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AIDS Children and Child Welfare

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Office of the Assistant Secretary for Planning and Evaluation

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AIDS CHILDREN AND CHILD WELFARE

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I. BACKGROUND

A. Purpose of Project

In 1981, Acquired Immunodeficiency Syndrome (AIDS) was first identified in adults, and a few years later it was identified in children. AIDS, and AIDS virus infection (or HIV infection), as a fatal disease of epidemic proportions in children, is quickly emerging as a major public health tragedy that places extreme demands on the already overburdened health and social service system of this country. The issues surrounding the care and treatment of children with AIDS, and their ramifications upon the health and social service systems are not yet fully known or understood.

Surveillance data that CDC has gathered show that as of December 31, 1987 there were a total of 737 cases of AIDS in children (CDC Surveillance Report, 1987). CDC estimates 3,000 cases of pediatric AIDS by 1991, and there are estimates that 10,000 - 20,000 infants and children will be infected with HIV by 1991 (Report of the Surgeon General's workshop). The vast majority (73 percent) of children who acquired AIDS come from families where one or both parents are intravenous (IV) drug abusers (Report of the Surgeon General's workshop). Most of the reported cases in the U.S. (58 percent) have been in New York City, New York; Newark, New Jersey; and Miami, Florida; three cities with large drug abusing populations (CDC Surveillance report, December 28, 1987).

Legal, social and medical issues associated with the problem have attracted the attention of the media, Congress and local and federal policy makers, all of whom are grappling with the services needed by these children, the depth and quality of services currently delivered, and the present and future financial burden and sources of funds. Since the problem is relatively new, there are few studies and inadequate data to support, test, or verify approaches or hypotheses aimed at alleviating the problem.

There have been reports of AIDS babies abandoned in hospitals and shortages of foster care placements for these children. It is also generally believed that medical and other costs of caring for these children are higher than for children with other special conditions.

In light of these and other growing problems and the lack of sufficient information, The Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services (DHHS), commissioned Macro Systems, Inc., to conduct a brief, exploratory study to obtain an initial understanding of the prevailing issues. This study will provide suggestions for further lines of inquiry into specific problems and issues.

This study is timely in nature because issues concerned with pediatric AIDS are constantly emerging and evolving. Much can be learned from the early experiences in

the three cities toward shaping future planning and effective responses for the nation. DHHS is taking a cross-cutting perspective of issues because service delivery to these children involves the linkage of several health and social service sectors of the overall service system. This study will enable DHHS to identify the issues that need further exploration in order to determine an efficacious and timely Federal response to this critical public health issue.

B. Scope of the Project

The goals of the study are to: define the issues related to providing care to children with AIDS; place parameters around the size and scope of the problem; and attempt to clarify some of the perceptions and approaches relevant to the problem. This project focuses on children with AIDS whose parents are, or have had sexual contact with, IV drug abusers. Their social service needs differ from the needs of the hemophilia and other blood transfusion populations. The study's focus is more on child welfare service problems, issues and needs than on medical treatment issues. However, the medical care system is intricately involved in providing both medical and social services to these children and, therefore, is included in this focus.

The specific objectives of the study are to:

1. Summarize what is known about the natural history of HIV infected children and the types of non-medical services appropriate for them.
2. Define service and financing policy issues.
3. Describe how the three cities with the highest incidence of HIV infected children are presently coping with the care of these children in terms of types of care and financing, issues that result, including problems and successes, and what they consider to be the prospects for the future.
4. Describe exemplary practices, i.e. specific activities and responses that appear to work in each city.

The number of pediatric AIDS cases continues to increase; knowledge about the medical aspects of the disease is still evolving; and responses to the problem are continuously formulated, tested and redefined. During the course of this study, a number of other studies and activities regarding children with AIDS were underway, or had recently been completed. Several of these are listed in Appendix A.

Resources designated for the study were limited to the defined scope of the project and thus precluded in-depth exploration of any one issue. The observations presented in this report provide a snapshot of the rapidly moving and changing situation of AIDS in children as it effects three cities, and hopefully provide a glimpse into the future in terms of what to expect and how to formulate appropriate and effective responses.

C. Methodology

The project methodology included four components: designing an analytic framework, reviewing the literature, conducting telephone discussions with people involved in AIDS policy issues, and conducting site visits to the three cities with the highest prevalence of children with AIDS.

An analytic framework was created to outline a means of depicting information obtained about issues, barriers and responses. It provided a direction and focus to the project. A preliminary framework was designed at the onset of the study and then revised after the literature review and telephone discussions to help direct the site visits and shape the analysis. The revised analytic framework appears in Appendix B.

The literature review included abstracts of papers presented at the Third International Conference On AIDS held in Washington, D.C., the report of the Surgeon General's Workshop in Philadelphia, and published papers in medical, public health and child welfare related journals. The literature review was not intended to be exhaustive, but to provide an overview of the salient cross-cutting issues. During the course of the project a number of new articles were published, and other unpublished reports were also brought to our attention. Time did not permit a written review of all of these materials; however, a bibliography of these resources is included in Appendix C, and summaries of the articles reviewed are included in Appendix D.

The literature review provided the background information necessary to conduct telephone discussions with key persons knowledgeable about the issues and policy implications. Time and limited resources did not permit us to contact every individual or organization with expertise or involvement in pediatric AIDS. we did attempt to contact a variety of organizations to obtain a complete picture of the different perceptions of the issues. Persons contacted had affiliations with national social service, AIDS service and minority organizations, Federal agencies, and congressional offices. A total of 21 organizations were contacted (Appendix E). Issues discussed included trends in the incidence and spread of the disease, degree of illness in children, level of care required, financing issues/approaches to the care of these children, and policy implications. Summaries of the telephone discussions appear in Appendix F. The site visit approach was based on the literature review and prior telephone discussions.

Major issues and critical questions that were repeatedly mentioned in the literature and/or during the telephone discussions included:

- What is the extent of the "boarder baby" situation; are all boarder babies also AIDS babies?
- How many AIDS, ARC and HIV positive children are there?
- A child with AIDS usually has a parent with AIDS. What are the health and social service needs of these families?
- These children and their families experience problems and barriers in obtaining needed health and social services. What are the barriers/problems that are

unique to AIDS and what are the barriers/problems that already existed and are exacerbated by AIDS?

The analytic framework was revised accordingly, site visits were scheduled and discussion issues and questions were sent to the sites prior to the visit to familiarize them with the topics to be discussed (Appendix G). Persons contacted and visited included those involved in various aspects of the problem including child welfare officials, foster parents, voluntary organizations and other community groups, hospital personnel, public health officials, and State and local government officials. A list of persons contacted at each site is included in Appendix H, and summaries of each site visit are included in Appendix I.

II. DESCRIPTION OF THE PROBLEM

A. Natural History of AIDS

AIDS is caused by the Human Immunodeficiency Virus (HIV). Maternal transmission of HIV most often occurs perinatally; however, there is some evidence that it can also occur prenatally and postnatally (via breast milk) (Pyum, 1987). Infants can test positive for passively transferred maternal HIV antibody for up to 15 months of age without actually being infected (MMWR, April 24, 1987). It is estimated that as much as 65 percent of infants born to infected mothers have HIV infection (MMWR, December 6, 1985).

The CDC has implemented an AIDS case reporting definition for use in national surveillance. To qualify as a case, there must be evidence of a damaged immune system and the presence of an "officially recognized" cancer, opportunistic infection, dementia or wasting. The pediatric AIDS case definition differs from adults. In children, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia are accepted indicators of AIDS. The laboratory criteria for HIV infection in infants less than 15 months of age are more stringent because of the potential that the detectable AIDS antibodies were passively acquired.

Clinical experience shows that children with documented HIV infection can also have symptoms of illness and yet not meet the strict CDC criteria for AIDS. On this account, the literature often refers to all HIV infected children, including those with AIDS, ARC and those who are HIV positive and symptomatic. Failure to thrive is a major feature of children with HIV infection. Downstate Medical Center in Now York City found that 80 percent of ARC/AIDS infants studied failed to thrive, and that 96 percent had neurological deficits. HIV infected children can also have a variety of other illnesses, including anemia, lymphoid interstitial pneumonitis, encephalopathy, recurrent bacterial infection, hepatitis and renal disease, to name a few.

Early medical intervention for the HIV infected infant is important. This can include nutritional support, treatment of infection and therapy with intravenous gamma globulin. Hospitalization is often required, but increasingly care and treatment can be provided on an outpatient basis. The mortality rate is high, especially if opportunistic infection is acquired in the first year of life.

B. Magnitude

As of December, 1987, CDC reported a total of 737 AIDS cases in children up to 13 years old (Exhibit 1). HIV infection in children is predominantly among blacks (54 percent), including children of parents coming from Haiti, and Hispanics (24 percent). In

addition, HIV infection in children is also a problem closely linked to IV drug abuse. Nationally, 77 percent of the officially reported pediatric AIDS cases had a parent with or at risk for AIDS primarily through either IV drug abuse or sexual contact with an IV drug abuser.

EXHIBIT 1. Children 0-13 Years With AIDS

Transmission Category	Total		Sex				Race								Deaths	
			Male		Female		White		Black		Hisp.		Other			
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Hemophilia/ Coagulation Disorder	40	5	37	5	3	0	27	4	6	1	6	1	1	0	26	4
Parent with/at risk of AIDS	566	77	285	39	281	38	68	9	352	48	142	19	4	1	338	46
Transfusion, Blood/ Components	97	13	57	8	40	5	52	7	25	3	20	3	0	0	65	9
Undetermined	34	5	18	2	16	2	11	1	16	2	7	1	0	0	18	2
TOTALS	737	100	397	54	340	46	158	21	399	54	175	24	5	1	447	61

SOURCE: CDC, AIDS Weekly Surveillance Report, December 28, 1987.
Cumulative since January 1, 1981.

New York has the largest number of cases of children with AIDS (245 or 33 percent), New Jersey has 13 percent of the cases and Florida has 12 percent of the cases (Exhibit 2). Cumulatively, these three States have 58 percent of all cases in the United States. Just a year and a half ago these States bore a larger portion of the problem (68 percent). Exhibit 3 shows how these three States are experiencing a progressive decrease in the percentage of pediatric AIDS cases. This indicates that other States in the U.S. are beginning to see an increased portion of pediatric AIDS cases and will experience increasing demands upon their service systems over time.

The magnitude of the pediatric AIDS epidemic and its impact on the health and social service systems cannot be limited to the children meeting the CDC AIDS case definition. The three cities visited have found that the children needing services include those who have AIDS and ARC, and those that are HIV positive.

The cumulative total of cases in New York, Florida and New Jersey that met the CDC definition for pediatric AIDS was 429 in 1987. However, the total number of children who have been followed by the hospitals visited in three cities in these States has been 860, twice as many as the number of AIDS cases. This total does not include HIV infected children followed by the other hospitals in these cities that were not visited, other hospitals in the State, or those unknown to the system.

