospital because of a lack of placement. However, interviewees did not always agree about when a specific case was medically ready for discharge. A few said that while the attending physician may determine a patient medically ready for discharge, this decision can sometimes be influenced by the need for beds and the need to keep the average length of hospital stay within the diagnosis-related-group (DRG) defined limits. There was some indication that the hospital caseworker and/or foster care agency caseworker did not always agree with the physician's decision.

Some hospital boarding situations were attributed to a desire to keep the child from entering into the foster care system while the natural parents made arrangements to take the child home or get an extended family member to take the child on an informal basis.

Another factor in keeping some children in the hospital longer than medically necessary may relate to a physician's lack of confidence in the ability of the foster care system to find a suitable placement for the child. That is, a child may be ready to leave the hospital, but is classified by the physician as requiring additional hospitalization. In such a case, the physician may think of the child as a boarder baby but does not initiate a request for placement.

Interviewees identified other procedural practices as contributing to the boarder baby problem, namely, initiating a home search only after the child is determined medically ready for discharge, which unnecessarily prolongs the hospital stay while placement arrangements are made.

Reasons cited for the lack of a boarder baby problem or the reduction in the problem within the last few years included the following:

- Instituting a tracking system.
- Effective and early discharge planning that included hospital social work staff and agency caseworkers.
- Existence/creation of group homes and transitional facilities.
- Efforts to keep children with natural families or find extended family members.

Future Problems

Although most sites were not experiencing problems with boarder babies, all expressed concern about the potential problems because of increasing numbers of medically fragile infants, especially drug-addicted infants, and the increasing numbers of HIV-infected children. Many interviewees said there was a need for intermediate care for HIV-infected and symptomatic children whose health care needs are greater than can be provided in a home environment but not severe enough to warrant hospitalization.

Conclusions

The HIV epidemic does not appear to be causing a boarder baby problem in any of the sites visited. With the exception of New York, the boarder baby problem in general is minimal. It is important to note that most sites did not have exact figures for the number of boarder babies, and there was not always agreement among interviewees at a particular site about what the estimated number was.

It is inappropriate for even one child to be kept in the hospital without medical need and to rely on the hospital environment as a sole source of care and nurturing. However, to concentrate legislative and financial responses on the boarder baby issue alone would detract from the other far more serious and immediate issues and needs of HIV-infected children.

The fact that the boarder baby problem exists in New York and that all jurisdictions experienced greater problems during the earlier days of the AIDS epidemic and fear future problems points to the role of the boarder baby problem as an early warning signal of foster care placement problems.

Recommendations

Recommendation 8.1

To minimize present and future boarder baby problems, state and local foster care systems should assure early identification of hospitalized children in need of placement. Such provisions should include:

- **a case management function**
- **tracking system**
- **collaboration and cooperation with hospital staff**

9. What are the issues surrounding HIV-infected adolescents?

Importance of Issue

Little is known about the number of HIV-infected adolescents in foster care and their medical needs. The CDC surveillance definition for reported AIDS cases is divided into two categories: children under the age of 13 and adults/adolescents. As of July 1989, there have been 1,681 reported AIDS cases in children under the age of 13 and 98,255 cases in adults/adolescents. Identifying the number of adolescents with AIDS is based on the age range defined for them. If we use 13 to 19 as the age range for adolescents, there have been approximately 300 cumulative cases of AIDS. If we add the number of young adults, aged 20 to 24, who almost certainly would have acquired AIDS during their teen years, there are an additional 3,500 cumulative cases of AIDS. Finally, as more effective drugs extend the lives of HIV-infected people, more children will be surviving and moving into adolescence.

Study Findings

The numbers of adolescents with HIV infection who are dependents of the state are not known with precision. All of the sites visited had minimal knowledge of how many of their adolescents were HIV-infected. However, all sites saw the infected adolescent as a significant future problem for the AIDS epidemic. Issues related to the HIV-infected adolescent who is in foster care include: acting out behavior, prostitution, drug-use, teenage pregnancy, running away, homelessness, lack of placements, and issues of testing and specialized counseling.

The testing issue is of special significance since, in most of the jurisdictions where site visits took place, an adolescent aged 12-13 may personally consent to being tested.

HIV antibody test results may affect residential or vocational placement of an adolescent. For example, the Job Corps program is a career-focused placement for adolescents. However, if a Job Corps candidate is HIV-seropositive, or if a Job Corps participant is found to be seropositive, the person is separated from the Corps directly or can lose their Corps-provided residence, which effectively results in separation.

A concern expressed repeatedly by state child welfare personnel is the potential liability posed by acting out HIV-infected adolescent wards of the state who may infect others.

Although the site visits focused on HIV-infected infants and children, several initiatives for HIV-infected adolescents did emerge during discussions. In one site, the child welfare agency works very closely with the Department of Public Health in dealing with HIV-infected adolescents. For example, a counselor from Public Health has been assigned to counsel, on an ongoing basis, an infected older adolescent about risky behaviors and the need for behavior change. A second site used a private provider who

has created two six-bed private homes to care for adolescents who define themselves as gay or lesbian, have need for intensive psychosocial services, and may be HIV-seropositive. In addition, this agency recruits, trains, and maintains ties with foster care families for placement of its adolescents.

Conclusions

The HIV-infected adolescent can pose significant problems. Adolescence is a time of acting out and experimentation. For the HIV-infected adolescent, the acting out and experimenting can be harmful to themselves and others.

Recommendations

Recommendation 9.1

State and local foster care agencies should undertake efforts to determine the number of HIV-infected adolescents in their care and their special problems and issues. Such an effort should include input from other government agencies and community groups with expertise in adolescent issues.

Recommendation 9.2

More studies should be initiated at the national level to define the breadth and scope of the problem of HIV infection in adolescents.