EXHIBIT 2. Cumulative Number of Children with AIDS by State 1981-1987		
State of Residence	**Number**	**Percent***
New York	245	33.2
New Jersey	98	13.3
Florida	86	11.7
California	55	7.5
Puerto Rico	30	4.1
Texas	30	4.1
Maryland	19	2.6
Massachusetts	18	2.4
Connecticut	17	2.3
Pennsylvania	15	2.0
Georgia	14	1.9
Illinois	13	1.8
Louisiana	9	1.2
Virginia	9	1.2
District of Columbia	8	1.1
Alabama	7	0.9
South Carolina	5	0.7
Missouri	4	0.5
North Carolina	4	0.5
Ohio	4	0.5
Oklahoma	4	0.5
Washington	4	0.5
Other States	39	5.3
TOTAL	737	100.0
SOURCE: CDC, AIDS Weekly Surveillance Report, 12-28-87 * Percentages may vary slightly due to rounding.		

Professionals who have been working closely with the problem feel that the magnitude is much larger than is currently known. For example, the New York City AIDS Surveillance Unit has estimated that there have been approximately 500 ARC cases and 2,000 HIV infected children. An HIV seropositivity research study demonstrated that within one section of New York City two out of every 100 women were HIV antibody seropositive. This finding was verified by a New York State seropositivity study of all births n the state for a one month period--very high risk areas were found to have approximately a 2.5 percent newborn seropositivity rate.

Other areas are experiencing similar disparities between the number of officially reported pediatric AIDS cases and the number of children in need of clinical and social services. For example, Washington, D.C. officially reported 14 cases of pediatric AIDS, but has a cumulative total of 116 HIV infected, ARC and AIDS children. In Georgia, 16

pediatric AIDS cases have been reported, but there have been approximately 56 HIV antibody positive, ARC and AIDS children. Since there is no consistent or widespread testing of newborns and/or pregnant women, estimates of the disparity between reported pediatric AIDS cases and the number of children managed in any given municipality cannot be determined precisely.

EXHIBIT 3. Change in Percentage of Cases of Children with AIDS in the Three Highest Morbidity States (New York, Florida, New Jersey)	
Date	**Percentage of Total Pediatric AIDS Cases**
June 1986	68.0%
December 1986	64.4%
June 1987	61.0%
December 1987	58.2%
SOURCE: CDC AIDS Weekly Surveillance Report, June 30, 1986, December 29, 1986, June 29, 1987 and December 28, 1987	

Projections for future numbers of cases in children and adolescents usually use the year 1991 as the target year. CDC estimates a cumulative total of 3,000 children with AIDS by that date. The New York City Health Department predicts that there will be 10,000 cumulative cases of AIDS, ARC and HIV positive children, and James Oleske, at Children's Hospital in Newark, New Jersey estimates 10,000 to 20,000 symptomatic HIV infected infants and children by 1991 (Report of the Surgeon General's Workshop). Although there are very few known cases of adolescents with ARC/AIDS at present, it can be reasonably predicted that they will begin to play a significant role in the future. Medical advances are extending the lives of children with AIDS, and children and young adolescents experiment with sexual activity and with drug use. In addition, the history of sexually transmitted disease control is that adolescents represent approximately 25 percent of those diseases, some of which are known precursors for subsequent HIV infection.

C. Service Delivery Needs

Caring for an HIV infected child poses special challenges. There are the demands of taking care of an ill child, including frequent visits to the hospital, special infection control precautions, managing special health needs and recurrent medical crises, and perhaps ultimately coping with the child's death. Because of the widespread fear of AIDS, it is sometimes difficult to obtain needed services such as dental care, day care, schooling, etc., and frequently there is ostracism by family and friends if the child's HIV status is known.

Most HIV infected children are from minority (black, Haitian and Hispanic) and impoverished families. It is not uncommon for the child to be the index case of AIDS in a family with other infected members. Often, one or both parents are or have been IV

drug abusers and are themselves ill or dying with ARC or AIDS, and the child may have a sibling with AIDS.

In addition to dealing with medical and social service needs, parents often must cope with the emotional trauma of their own or each other's illness or death, and the guilt of having passed the HIV infection to their child. These families are also in need of income support, housing assistance, transportation, in-home care and assistance in obtaining these benefits. Historically, the minority and IV drug abusing populations have had difficulty accessing the health and social service systems.

For children whose parents are too ill to care for them, whose parents have died, or who have been abandoned by their parents, alternative guardianship arrangements are required. These arrangements have included extended families (most often a grandmother), foster families, and congregate care homes. If no alternatives are found, the child becomes a hospital "boarder baby," or a child who resides in a medical facility without medical justification.

The number of boarder babies nationwide and the percentage of boarder babies who have AIDS are unknown. Of the sites visited, New York City has had the most extensive problem. There were 42 boarder babies during one month in 1987, 35 of whom were HIV infected. The other sites have had only two to three boarder babies at one time. Many boarder babies' hospital stays are prolonged because of problems in finding foster care homes or in processing the necessary paperwork to place them in alternate care arrangements.

D. Financial Aspects

No published data were found on the total costs of providing care to children with AIDS. There are a number of different estimates on the costs of care for AIDS in general, or specifically for adults. Total lifetime costs were estimated at $4.85 billion in 1985 in 1985, $8.64 billion in 1986 and projected to increase to $66.5 billion by 1991 (Scitovsky, 1987). Estimates for hospital care only, from diagnosis to death, range from $27,571 per case in San Francisco, California (Scitovsky, 1986) to $50,000 per case (National Academy of Science, 1986) to $140,000 per case (Hardy, 1986).

An analysis of the cost of care for HIV infected children at Harlem Hospital reports an average cost of $500 per day per child. The per diem ranged from $300 to $2,400. The study also showed that 30 percent of the total length of stay and 20 percent of the total cost were for unnecessary hospitalizations.

The major sources of payment for adult AIDS patients are private insurance and Medicaid (Luehrs, 1986). Drug abusers and pediatric cases are more likely to rely on Medicaid as the payment source. Persons fitting the CDC case definition of AIDS are presumed to be disabled under Social Security Administration (SSA) regulation and therefore are eligible for Medicaid if they also meet the income eligibility criteria for

supplemental security income (SSI). This eligibility criteria does not extend to children with ARC or HIV infection. Families that are already on Aid for Families with Dependent Children (AFDC) are automatically eligible for Medicaid in most States, which is often the case for children infected with HIV. AIDS costs will increasingly impact upon the Medicaid system because of the enormous expense in caring for these children and families. The potential exists for an overwhelming cost burden as the number of cases increase.

E. Service Delivery Approaches and Problems

Testing and screening of newborns for HIV is not done routinely in any of the sites visited. The HIV infected child is first known to the service system when he/she becomes symptomatic and enters the health care system. This may be at birth, if circumstances suggest the possibility of HIV infection and testing is done. Otherwise, recognition is delayed until later in infancy. In all three cities, the hospital is the initial provider of services to HIV infected children, although many are already known to the social service system because of other family situations.

The composition of the team of professionals delivering services to HIV infected children at the hospitals visited range from two overworked pediatricians at Harlem Hospital to care teams comprised of pediatricians, social workers, nurses and psychologists or psychiatrists. The most comprehensively staffed care teams are located at medical schools and affiliated hospitals that have been able to help support these positions through research grants.

Some hospitals have reported difficulties in hiring new staff to care for HIV infected children. Harlem hospital has several social work and nurse positions that they have been unable to fill. This is due in part to preexisting staff shortages, fear of AIDS among professionals, and insufficient salaries. Hospitals with additional grant resources have had better success in filling staff positions, but have also experienced more difficulty than usual in finding staff because of the fear of AIDS. Most of the staff visited at the hospitals in New York, Miami and Newark are those who became involved early in the epidemic and have dedicated themselves to providing services to HIV infected children.

The additional resources from the research grants have enhanced the development of medical and social service expertise in the recipient hospitals. Many of the services needed by HIV infected children are unavailable in the community, or community agencies are unwilling to accept these children because of a fear of AIDS. As a result hospitals have taken on new and expanded activities, including case management and outreach and some have begun to provide services such as day care, counseling and training and education of the community. They have evolved into pediatric AIDS treatment and case management centers.

The types of services provided to children with HIV infection at all hospitals visited are focused on the family needs as much as possible. One approach included home visits by a nurse and social worker to assess the family's needs. Another approach included referral to the visiting nurse association to provide in-home care.

The Children's Hospital of New Jersey, in collaboration with the New Jersey Department of Human Services, has described a continuum of care that includes training and education of staff and community service providers; medical consultation for emergency care, regular medical care, and medical case monitoring to ensure consistency in care. A range of social services is also described, comprised of: case advocacy in terms of assisting the family to obtain needed services; working with State agencies and communities to develop needed but unavailable services; providing individual and group support to address psychosocial and service needs of natural parents and foster parents; providing homemaker and in-home care services; providing transportation to and from medical appointments, and placement in alternative care for both respite care and regular long term placements.

The persons interviewed identified a need for a coordinated maternal-infant approach to medical care and social service delivery. Under the present system, mothers/parents are treated under different care systems than their children. One example of this is the referral and reimbursement mechanism for in-home care in Newark. When a home visit is made for the child, there is usually the need to provide services for the mother as well. Under the present system, in-home care for the mother takes place under a separate referral system, so that the mother's and child's care are not provided in the same visit. Since both the mother and the child are likely to be in need of medical care, the children's medical and social service providers should maintain close contact with the mother's medical and social service providers to ensure that appropriate services are being delivered to both, and that their care is coordinated. Prescribed medical care and other services for the child need to take into account the mother's health condition and home situation.

Service providers also identified social service/reimbursement eligibility problems and processing issues. An extreme example of this occurred at Harlem Hospital, where in addition to lack of funds and difficulty in recruiting personnel, the complexity and intricacies of coordinating Medicaid, AFDC, SSI and other financial support programs have posed serious obstacles to appropriate care and availability of social support for the children and families in desperate need. In one case, the bureaucratic intricacies in providing appropriate support for a grandmother to care for an AIDS infected youngster could not be surmounted, and the child has remained in the hospital for over two years. This unfortunate outcome occurred despite pleas made by the Chief of Pediatrics to high placed city, regional and Federal officials. One official returned to Harlem Hospital with $191 and a box of used toys that were the result of a collection taken up by office personnel in lieu of an ability to generate and make the system responsive to obvious patient and family needs.

Another example is the complicated process of obtaining Medicaid coverage in Hudson County, New Jersey, where three separate applications are required and eligibility must be renewed every three months. Service providers there report that 47 out of 100 high risk parents do not have Medicaid coverage. Personnel in Miami also report that the application process for SSI and AFDC is extremely complicated, the stipends are too low, and in some cases, processing has taken as long as six weeks. These problems were identified as intrinsic to the system as a whole, not as unique to AIDS/HIV infection. However, the immediacy of the needs of the AIDS/HIV infected population has highlighted these problems. Problems that are specifically AIDS related include finding agencies and community services willing to provide services to HIV infected clientele. Persons interviewed cited a need for extensive community education to put the realities of HIV transmissibility into perspective.

When a child is in need of a foster care home, the hospital usually contacts the city or state child service agency. Service providers interviewed in all three cities indicated a preference for placing a child with a member of the extended family, i.e., "kinship foster care." In fact, in some communities such as the Haitian community in Miami, the willingness and ability of extended family members to care for the children is so strong that few HIV infected children abandoned or without parents are in need of foster care homes.

There are a number of issues and barriers to the kinship foster care option. In many cases, the grandmother or aunt who assumes the care of the child does not have adequate financial resources to care for the child or cover the extensive medical expenses that are likely to occur. In some jurisdictions, an extended family member can qualify for foster care payments, and in some cases the family may qualify for AFDC and Medicaid. However, in order to obtain these income support services, the extended family member must assume legal guardianship of the child which involves going through a court process to declare the parent incompetent, abusive, or neglectful. Many families are unwilling to do this out of loyalty to their offspring or siblings.

Service providers at the sites visited report that kinship foster care is neither adequately reimbursed nor expeditiously available. They feel that the shortage of foster care homes would not be as acute if adequate provisions for this option were made.

In most areas visited the city or State agency contracts with a number of private agencies to provide foster care services. There is a reported shortage of foster care agencies willing to include HIV infected children in their caseloads. Two agencies in New York and Miami have developed special programs specifically geared toward placing HIV infected children, and in Newark, the Foster Parents Association has become involved in addressing the issues of foster parent recruitment. All three jurisdictions offer enhanced reimbursement rates for foster families that take HIV infected children. For example, in New York the reimbursement rate for HIV seropositive children is $1,134 per month as compared to the regular rate of $165-$342 per month, depending on age and a special rate of $748 per month for special needs children (handicapped, boarder babies, or other hard-to-place). There are additional allowances

for clothing and other miscellaneous expenses that are determined on a per child basis by the contracting agency. In Miami, a foster parent receives $2,700 per month for an AIDS/ARC child, and no additional allowances are awarded. This compares to the regular rate of $183-$240 per month depending on age.

The Leake and Watts Children's Home, one of the contracting agencies in New York, has created a special division to handle foster care placement of HIV infected children. The agency social workers in this division receive an additional $3,000 per year. Leake and Watts has been able to place 24 HIV infected children over a 24-month period. Their best source of recruitment has been referrals from foster families already caring for HIV infected children. Recruitment efforts by other agencies visited included public service announcements, information dissemination and education.

All three cities report that children who are already in foster care homes when HIV infection is discovered are rarely turned away by the foster family. Many have already bonded with the child, and after some education about HIV infection and transmissibility, the families opt to keep the child. Persons involved in foster care in all three cities identified a number of foster care needs and issues. Extensive orientation, training and support services for respite care, day care, homemaker services, are needed, as well as attention to emotional needs. Several persons interviewed indicated that there weren't resources to study and qualify families quickly enough to meet the growing needs. Other issues raised included confidentiality, and how many HIV infected children should be placed in one home.

The use of congregate care homes for HIV infected children raises another set of issues. The personnel running the homes that we visited viewed this alternative as a temporary placement until an appropriate foster care home could be found. They felt that it was a better alternative than allowing the children to stay in the hospital when there was no medical need to be there. Others felt strongly that congregate care homes were not good alternatives because they do not provide an adequate family environment, the risk of illness is too high, and the concept may appear to condone the isolation of HIV positive children from their extended families and community. Congregate care is not an inexpensive option. St. Claire's Home for Children reports a cost of $240 per day per child ($100,000 per year). It is, however, half of some of the estimated hospital costs. Congregate care homes may also experience problems with community acceptance.

Each of the three cities visited had a different approach to the management and coordination of services. In Miami, a planning process that involved a variety of community interests was instigated early in the epidemic. Public health was notably absent from this process. As part of the planning approach, service needs were defined and a special management office was created to handle contracting with organizations to provide care and management services, education and training, and to conduct research. This office is the central receptacle for all AIDS related funding for South Florida. Newark has created a State level management group that includes representation from various State departments, the Foster Parents Association and

community service organizations. New York does not have a centralized planning body, but does have a network of dedicated professionals who provide services and coordinate services to some extent by staying in contact with each other.

Service providers in all three cities were so engrossed in meeting the present pressing and undermet needs of children with AIDS that none had any plans for how to respond to the projected increases in HIV infected children. Although most hospitals visited appeared to be able to handle their present caseloads of children with HIV infection, they also appeared to be at their limit in terms of physical space, staff and resources.

III. DISCUSSION

This study has identified a number of key issues and problems in attempting to deliver services that have been encountered by the three cities with the greatest prevalence of children with AIDS. Following is a discussion of the most pressing issues that were raised and implications for the future.

A. Magnitude

There is a large discrepancy between the reported number of AIDS cases in children and the number of HIV infected children in need of services. Characterization of the magnitude of the problem of AIDS in children has focused on the number of AIDS cases reported to CDC when in fact the number of children in need of services may be 2.5 to 15 times greater. The total number of pediatric AIDS cases reported to CDC by New York, New Jersey and Florida was 429, which contrasts with a total of 860 cases of HIV infected children that have actually been treated by the hospitals visited during the site visits. This total also does not include children treated in other cities and hospitals not included in the site visits, or unknown cases. Other areas report similar discrepancies. Washington, D.C. reported eight cases of children with AIDS and 116 HIV infected children, and Georgia reported 16 cases of children with AIDS and 56 HIV infected children.

Projections for the number of cases by 1991 range from 3,000 official AIDS cases to 20,000 HIV infected children. The mortality rate for AIDS is 61 percent nationwide, so the number of children in need of services won't be as high. However, the mortality rates for ARC and HIV infection are unknown, but can be assumed to be lower. Projections have focused on the year 1991, and this has detracted from the reality that the problem will continue to grow in 1992, 1993 and for some undetermined time into the future.

The concentration of AIDS cases in children in New York, New Jersey and Florida has lessened over the last few years. This is not an indication that their numbers have decreased or that their problems have eased, but instead is an indication that other states/cities are experiencing growing numbers and will soon need to deal with the same problems New York, Newark, and Miami have faced. In preparing service delivery approaches, cities and States that are new to the problem should consider the total number of HIV infected children to estimate demand for services.

The continual increase in the number of infants, children and adolescents with HIV infection, ARC or AIDS has greater impact on the health and social service system than adults with HIV/ARC/AIDS. Children are more dependent for obtaining access to the health care and social service system, they cannot manage their own affairs, and they have a more immediate need for medical management and social services.

Studies have demonstrated that AIDS in children progresses more rapidly than in adults.

B. Health and Social Service Care System Demands

The site visits illustrated the demands that the AIDS epidemic has placed on the health and social service care systems. The population in need of services is an already needy population, typically black, Haitian or Hispanic, IV drug abusers and single parent families. Added to the problems perpetuated by these conditions is that, often with the discovery of an HIV infected child comes the discovery of an HIV infected parent and/or sibling, and ultimately social ostracism, illness and death. The immediacy of AIDS has highlighted the fragmented nature of the care systems, and the eligibility and processing problems inherent in these systems. The additional needs of this population stress an already overburdened health and social service delivery system and heighten the need for new perspectives on service delivery, including a family focus and better coordination of services.

There is a need to make available specialized services for this population. HIV infected/ARC/AIDS children and their families require frequent transportation to health care and specialized medical facilities--and these services are sorely lacking. Many of the children with ARC/AIDS suffer from neurologic symptoms which lead to developmental disabilities. These children require specialized early childhood education programs, which are in very short supply. The general population's fears about AIDS transmission exacerbates this problem by excluding the ARC/AIDS children from normal educational settings. Finally, the caretakers of children with HIV infection/ARC/AIDS, be they parents, foster parents, adoptive parents, or extended family members, need respite care--facilities that are prepared to accept and manage these children for short periods of time. Respite care facilities are almost nonexistent.

Other issues that need to be addressed include coordinated medical care for parents and children, day care for infected children and their infected siblings, assistance to parents in planning for guardianship arrangements in the event of their death, and psychosocial support in dealing with the stress of their situation. There are children infected with HIV who act out because of the disruption caused by the disease, or who will have to deal with the future situation of parental and/or sibling death and loss of a family and/or home. There is a need for early and close coordination between the hospital and the social service systems.

Even without the advent of the AIDS epidemic, the foster care system has been experiencing difficulties. The available pool of new foster parents has been decreasing, because of the increase of women working outside the home and because of inadequate reimbursement rates. A child with HIV infection, ARC or AIDS stresses the foster care system even further, because of the specialized needs, concerns and perceived stigma. It has been difficult to recruit foster parents for these children. There is a need for specialized training for potential foster parents in caring for these children,

infection control procedures, and dealing with confidentiality of medical information to determine "who needs to know" about the child's HIV-infection. There is also a need to offer additional support and relief to these parents. Foster care reimbursement must be at a level that is appropriate for the childrens'/foster parents' needs, including social and respite care support. There is a need to expand the pool of potential foster parents by recruiting extended family members (grandparents, aunts, uncles) and by considering multiple child placements within a foster home. There is also a need for greater responsiveness of the system in qualifying families for services.

The use of the CDC AIDS case definition to determine eligibility for services and financial support has excluded a major portion of the population in need from obtaining services. The case definition was originally implemented for disease surveillance purposes, and its use for other purposes has proven to be inappropriate.

C. Boarder Babies

Much of the media attention and legislative response to the needs of AIDS in children has focused on the "boarder baby" problem. As illustrated during the site visits, boarder babies are one small part of the service needs of the population of HIV infected children. The extent of the boarder baby problem varies from city to city. New York has experienced the greatest problem, but some "boarder babies" may be waiting for arrangements for a parent, grandparent or other relative to assume responsibility and do not represent a long term problem.

Although the boarder baby problem is not large in sheer numbers, it is a continuing problem. As one child is placed, another may become medically ready for discharge and yet may have to stay in the hospital for lack of a foster home. The hospital cannot provide an adequately nurturing home environment for these children and the cost of care is excessive. Even a few boarder babies can place an undue burden on the system.

The boarder baby problem can become significant in the future because of the general lack of foster parents in the United States, the lack of foster parents willing to care for an HIV infected child, the increasing incidence and prevalence of children with HIV infection, and the increasing number of AIDS related deaths of parents who are still caring for their HIV infected children. The expense of handling a boarder baby can be as high as $200,000 per year and as medical expertise in extending the lives of HIV infected children increases, the costs for boarder babies in hospitals will increase accordingly. The boarder baby problem, however, should not detract from the other, more prevalent needs of HIV infected children and their parents.

D. Financial Resources

Several medical schools and their affiliated hospitals have sought and received federal research grants related to pediatric AIDS and HIV infection. Many of these research grants include the delivery of services related to the research protocols. This has allowed the medical school/affiliated hospital to acquire the services of nurses, social workers, and outreach workers and to provide better access to health and social services. The lack of availability of professionals in community organizations and agencies willing to provide services to HIV infected children has posed a problem to hospital care providers. This highlights a need for education and outreach to the community, as well as training and retraining of caregivers.

The grant dollars have allowed the recipient hospitals to become pediatric AIDS centers with medical and social service expertise. However, the grant monies are not a permanent solution. They provide short-term relief for selected populations served by the recipient hospitals. Furthermore, the grants will not be continued indefinitely and cannot begin to provide all the resources necessary for the services needed by the AIDS, ARC and HIV infected families.

This study also suggests the importance of enhanced reimbursement rates for foster families and enhanced salaries for professionals caring for HIV infected children. Reasons cited for enhanced rates and salaries included:

- Compensation for the added precautions necessary to reduce the child's risk of infection
- Compensation for the caregivers increased emotional stress and demands
- To provide a financial incentive to prospective caregivers

E. Planning

Community planning of services for children with HIV infection should take into account the special needs of this population. It should consider that "AIDS in children is AIDS in families." These families have unique and expensive needs requiring specialized medical care, in-home services, and income and psychosocial support, to name a few. Some of the current population of HIV infected children will die, some will survive and eventually enter the school system, and others will manifest severe disabilities and require supportive services. All of these groups will pose new sets of issues for communities to address. In the future, as these children approach adolescence, some will experiment with drugs and sex, thereby placing others at risk. There are presently more than 200 adolescents with AIDS. Uninfected adolescents are also a potential reservoir for acquiring new infection because of sexual and drug abuse experimentation. Specialized educational and outreach programs are needed to reach this population. Communities will face the need to plan for primary and secondary prevention activities with special emphasis on groups that are difficult to reach. Communities need to be aware of the complex service needs posed by the AIDS

epidemic in infants, children, adolescents and their families, and to focus specialized outreach and prevention programs to this group.

In addition to planning for the present needs of the current population of HIV infected children and their changing needs as they grow older, communities must also be prepared to plan for the increasing number of children that will be born with HIV infection.

Even in cities that have maximized resources and provided effective coordination of services for the present population of HIV infected children, any significant increase in AIDS stricken children may have an overwhelming impact upon resources and personnel. It may result in an increase of boarder babies and create a major additional burden on hospitals, foster care placement agencies, and other service providers. It could also magnify the financial drain upon Medicaid and other financial aid programs.

As the number of cases rises in cities that have not yet had to deal with large numbers of HIV infected children and their accompanying problems and needs, plans will have to be made to target resources to address these needs. The early experiences of New York, New Jersey and Miami can lend some guidance to these cities' planning processes to help alleviate potential problems in service delivery.

Miami's planning approach, which includes a centralized regional planning group with a broad range of community representatives and one AIDS services contracting source, appears to be the best equipped to handle the likely increased number of cases. Planning for AIDS in children should be included within a community AIDS planning process for all AIDS-stricken populations but should focus on the unique issues and circumstances of HIV infected children. The planning process should involve those providing direct services to children with HIV infection and their families. A planning process that is too far removed from the service deliverers may not have the appropriate interactions needed to design effective and coordinated responses to service needs.

The evolving nature of the epidemic of AIDS in children calls for continual monitoring of trends in case numbers, service demands and economic impact, as well as changing opinions about testing, screening, confidentiality, community acceptance and support. All of these result in shifts that may outdate present solutions. Such forces argue for periodically evaluating the situation, planning for change, and anticipating increasing or different pressures upon the system. It became apparent that these and other issues demanded further attention and study. These issues are outlined in Appendix J. Each community planning process must have an element that relates these continued changes specifically to the service delivery approaches for children with HIV infection.

APPENDIX A. PEDIATRIC AIDS ACTIVITIES AND REPORTS

Report of the The Surgeon General's Workshop on Children with HIV Infection and Their Families

American Academy of Pediatrics--Task Force on Pediatric AIDS

Child Welfare League of America--National Task Force on Children and AIDS

House of Representatives Select Committee on Children, Youth and Families--Report on the Impact of AIDS on Children

Region II Office of Human Development Services--Report on New Jersey and New York Boarder Babies

National Commission to Prevent Infant Mortality--Perinatal AIDS Report

Interim Report of the Presidential Commission on Human Immunodeficiency Virus

APPENDIX B. ANALYTIC FRAMEWORK

Overview

The intent of this analytic framework is to outline a means of depicting information obtained about issues, barriers and solutions regarding AIDS in children. It allows for a direction and a focus to the problem. The "Overview" has presented in a preliminary way the results of phone discussions with people who provide largely a national perspective. This "analytic framework" will be used to direct the fact finding at the site visits and to shape the further analysis of the new data and the information previously obtained via telephone interviews.

Framework

A. Magnitude of the Problem

1. Define the range, parameters and limitations for protecting the number of childhood cases of AIDS into the future. Use 1991 as an end point for projection.
2. Consider the effect of "childhood AIDS case definition" changes on the projection analysis.
3. Discuss the inexactness and variability of case number projections.

B. Impact on Systems

1. Analyze the effect of childhood AIDS on the hospital and medical services system, including the following:
   - Delivery of services
   - Staffing patterns, needs and problems
   - Boarder babies--a new problem?
   - Cost of services
   - Future problems for hospital/medical services
   - Confidentiality issues
   - Training/education

2. Describe the effect of childhood AIDS on the social services system, including the following:
   - Delivery of services
   - Range of services delivered
   - New, innovative and expanded services
   - Staffing patterns, needs and problems
   - Interaction with other system components
   - Dealing with "families with AIDS"
   - Cost of services

- Future problems for social services
- Confidentiality issues
- Training/education

3. Examine the financial aspect of the childhood AIDS problem, including the following:
   - Sources of present funding
   - Changes in funding source patterns
   - Potential sources of future funding

C. Barriers

1. Discuss the barriers related to:
   - Delivery of health/medical services (B.I.)
   - Delivery of social services (B.2.)
   - Restrictions and/or limitations of finances (B.3)

D. Approaches/Strategies

1. Discuss, within the context of available resources, the means for overcoming barriers to:
   - Delivery of health/medical services (B.1)
   - Delivery of social services (B.2)

2. Discuss the needed resources to overcome barriers to:
   - Delivery of health/medical services (B.1)
   - Delivery of social services (B.2)

3. Outline present and future legislation which will impact on childhood AIDS, specifically on the following:
   - Delivery of health/medical services (B.1)
   - Delivery of social services (B.2)
   - Availability of finances (B.3)

E. The Future of AIDS in Children

1. Relate the range of projected number of AIDS cases to the following:
   - Hospital/medical services future impact (B.1)
   - Social services future impact (B.2)
   - Financial cost of future cases (B.3)

F. Suggestions for Additional Analysis

1. Outline the need for analysis of additional components and resources of the AIDS problem, including:
   - Role of religious and voluntary organizations
   - Role of the private sector

- Role of the community
- Effect on public health programs
- Educating children with AIDS

APPENDIX C. RESOURCE DOCUMENTS*

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* This resource list was utilized for background analysis and is not meant as an exhaustive bibliography of AIDS in children.

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APPENDIX D. LITERATURE REVIEW SUMMARIES

Author: N/A

Title: Confronting AIDS

Source, date: National Academy of Sciences, 1986

Categories: legislative; private; health care financing; cost

Location/Population: N/A

Summary:

Primary recommendations related to AIDS:

- pediatric AIDS will increase 10-fold to more than 3,000 cases by 1991 (p. 8)
- "AIDS units or teams should be established in high incidence areas (p. 19)
- infected children may reach adulthood and constitute a continuing reservoir of potential infection
- only one case of AIDS transferred through breast milk (p. 56)
- cost from diagnosis to death--$50,000 (p. 21)
- NYC: AIDS patients who are IV drug abusers may occupy more than 10% of municipal hospital beds (p. 22)
- $1 billion needed for education and prevention by 1990

Issues/Recommendations: N/A

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Author: N/A

Title: Specter of AIDS is No Respecter of Age

Source, date: National Association of Social Worker's News, September 1987, page 3.

Categories: Social services, family

Location/Population: N/A

Summary:

A family with AIDS is usually poor and hispanic at black. They are subject to an atmosphere of stigma and condemnation. Caring for children with AIDS requires multifaceted assistance to the entire family, including helping parents cope with denial, sorrow, guilt; mobilizing family support; making child custody arrangements; changing sexual behaviors to prevent transmission; and obtaining income support, medical care, and housing assistance. Services and education must be given in a culturally sensitive way to be effective. Poverty and drug abuse are major contributors to the spread of AIDS and must be addressed. Ignorance, fear and discrimination can block the delivery of services, once social workers can identify their own concerns they will be better able to help other professions.

Issues/Recommendations: N/A

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Author: G. R. Anderson

Title: Children and AIDS: Implications for Child Welfare

Source, date: Child Welfare LXIII(1):62-73, Jan.-Feb. 1984

Categories: foster care, welfare system

Location/Population: N/A

Summary:

Pediatric AIDS occurs predominantly in children of poor and minority families, where one or both parents are drug abusers. Problems in foster care placement have arisen from agencies' reluctance or refusal to place a child with AIDS and difficulty in finding parents willing to take a child with AIDS. The foster care agency must communicate accurately the nature of the illness without overly frightening potential foster parents, yet cannot falsely minimize the risks. Foster parents caring for a child with AIDS face special challenges:

- ostracism in obtaining needed services (dental, school, etc.)
- ostracism among friends and neighbors
- frequent visits to medical centers and managing medication regimen
- recurrent and serious medical crises, and potential loss of the child

Issues/Recommendations:

Child welfare agencies are caught between the legitimate needs to protect foster families and place children in need. Challenge for agencies to identify, train and intensively support foster parents.

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Author: M. Boland, M. Tasker, P. Evans and J. Keresztes

Title: Helping Children with AIDS: The role of the Child Welfare Worker

Source, date: Public Welfare, Winter 1987, p. 23-29

Categories: Social services, welfare system

Location/Population: N/A

Summary:

Children with AIDS and their families present challenges to human service agencies and the multiple problems produced by AIDS require a high degree of collaboration and cooperation among agencies, workers and families. 25% of children in Children's Hospital in Newark are already in foster care before AIDS is diagnosed. Foster care parents need special assistance. Agencies often refuse to provide services, and service workers in public and private companies often don't understand how AIDS is transmitted. Concealing the diagnosis may obtain service but does nothing to improve accessibility. Services needed include transportation, respite care, baby sitting, home care, help in obtaining benefits, emotional support and counseling, basic training and education for service workers, resource materials, recruitment and training for foster parents, use of consultants with expertise in Health care for AIDS children and support groups for workers and foster parents.

Issues/Recommendations: N/A

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Author: CDC

Title: Unexplained Immunodeficiency and Opportunistic Infections in Infants--New York, New Jersey, California

Source, date: MMWR, Dec. 17, 1982, 31:665-667

Categories: natural history/epidemiology; public health

Location/Population: N/A

Summary:

First reports of four infants (under two years of age) with unexplained cellular immunodeficiency and opportunistic infections. Three were minority (black/Hispanic/Haitian); one was white. Two of the infants had mothers with a history of prostitution. All four died. Report also notes studies underway on 18 other infants with immunodeficiency. Of nine mothers with histories known, seven are reported to be IV drug abusers.

Importance: First cases of AIDS in infants. Hooks in--minority--parents with drug abuse.

Issues/Recommendations: N/A

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Author: CDC

Title: Education and Foster Care of Children Infected With Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus

Source, date: MMWR August 30, 1985, 34:517-521

Categories: social services, legislative, education

Location/Population: N/A

Summary:

Recommendations for all children infected with the virus and/or with AIDS. Recommendations do not apply to siblings, unless they are infected. None of the cases of HIV infection have been transmitted in schools, day-care centers, foster care settings or person-to-person casual contact. HIV infected children could be at risk for infectious disease. Decisions regarding the type of educational and care setting for HIV infected children should be based on behavior, neurological development and physical condition of the child. Care of infected infants should be done by people trained in infection control.

Importance: Tie to school board recommendations--keeping kids out of school. No basis in fact.

Issues/Recommendations: N/A

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Author: CDC

Title: Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenogathy-Associated Virus and Acquired Immunodeficiency Syndrome

Source, date: MMWR, Dec. 6, 1985, 34:721-26, 731-32

Categories: natural history/epidemiology

Location/Population: N/A

Summary:

It is believed that HIV transmitted from infected mother to fetus or offspring during pregnancy, labor, delivery or shortly thereafter. 65 percent of infants born to infected mothers had HIV infections. High value!

Importance: 65 percent of infants born to infected mothers can be infected.

References:

International AIDS-Conference, April 14-17, 1985
Scott, G.B., JAMA 1985, 253:363-366

Issues/Recommendations: N/A

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Author: CDC

Title: Apparent Transmission of Human T-Lymphotropic Virus Type III/Lymphademopathy-Associated Virus from a Child to a Mother providing Health Care

Source, date: MMWR, Feb. 7, 1986, 35:76-9

Categories: natural history/epidemiology, medical services

Location/Population: N/A

Summary:

A 24-month old male child had transfusion related HIV infection and the mother had been infected while providing nursing care that involved unprotected exposure to the child's blood and body secretions and excretions. Drawing blood, cleaning ostomy bags (7 months), rectal tube insertion, changing nasogastric feeding tubes weekly. Never wore gloves. Many times, did not wash hands.

One other case known: a woman who cared for a Ghanian man with AIDS--eczema and cuts existed (Gring, P. Comm. Dis. Reports 1985, 42:4).

Importance: Only two cases. Both had high exposure to body fluids with no care or protection taken.

Issues/Recommendations: N/A

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Author: CDC

Title: Immunization of Children Infected with Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus

Source, date: MMWR September 26, 1986, 35:595-98, 603-06

Categories: public health, costs, natural history/epidemiology

Location/Population: N/A

Summary:

Goals of recommendations is to assist health care workers in developing policies for immunizing children with HIV infection. 50 percent of children with AIDS are diagnosed in the first year of life, and 82 percent by three years of age. 65 percent of pediatric cases are fatal.

Children born to women who are at risk of HIV infection or infected should be evaluated.

General recommendations: avoid live virus or live bacterial vaccines on AIDS or HIV infected. All others, follow ACIP.

Importance: High incidence of pediatric AIDS areas can have an effect on immunization coverage in the area.

Issues/Recommendations: N/A

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Author: CDC

Title: Acquired Immunodeficiency Syndrome (AIDS) Among Blacks & Hispanics--United States

Source, date: MMWR 1986, October 24, 35:655-58, 663-66

Categories: natural history, epidemiology; public health

Location/Population: New York, New Jersey, Florida

Summary:

58% of pediatric AIDS cases are among blacks and 22% among Hispanics. The incidence of pediatric AIDS is 15.1 (black) and 9.1 (Hispanic) as compared to whites. 73% of black cases and 70% of Hispanic cases live in New York, New Jersey or Florida. 51% of black pediatric AIDS cases and 31% of Hispanic cases had parents who abuse drugs

Issues/Recommendations:

Major problem in minority communities. 80% of pediatric cases among minorities.

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Author: CDC

Title: Update: Acquired Immune Deficiency Syndrome--U.S.

Source, date: MMWR Dec. 12, 1986, 35:757-66

Categories: natural history/epidemiology; education

Location/Population: school children; minorities

Summary:

Article includes information on pediatric AIDS: 57% black and 22% Hispanic. 79 percent of pediatric cases came from families in which one or both parents had AIDS **or** were at increased risk for developing AIDS. In addition, of pediatric cases: six percent had hemophilia and 13 percent had received blood.

Five to 15-year old children are 16 percent of the U.S. population, and are the main school population. 0.2 percent of total AIDS cases are in this category--a strong case against casual contact/mosquitoes. Also, 98% (61/62) of these cases are in an established risk category.

Issues/Recommendations:

Children with AIDS are in known risk categories

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Author: CDC

Title: Classification System for Human Immunodeficiency Virus (HIV) Infection in Children Under 13 Years of Age.

Source, date: MMWR April 24, 1987, 36(15):225-230

Categories: natural history/epidemiology; medical services

Location/Population: N/A

Summary:

Until publication of this article, no standard definitions for manifestations of HIV infections in children had been produced. Since passively transferred maternal HIV antibody can persist for up to 15 months in the child, two definitions of AIDS were defined--one for infants and children up to 15 months of age who have acquired the disease perinatally and another for older children with perinatal infections and children of all ages who acquired HIV through other means. An accompanying editorial states that the infected child is usually the first to be symptomatic and stresses the need to evaluate other members of the family--particularly the mother.

Importance: AIDS child may lead to mother/father or other siblings with AIDS, ARC or infection.

Issues/Recommendations: N/A

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Author: N. Halfon & L. Klee

Title: Health Services for California's Foster Children: Current Practices and Policy Recommendations

Source, date: Pediatrics 80(2):183-191, 1987

Categories: medical services, welfare system

Location/Population: California

Summary:

Study looked at health services to foster children in 14 counties in California. Services, were generally poorly organized, fragmented and did not guarantee delivery of appropriate health care. Study also describes the difficulties existing in obtaining and using Medicaid-reimbursed services. For example: In 1978, 98.2% pediatricians participated in Medicaid Programs 1983, 91.4%.

Issues/Recommendations:

1. Single health care provider should serve as case manager
2. Services should be capitated (per child allocation)
3. Dependent children should be exempt from limitations on physician and psychological services

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Author: Ann M. Hardy, K. Rauch, et. al.

Title: The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States

Source, date: JAMA 1986, 255:209-211

Categories: cost; health care financing

Location/Population: adults

Summary:

Analyzed first 10,000 cases of adult AIDS. Data obtained from New York City, Philadelphia, San Francisco.

10,000 patients

- spent 1.6 million days in hospital: $1.4 billion
- lost 8,387 years of work: $4.8 billion

Issue s/Recommendations:

Cost analysis of only hospital care = $140,000 per case. Children's costs may be higher: home care, longer hospital stays, foster care

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Author: David D. Ho, Roger J. Pomerantz & Joan C. Kaplan

Title: Pathogenesis of Infection with the Human Immunodeficiency Virus

Source, date: New England Journal of Medicine 317(5):278-286

Categories: natural history; medical services

Location/Population: N/A

Summary:

Ho et. al. offers an excellent, updated and comprehensive review of the mechanism of disease genesis by the Human Immunodeficiency virus. The primary clinical syndromes resulting from HIV infection are AIDS and AIDS dementia complex (also called subacute encephalitis and AIDS encephalopathy). The author's review of the literature demonstrates that approximately 60% of AIDS patients have neurologic symptoms, and 80-90% are found to have neuropathologic changes at necropsy. Subacute encephalitis is the most common neurologic problem in AIDS and is characterized by poor memory, inability to concentrate, apathy and psychomoter retardation. In addition, focal motor abnormalities and behavioral changes may occur, leading to a full-blown dementia complex.

The article also reviews the persistence of HIV, concluding that very little cell-free virus is found in infected persons and that less than 0.01% of circulating lymphocytes express detectable HIV messenger RNA. Thus, much of the HIV appears not to be susceptible to immune clearance!

Importance: Mothers of AIDS kids will be showing neurologic/psychologic problems. Will effect child care ability/stability of home/need for home care/additional breakup of family.

Issues/Recommendations: N/A

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Author: R. Horowitz and A. Davis

Title: Pediatric AIDS: Emerging Policies

Source, date: Children's Legal Rights Journal, Volume 7, No. 3

Categories: education, foster care, policies

Location/Population: N/A

Summary:

Guidelines regarding education have been established by NEA, CDC and AAP. All three recommend that only those most likely to infect others be excluded froin public school. NEA and CDC also have guidelines for foster care and day care. Many states have adopted policies on educational placement similar to CDC's and NEA's. A few have made sane significant changes (e.g., requiring notification of school system and department of health when a case is diagnosed). By 1985, nine states had enacted some form of AIDS legislation, a relatively small number deal with pediatric AIDS. Some legal challenges have arisen; the NY court decision upholding the cities policy to allow AIDS children to attend school is summarized. This is an important case since tne policy was modeled after CDC's recommendation.

Issues about public care of children with AIDS have not received as much attention. Although CDC's recommendations address day care and foster care, they recommend restricted day care for preschool AIDS victims, and screening high risk children in foster care of adoption agencies. Several state agencies' policies are described.

Issues/Recommendations:

- Foster and adoptive parents need to be aware of existence of AIDS to ensure proper medical care and precautions
- Agencies could be found liable if they fail to alert families
- CDC's guidelines are being widely accepted
- Welfare agencies seem to be recognizing the low level of risk of transmission and policies are reflecting this
- Policies are stressing public education and awareness

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Author: M. Jamieson & J. Campbell

Title: The St. Anthony Park Block Nurse Program

Source, date: American Journal of Public Health, 77(9):1227-1228, 1987

Categories: social services, medical services

Location/Population: Minnesota

Summary:

Report of a community based initiative--the cornerstone of a program is to enhance the ability of a family to meet the needs of its own members:

- block nurses: Public Health nurses who live in the neighborhood (provide professional nursing care)
- block companions: neighborhood residents who provide home aide and homemaker services
- block volunteers: neighbors trained to provide counseling and emotional support

Issues/Recommendations:

Plan focused to elderly, but could be applied to AIDS family problem.

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Author: J. Luehrs, E. Orlebeke, M. Marlis

Title: AIDS and Medicaid: The role of Medicaid in treating those with AIDS

Source, date: Public Welfare, Summer 1986, 9. 20-28

Categories: financing, costs

Location/Population: N/A

Summary:

Data on Medicaid costs are limited. Most cases are paid for by private insurance or Medicaid. Drug abusers are more likely to rely on public funding. The 1983 SSA directive; person with diagnosis of AIDS is presumed to be disabled, makes these persons eligible for Medicaid if they also meet income and resource standards for SSI. (Families on AFDC are automatically eligible for Medicaid). MI and MD have collected limited data on Medicaid expenditures. In MI, the average cost per patient was $52,230 with average of 20-month eligibility. In MD average was between $13,000 and $18,800 per patient with 8-month eligibility. MediCal (CA Medicaid) reported $59,000 average cost per patient. Costs can vary between high risk groups and the infections they are likely to have. San Francisco General Hospital's low costs of $25-32,000 per patient may be attributable to their comprehensive case management approach. Two types of Medicaid waivers may improve Medicaid coverage for AIDS patients: Freedom of choice waivers and home and community-based model waivers. Both require data showing cost savings of alternatives as compared to traditional hospital care.

Issues/Recommendations:

- Impact of AIDS on Medicaid costs is unclear
- As more IV drug users, their spouses and children become infected with AIDS, the Medicaid costs will rise and will impact on state budgets
- States may need to use wavier programs more extensively to provide alternative, cost-reduced care

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Author: Terence Monmaney

Title: Kids With AIDS

Source, date: Newsweek, September 7, 1987, p. 51-59

Categories: Social services, medical care, foster care

Location/Population: New York

Summary:

Celeste Carrion, age 9 and brother both have AIDS. Mother died of AIDS and the father also has AIDS. The children now live with their grandmother. They represent the typical pediatric AIDS case--poor, hispanic (or black), and drug addicted parent(s) who also have AIDS. Dr. James Okeske, from College of Medicine and Dentistry of New Jersey estimates that the number of pediatric AIDS cases could reach 20,000 by 1991. In New York, an estimated 1,000 HIV-infected babies will be born this year. In the past year there have been nine cases in New York in whicl neither parent abused drugs but the mother's former lover did, an indication that the problem could move into the heterosexual non drug abusing population.

Those dealing with pediatric AIDS predict that the system cannot handle the problem; there has been resistance among health care professionals to provide services, and the general public is overreacting with fear. Money is needed for medical research, treatment and foster care.

About half of the babies born to AIDS-infected mothers have been infected; symptoms often don't appear for 3-4 months. Early treatment is important because AIDS tends to cause bacterial infections and babies can die from the infection very quickly. Some doctors use gamma globulin treatment; others are skeptical of its success relative to its expense--about $18,000 per patient per year. Another experimental drug, AZT, is currently being tested in 30 children. The Einstein College of Medicine in New York and the Newark Children's Hospital see many pediatric AIDS cases and sue multidisciplinary support teams to treat the many medical needs of the patients, including psychologists, physical therapists, speech specialists, and counselors. Counseling the family is as important as treating the child.

Issues/Recomendations: N/A

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Author: S. Pahwa, M. Kaplan, et. al

Title: Spectrum of Human T-Cell Lymphotrophic Virus Type III Infection in Children

Source, date: JAMA 1986, 255:2299-2305

Categories: medical services; natural history/epiderniology

Location/Population: New York (Nassua County & Brooklyn)/Children

Summary:

This article reviews the spectrum of diseases and symptomology related to pediatric AIDS, including: opportunistic infections, bacterial infections; pneumonitis malignancies and neurologic abnormalities. The author followed up 29 children with AIDS for up to 20 months. Eleven out of 29 died and nine out of 20 mothers of these children had either ARC or AIDS. In addition, the authors found five AIDS children with severe neuropathy.

Issues/Recommendations:

Children have many infections and diseases related to AIDS. Children may be surviving longer than adults. Mothers have the disease 45%.

Management of neuropathies very expensive

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Author: K.H. Pyum, H.D. Ochs, et. al.

Title: Perinatal Infection with Immunodeficiency Virus

Source, date: New England Journal of Medicine 317(10):GII-GI4, 1987

Categories: medical

Location/Population: one child

Summary:

1. Transmission of HIV can occur prenatally, perinatally, postnatally (via breast milk). This in-depth immunologic study on a newborn clearly demonstrated a perinatal source infection.
2. Article references nine 65-95% transmission to infants (JAMA, 1985, 253:363-6; Lancet, 1985, 2:1018)

Issues/Recommendations:

Transmission to infants may occur primarily perinatally. Does this mean that Caesarean sections, as with herpes, are to be recommended? What are costs and risks?

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Author: N. Ralph, C. Spigner

Title: Contraceptive Practices Among Female Heroin Addicts

Source, date: American Journal of Public Health 1986, 76 (8) :1016-1017

Categories: natural history/epidemiology

Location/Population: Women

Summary:

The authors review information known about female addicts: (1) 10,000 babies are born to IV drug using women per year, (2) most IV drug abusing women (26%) used any type of contraception of the 26%, only 6% used foam or condoms. Thus, less than 2% used an effective barrier method.

Issues/Recommendations:

Can calculate potential pool of infected babies:

1. 5 women IV drug abusers infected: 501
2. chance of-transferring to baby: 33%
   - 10,000 babies born per year to IV drug abusing women
   - 5,000 babies born per year to infected mothers
   - 1,650 babies born per year infected with AIDS virus
   - 1,650 x 5 8,250 cumulative from 1987-1990

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Author: A.A. Scitovsky & D. P. Rice

Title: Estimate of the Direct and Indirect Cost of Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991.

Source, date: Public Health Reports, 1987, 102(l):5-17

Categories: cost, health care financing

Location/Population: adult

Summary:

Personal medical costs estimated at $630 million (1985), $1.1 billion (1986) and $8.5 billion in 1991.

Nonpersonal costs (research, testing, education, support services $319 million (1985), $542 million (1986) to $2.3 billion in 1991.

Loss of productivity (premature mortality) $3.9 billion (1985), $7 billion (1986) to $55.6 billion in 1991.

Offer a very useful formula:

$$\text{Cost} = N_{(\text{total cases above}} \times [(a \times b \times c) + d]$$

a = admissions/case
b = # hospital days per admission
c = change/hospital day
d = outpatient charge per case

Issues/Recommendations:

Overall, cost is estimated at $66 billion in 1991. The subcost for children with AIDS must be higher, as (1) hospital stays are longer, (2) loss of productivity is greater.

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Author: A.A. Scitovsky, M. Cline, P.R. Lee

Title: Medical Costs of Patients with AIDS in San Francisco

Source, date: JAMA 1986 256(22):3103-3106

Categories: cost, health care financing

Location/Population: adult, San Francisco

Summary:

Group calculates direct inpatient care for adult gay men in San Francisco General Hospital to be $27,571 from diagnosis to death (224 days on average). Number of hospital admissions, 3.2, days in hospital per admission was 34.7

Issues/Recommendations:

Estimates for direct cost for children can be expected to be higher, as children live longer, and stay in the hospital longer.

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Author: G.B. Scott, M.A. Fischl, et. al.

Title: Mothers of Infants with Acquired Immunodeficiency Syndrome

Source, date: JAMA 1985 253:363-366

Categories: public health; natural history/epidemiology

Location/Population: Florida/mothers

Summary:

Group studied the mothers of 16 infants with AIDS. Fifteen out of 16 mothers were symptom free at the time of their child's births. Five mothers developed AIDS, seven developed ARC. Vius, 81 % were (1) , or became (12) sick.

Issues/Recommendations:

The mother of an infant with AIDS is at increased risk for development of AIDS or ARC. Effects foster care, home care, etc.

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Author: P. Thomas, H. Jaffe, et. al.

Title: Unexplained Immunodeficiency in Children

Source, date: JAMA 1984, 252:639-644

Categories: public health; natural history

Location/Population: children

Summary:

This was one of the first publications linking AIDS to infants. The data is limited because it was before testing was available for AIDS antibody. The key finding is that a high proportion of infants were premature--38% (10/26).

Issues/Recommendations:

38 percent of AIDS infants were premature--added burden on the Public Health System.

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Author: Arthur Beau White, Ph.D.

Title: Intravenous Drug Abuse and Pediatric AIDS

Source, date: August 8, 1987, unpublished

Categories: drug abuse, clinical

Location/Population: Newark, NJ

Summary:

The article reviews the clinical description of AIDS and its pathogenesis and transmission. New Jersey ranks 5th in the number of AIDS cases; the vast majority of which are located in the Newark area. The most typical AIDS patients in this area are IV drug abusers. It is estimated that among the 35,000 IV drug abuser populations, two out of three are HIV infected. Their sexual partners and offspring are at high risk of becoming infected. Infants are also at high risk for low birth weight, drug withdrawal and environmental and emotional deprivation. The median age of onset of AIDS is six months; very few survive over an extended period of time. Educating high risk women is important and presents a challenge.

Issues/Recommendations: N/A

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APPENDIX E. ORGANIZATIONS CONTACTED

National Associations

- National Coalition of Hispanic Health and Human Services Organizations
- Child Welfare League of America
- Children's Defense Fund
- National Urban League
- Council of Churches--Minority Task Force on AIDS
- National Association of Children's Hospitals and Related Institutions
- American Public Welfare Association
- National Association of Social Workers
- American Academy of Pediatrics
- National Governor's Association
- National AIDS Network
- National Conference of Puerto Rican Women
- National Hemophilia Foundation

Federal

- Office of Minority Health (OASH)
- Maternal and Child Health (HRSA)
- Children's Bureau
- Office of AIDS Programs (HRSA)

Legislative

- Senator Arlen Specter's Office
- Select Committee on Children, Youth and Families
- Senator Metzenbaum's Office
- Representative Rangells Office--Select Committee on Narcotics Abuse and Control

APPENDIX F. TELEPHONE DISCUSSION SUMMARIES

Summary--Social Service/Welfare/Professional Organizations

Activities of national organizations regarding children with AIDS range from information dissemination and policy statements to holding conferences and creating task forces to deal with the issues.

Major issues identified by these contacts included:

- Cities/states denial of the problem (not affected yet)
- Need for education
- Affects all aspects of child welfare system
- Problem with professional and public attitudes
- Funding problems
- Resources for treatment are scarce
- Finding appropriate services is difficult
- Many of the barriers/problems already existed; AIDS exacerbates these problems
- Already from fragile home environment
- Adolescent issues
- Medicaid
  - processing can take from 45-90 days
  - service coverage (waiver programs)
  - how pediatric AIDS will impact on Medicaid as a whole
  - lack of providers

Specific activities undertaken by these groups are summarized below:

<u>Child Welfare League of America (CWLA)</u>

- June 1987 conference
- 50 person task force to deal with:
  - the disease
  - agency/administrative policies
  - program procedures
  - public policy implication
- Reports motivation and interest in the problem among their membership, cites need for education

National Association of Social Workers (NASW)

- Very active with general AIDS issue
- Has policy statement regarding AIDS in schools
- September annual conference--several presentations related to AIDS

American Public Welfare Association (APWA)

- 1986 conference for state and local child welfare administrators regarding policy implications of AIDS

Childrens Defense Fund (CDF)

- Not taking active lobby role now--"monitoring" the issue
- Not a priority, but prepared to deal with issues as they relate to their other activities

National Association of Childrens Hospitals and Related Institutions (NACHRI)

- Monitoring issue--information dissemination to members
- Testified at Moynihan's hearings
- Feels that hospitals are able to absorb problem now

National Governors Association (NGA)

- Has policy positions regarding AIDS in general
- Concentrating on disseminating information to members (AIDS in general)
- Preparing issues briefs for state Medicaid administrators
- Feels that any policy alternatives to deal with AIDS must be evaluated for how they will affect the system as a whole (e.g., Medicaid)

American Academy of Pediatrics

- AIDS Task Force initially charged to focus on (1) infection prevention in maternal and delivery care units, and (2) infection control in office/clinic/health care settings.
- Work group reports from Surgeon General's conference will be used to publish summaries in the AAP newsletter with editorials from committee members.
- Major issues or barriers identified include guidelines for adoption, funding for disability and confidentiality
- AIDS problems are new; it is universally fatal, has stigma attached to it and is venereally transmitted.

Summary--Congressional Staff

A number of different bills have been introduced in both the House and Senate, some specific to children with AIDS and some in response to the AIDS problem in general with provisions that would impact on children with AIDS. There have also been several different hearings held.

A variety of issues were identified by the Senate, Representative and Committee staff contacted. These included:

- Problems with Medicare/Medicaid processing
- Fragmented services, lack of coordination between social services and health care
- Future impact on Medicaid--AIDS is a high cost category--how will this impact on basic health care covered by Medicaid?
- Payment demands (nonreimbursed care)
- Array of services required
- Limited understanding of the disease--difficult to predict future needs
- These children are not only medically fragile, but already part of an impoverished, minority, population.
- Problems encountered are old problems/pitfalls in the system--AIDS simply exacerbates and brings to the forefront these problems.

Summary--Minority and AIDS Service Organizations

The National Urban League felt that the public knows little or nothing about the pediatric AIDS problem and that there is very little information being disseminated to the general public. Minority organizations need resources--specifically dollars--for launching an information/education effort through their affiliated chapters. In addition, it was felt that the Federal Government should provide leadership in this area because of its potential magnitude. An invitation was extended to visit the local affiliates in New York, Newark and Miami during the site analysis phase of the project.

The Minority Task Force on AIDS of the Council of Churches, City of New York is fully involved in delivery of services to AIDS families. There is a strong desire to maintain family structure during the management of AIDS in families. Suggestions were made for welfare reform to allow case management for the family, as opposed to individuals. An "AIDS Care Corps" was recommended along the lines of the Peace Corps. The Corps would be federally operated and fund local personnel to act as homemakers, counselors, companions, and surrogate parents to AIDS families. The primary reason for federal management of the program is to bypass the union limitations and job categories which presently exist at the local level. In addition, the present system of support to AIDS families cannot be sustained by volunteers for an indefinite time period. Other suggestions included:

1. Need to allow cross-race adoption
2. Need to work with and support women coming out of prison
3. Need specially allocated funds for providing appropriate nutrition and food preparation training to women
4. Need to make telephone service a necessity
5. Need allowances for travel--hospital, day care, etc.

The National Conference of Puerto Rican Women is in the planning stages for an adolescent pregnancy media campaign. They have been asked by the federal contractor to add in information about AIDS and pediatric AIDS. The organization felt very strongly that there is a great need for AIDS awareness to at risk females and their partners: at hangouts, methadone programs and via specialized media. In addition, there is not enough foster care services for children with AIDS.

COSSSMHO, an Hispanic coordinating organization noted that they are part of an advisory group for the Ford Foundation for analyzing the pediatric AIDS problem into the year 2000. The group has made projections, but no information can be released until the Ford Foundation Board of Trustees reviews and approves the material. However, site visits to organizations and facilities working on the pediatric AIDS problem has led the group to appreciate the fact that pediatric AIDS is a family issue, and that the health care system is very sympathetic to AIDS babies, but not to their HIV infected, or AIDS parents. COSSMHO believes that the system has generally not reached the groups at highest risk for health related problems--AIDS only magnifies the problem COSSMHO feels that there should be greater work with child abuse and sexual abuse groups as well as with the Justice Department which has, and funds, major outreach projects.

Summary--Federal Agencies

The Office of Minority Health of the Office of the Assistant Secretary for Health felt that finances were the critical issue related to pediatric AIDS. Pediatric AIDS also demonstrates major geographic differences, such that cities like New York will, face severe fiscal crises, including hospital closings and hospitals picking and choosing AIDS patients. Pediatric AIDS is a minority problem. It compounds the many other health related problems already facing this group. Pediatric AIDS will have many more survivors than with adult AIDS, most will be unprovided for. A recommendation was made to review and refer to Secretary Heckler's Report on Minority Health to appreciate the impact of other major health problems on the minority communities of the United States.

Health Resources and Services Administration has focused its activities on planning and holding AIDS meetings for constituency groups, specifically, AAP and ACOG. The Surgeon General's "Workshop on Children with HIV Infection and their Families" (April 6-9, 1987) offered a series of recommendations. Several of the key points are:

1. Need ongoing education and training of health professionals
2. The education efforts should not be a "one shot" activity, need ongoing repetitive efforts, which happen to be very manpower dependent (labor intensive).

HRSA outlined four areas of importance in pediatric AIDS:

1. The need for early detection for high risk women. Women should be provided the opportunity for confidential testing.
2. There is a need to assist school communities in creating policies for dealing with AIDS.
3. Must work out strategies for dealing with adolescents.
4. Look into the New Jersey program for dealing with boarder babies, specifically the use and funding of group homes.

APPENDIX G. DISCUSSION GUIDE

1. Nature and extent of involvement with AIDS children

   Probes:
   - direct care, e.g., medical, foster care placement
   - policy level
   - administration
   - research
   - portion of time spent
   - how long in this role

2. Number of AIDS children

   Probes:
   - stage of illness
   - demographics for locality/city/state/national
   - estimates for the future
   - how they are identified/reported

3. Approach to caring for AIDS children

   Probes:
   - identification
   - medical care
     - inpatient
     - outpatient
   - physician's role
   - case management
   - social services
   - foster care placement
   - day care
   - group home care
   - in-home care
   - referrals
   - confidentiality
   - services
   - transportation

4. Recruitment of caregivers

   Probes:
   - availability
   - training
   - incentives

5. Hospital/non hospital costs associated with caring for AIDS children
   - per day
   - lifetime
   - foster care parents
   - additional staff training
   - additional support/counseling for foster care parents

6. Financing care

   Probes:
   - private insurance
   - Medicaid
   - Medicare
   - Title IV-E
   - AFDC
   - hospital
   - local
   - other

7. Issues/barriers to caring for AIDS children

8. Recommendations for improved care/alternative forms of care

9. Appropriate role for Federal, State and local governments, and private/religious organizations

10. State/local legislation dealing with the issues of AIDS children
    - Bill name/number/sponsor
    - description/comments

11. School policies

12. Prevention efforts

APPENDIX H. SITE VISIT INTERVIEWEES

New York City

Harlem Hospital, Manhattan
Margaret Heagarty, M.D.
Elaine Abrams, M.D.

Einstein Medical School/Center, Bronx
Ms. Toni Cabat, M.S.W.

SUNY Downstate/Kings County Medical Center, Brooklyn
Senih Fikrig, M.D.
Joan H. Hittelman, Ph.D.
Herman Mendez, M.D.
Ann Sunderland, M.S.W.

DHHS Region II Office
Ms. Carolyn A. Woodard, Regional Administrator
Mr. Dennis J. Coughlin, Regional Program Director
Ms. Elaine D. Williams, Deputy Regional Administrator

New York City Personnel
Stephen Joseph, M.D., Deputy Commissioner of Health
Mr. Clarence Gadsden, Deputy Commissioner for Community Services
Pauline Thomas, M.D., Director of AIDS Surveillance
Betsy Mayberry, M.S.W. Director of Special Services for Children

State of New York Division of Substance Abuse
Don Des Jarlais, Ph.D.

Hale House, Hale House Cradle
Lorraine Hale, Ph.D., President and Chief Operating Officer

Leake and Watts Children's Home
Phyllis Gurdin, M.S.W., C.S.W.

Newark/Jersey City/Trenton, New Jersey

Children's Hospital of New Jersey, Newark
James Oleske, M.D.
Mary G. Boland, R.N., P.N.P.
Mary Soituner, M.S.W.
Patricia Evans, M.S.W.

Jersey City Medical Center Pediatrics Unit
Sophie Pierog, M.D.
Oradee Chandavasu, M.D.
Renuka Nigan, M.D.
Mariann Moore, M.S.W.
Mr. Bill White, Administrator
Ms. Maria Ramirez

Community Health Care of North Jersey
Elaine Lugovoy, R.N., M.A.
Lynn Czarniecki, R.N., M.S.N.

State of New Jersey Pediatric AIDS Committee
Ms. Sue Dondiego, New Jersey Foster Parents' Association
Mr. Ted Allen, New Jersey State Central Region Administration
Mr. Marc Cherna, State of New Jersey Division of Youth and Family Services
Lourdes M. Frau, M.D., New Jersey Department of Health
Ms. Joyce Jackson, Now Jersey Department of Health
Ms. Constance Ryan, Now Jersey Department of Health
Ms. Jane DeMaio, New Jersey Department of Education
Karl Manger, M.A., Hyacinth Foundation
Alison Schwartz, M.P.H., Hyacinth Foundation
Steven Young, M.S.P.H., Now Jersey Department of Health

St. Claire's Home for Children, Elizabeth
Terrance Zealand, Ph.D.
Ms. Faye Zealand
Sister Joy Yokoyama
Ann Marie Sheridan, R.N.C., B.S.N.

Florida

State Personnel
Jeanne Easton, A.P.N.P., AIDS Program Manager for Dade County
Barbara K. Loyd, Florida State Contracts Office

Health Crisis Network
Sally Dodds, A.C.S.W., Executive Director,

South Florida AIDS Network
Philip Plummer, M.S.W.

Jackson Memorial Hospital
Gwendolyn Scott, M.D.
Jeffrey Seibert, Ph.D.
Ana Garcia
Ginnette DeGraff, R.N.

Children's Home Society
Mary Louise Cole, Ph.D.
Sema Coppersmith, M.S.W.

Health Council of South Florida
Lawrence Mack

APPENDIX I. SITE VISIT SUMMARIES

A. New York City

The New York City site visit took place from October 26-29, 1987. The site team included Mr. Martin Kotler, Dr. Stephen Margolis and Ms. Lela Baughman of MACRO and Mr. Jerry Silverman of ASPE.

1. Organizations Visited

Three hospitals/medical centers, in three boroughs of New York were visited, including Harlem Hospital in Manhattan, Einstein medical School/Center in the Bronx and SUNY Downstate/Kings County Medical Center in Brooklyn. Ninety-six percent of New York City's AIDS or AIDS related illnesses in children are managed by these units.

The Regional Administrator and staff members of the DHHS Region II Office were interviewed because of their interest in the "boarder baby" problem related to AIDS. The staff had prepared a report on "boarder babies" in New York and New Jersey.

New York City personnel interviewed included the Commissioner of Health, the Deputy Commissioner for Community Services, the Director of AIDS Surveillance, and the Director of Special Services for Children.

Staff of the State of New York Division of Substance Abuse were interviewed because approximately 79 percent of children with AIDS are related to a parent who is an IV drug abuser (AIDS Surveillance Update).

The President and Chief Operating officer of Hale House and Hale House Cradle, a home for totally abandoned or temporarily placed children and infants was visited. in addition, the Leake and Watt's Children's Home, which places children in foster care was interviewed by telephone.

2. Magnitude of the Problem

As of September 30, 1987, the City of New York reported a total of 221 cases of AIDS in children, according to the official CDC case definition, of which 161 cases, 73 percent had died by the reporting date. Seventy-nine percent of the cases were the probable result of maternal transmission where one or both parents were IV drug abusers, or the mother was a former sex partner of an IV drug abuser. 59 percent of mothers of pediatric AIDS cases are black, 32 percent Hispanic and nine percent are white.

The City of New York does not routinely perform HIV antibody tests on pregnant women or neonates. All available HIV antibody seropositivity information were from small-scale studies currently in progress. According to the AIDS Surveillance Unit, there have been approximately 500 case of AIDS Related Complex (ARC) and a "guesstimate" of 2,000 seropositive infants and children, cumulatively. In addition, the reporting system in place in New York City has been checked and found to match in 94 percent of reported cases. Many studies are being developed, or have begun that will increase the database related to children with HIV infection, ARC or AIDS in New York.

In a pilot, prospective prenatal care study with seropositive, pregnant women, only nine percent chose to terminate their pregnancy after counseling efforts. Only two measles related deaths in children with AIDS who have been immunized with live virus vaccines have been noted.

The City of New York has approximately a total of 18,500 children in foster care placement. There are approximately 100 ARC/AIDS children in foster care of which 14 died during the last year. During September, 1987, 35 infants and children with HIV infection, ARC or AIDS who were medically ready for discharge from a hospital were still in residence or "boarder babies." This represents 80 percent of all boarder babies in New York City.

Predictions have been made concerning the future magnitude of the pediatric HIV/ARC/AIDS problem for New York City. The CDC predicts that by 1991 there will be a cumulative total of 3,000 officially defined pediatric AIDS cases in the United States, approximately 1,000 of which will be in New York. The Health Department of the city of New York predicts approximately 10,000 cumulative pediatric HIV/ARC/AIDS cases in the United States. The State of New York Substance Abuse Agency predicts that approximately 2,000 HIV/ARC/AIDS children will be born to IV drug abusing mothers by 1991. This projection is based upon 50,000 IV drug abusing women and 100,000 sexual partners of IV drug abusers in New York City.

3. Description and Response of the System

Children with AIDS, ARC or who are HIV antibody seropositive in New York City are first managed by one of the major hospital centers. The types of services offered to both the children and their parents is a function of the staff and resources of the hospital.

Harlem Hospital. The Harlem Hospital pediatrics unit has a dedicated Chief of Pediatrics and an AIDS team composed of one physician for six to eight hospitalized HIV infected children. Harlem Hospital is dependent on tax levy funds and is underfunded, and this has led to periodic shortages in necessary pharmaceuticals. In addition, it has been very difficult to fill open positions for nurses and social workers.

The pediatric unit has 60 beds, and cumulatively, 60 HIV infected children have been managed on the unit since 1982. The maximum number of HIV infected children on the unit at any one time has been 12.

An analysis of the cost for caring for 37 children with HIV infection since 1982, has been $3,362,596, of which 30 percent of the hospital days and 20 percent of the cost have been estimated as unnecessary for medical reasons. The per diem ranged from $300 to $2,400, with an average of $500.

The staff has not been able to plan for increases in HIV infected children or increases in boarder babies expected over the next four years. The Harlem Hospital AIDS Unit has attracted a lot of recent national attention, including a visit by the Administrator of HCFA and the Surgeon General of the United States.

Harlem Hospital, serving one of the poorest and most heavily drug infected areas in the country, has limited resources to apply to pediatric AIDS. In addition to lack of funds, difficulty in recruiting personnel, the complexity and intricacies of coordinating Medicaid, AFDC, SSI and other financial support programs pose serious obstacles to appropriate care and availability of social support for the children and families in desperate need. For example, the bureaucratic intricacies in providing appropriate support for a grandmother to care for an AIDS infected youngster could not be surmounted, and the child has remained in the hospital for over two years. This unfortunate outcome occurred despite pleas made by the Chief of Pediatrics to high placed city, regional and Federal officials. One official returned to Harlem Hospital with $191 and a box of used toys that were the result of a collection taken up by office personnel in lieu of an ability to generate and make the system responsive to obvious patient and family needs.

Albert Einstein Medical School. The Albert Einstein Medical School/Center complex handles 34 percent of New York City's HIV infected children. There are four hospitals, geographically dispersed within the Bronx, that are involved in the Einstein consortium: Montefiore Hospital, Einstein College Hospital, Jacobi Hospital and North Central Bronx Hospital. Each hospital has different medical specializations and children/infants in need of hospitalization are placed in the appropriate facility.

The Einstein consortium has two major AIDS pediatric immunology grants from NIH which allow HIV infected children/infants to be enrolled in either an immunoglobin therapy study or a perinatal transmission study. They also receive funding from the State, and a Robert Wood Johnson Grant for Comprehensive Family Care. Physician, nurse and social worker positions are covered by the funding sources for the studies and for relevant service delivery.

Approximately 300 seropositive children/infants are presently enrolled in the immunoglobin therapy study on an outpatient basis, of which approximately 30 symptomatic children require short stay admissions on a biweekly basis. Today, if a child/infant is HIV seropositive, a nurse and social worker can evaluate the home

situation. In addition, there is an AIDS pediatric hotline and specialized service delivery components available to families and their HIV infected children.

In 1984 there were four to six ARC/AIDS boarder babies, but all of them have since been placed in foster care.

The Einstein staff opposes the use of group/congregate care facilities. Their feeling is that foster care, with the easing of extended family member eligibility, and additional respite care and specialized day care for working foster parents could handle the boarder baby problem. They are also concerned that group care will increase the likelihood of transmission of opportunistic infection among AIDS infected infants.

The staff has planned for the projected increases in HIV infected children or boarder babies over the next four years.

SUNY Downstate Kings County. The SUNY Downstate/Kings County complex has managed 110 pediatric HIV infected children since 1981, of which 44 have died. Children are admitted to either the King County Hospital or the Downstate medical Center. There are three to four children hospitalized at any one time; however, there have been as many as eight to nine hospitalized. There has been a total of seven boarder babies. Daily costs are $552 per day.

The SUNY Downstate/Kings County group have major pediatric AIDS research grants which allows the staffing and servicing of their HIV infected children. A study carried out at the medical center revealed that 2 percent of the pregnant women coming for prenatal care are HIV seropositive, and 58 percent of those infected admitted or knew of any involvement in high risk behavior.

Another study of 28 ARC/AIDS infants, demonstrated that 27 had neurological deficits and 85 percent failed to thrive. The staff has not planned for the projected increases in the number of HIV infected children, or increase in boarder babies over the next four years. There was a general feeling on the part of the SUNY Downstate/Kings County Staff that voluntary child service agencies and New York City agencies were not actively and vigorously dealing with HIV infected, ARC or AIDS children, and that this needed to be corrected. In addition, there have been breeches of confidentiality within these agencies.

The group felt that there was a need for use of extended family members and community members as foster care parents and that there was a need for a day care/respite facility near the medical complex. The staff strongly opposes the use of congregate care homes.

Foster Care Services. The City of New York has approximately 18,500 children in foster care placement. There are approximately 100 ARC/AIDS children in foster care of which 14 died during the last year. The majority of HIV positive children in foster care were placed before their seropositivity was known. During September, 1987, 35 infants

and children with HIV infection, ARC or AIDS who were medically ready for discharge from a hospital were still in residence or 'boarder babies." This represents 80 percent of all boarder babies in New York City.

Foster care is handled by New York City's Special Services for Children (SSC). SSC contracts with a number of agencies to assist in foster care placement. The primary agencies for foster care placement of children with AIDS are the Leake and Watts Children's Home, New York Foundling home, and the Archdiocese of New York. New York City has authorized the payment of $1,134 per month to foster parents of HIV seropositive children. This compares to the regular rate of $165-$342 per month depending upon age, and the special rate for special needs children (handicaps, boarder babies, other hard-to-place) of $748/month. There are additional allowances for clothing and other miscellaneous expenses which are determined on a per child basis by the contracting agency.

Two draft documents have been promulgated related to foster care for HIV infected children, namely: "New York City HIV Testing Policy for Foster Boarding Home Children" and the "Department of Health Protocol for Implementing HIV Testing: Policy For Foster Boarding Home Children." These policies mandate a training requirement for foster parents of HIV seropositive children; define a stringent mechanism for testing of foster children; outline the appropriate confidentiality issues related to testing; and ensure that seropositive children will be retested every three months.

The SSC is in the process of putting into place alternate models for managing families with AIDS, namely: recruiting homemakers for assignment to AIDS families; and creating congregate shelters for AIDS families. The City of New York is handling social service costs related to HIV infected children, but would like to see changes in New York State Medicaid reimbursement, homemaker services and foster care funding.

The Leake and Watts Children's Home has created a special division to handle foster care placement of HIV infected children. Twenty-four infected children have been placed in a 24-month period. The agency was originally utilized by the Einstein consortium, but is now under contract to New York City's SSC. It receives a stipend of $100/day/child from SSC for administrative activities. Each foster parent of a symptomatic HIV infected child receives $1,134/month which is a pass through from SSC. The agency determines an additional stipend ranging from $400-$800 per month for special needs and the placement of a home helper, under special circumstances. This comes out of the agencies' administrative reimbursements. The agency social workers dealing with HIV infected children are paid an additional $3,000 per year. Leake and Watts have been able to find people who are interested in becoming foster parents. Their best source has been referral from families who already are foster parents.

Hale House and the newly formed Hale House Cradle are designed as temporary homes for women and their children, or for the temporary housing of infants and children while the mothers are in drug treatment, incarcerated or recuperating. Mother Hale and her daughter Dr. Lorraine Hale are opposed to foster care because of a study

showing the 60 percent of the studied children were sexually abused in foster homes. SSC funds Hale House at a rate of $161/day/child to manage up to 15 children, although they always have 20 children in residence. The children range from newborn to three years of age and there are four HIV infected children in residence. Hale House does not lack finances or personnel, but it is desperately lacking an appropriate facility for future activities.

B. Newark/Jersey City/Trenton

The New Jersey visit took place on November 2 and 3, 1987 Ms. Lela Baughman and Dr. Stephen Margolis conducted the site visit.

1. Organizations Visited

Two hospitals in two major New Jersey cities were visited, including Children's Hospital of New Jersey in Newark and the Pediatrics Unit of the Jersey City Medical Center. In addition, interviews were conducted with personnel from the Community Health Care of North Jersey, a visiting nurse service which works very closely with the Children's Hospital of New Jersey and carries out home care management of HIV infected children.

The State of New Jersey has a pediatric AIDS committee that deals with social service, foster care and funding issues. The committee has the following membership who were interviewed: New Jersey Foster Parents Association; New Jersey State Central Region Administration; State of New Jersey Division of Youth and Family Services; the New Jersey Department of Health; the New Jersey Department of Education; and the Hyaninth Foundation.

The St. Claire's Home for Children in Elizabeth, New Jersey is a five child group home for HIV infected children. In addition, the organization operates the AIDS Resource Foundation for Children, in Newark, New Jersey. The personnel were interviewed at the Elizabeth facility.

2. Magnitude of the Problem

New Jersey, as of October 1, 1987, had 84 officially reported cases of AIDS in children. Seventy-five, or 89 percent of the pediatric AIDS cases were from a parent with, or at risk for AIDS. Sixty-two percent of the pediatric cases are black, 20 percent are Hispanic and 12 percent are white. The State of New Jersey is readjusting its reporting system to account for the expanded CDC AIDS definition and a review of the State's ARC registry, which contains approximately 3,000 adult and pediatric cases. As the State AIDS surveillance report concludes: "Because of the combined influence of these factors, predictions of trends are now extremely unreliable. When things settle down, we can estimate that there will be 50 percent more AIDS cases reported in any given time period than under the old definition. As we gather more data, we will be

better able to expand our monthly surveillance reports to reflect the impact of the new changes."

There are 102 children with HIV infection, ARC or AIDS known to the Division of Youth and Family Services. Twenty-two are in foster care, 62 at home, 12 in the hospital, five in a group home and one is missing or unknown.

The personnel of the Children's Hospital of New Jersey in Newark, calculate that there have been between 150-200 children with AIDS, ARC or symptomatic HIV infection treated at Children's hospital since 1981. The hospital is following 96 children, of whom 62 percent are black, two percent are of Haitian descent, 16 percent are Hispanic and 20 percent are white. Ninety percent of the 96 children had mothers who were IV drug abusers or sexual contacts to men at risk for AIDS. At any one time, 12-20 of the children from Newark with ARC or AIDS are managed by the visiting nurse service. The Jersey City Medical Center, the other primary management facility for HIV infected children, has registered 20 children with AIDS, of which three have died.

3. Description and Response of the System

Children's Hospital of New Jersey. A great majority of AIDS patients in the Essex County area are handled by the Children's Hospital of New Jersey in Newark. The pediatric AIDS team of the Children's Hospital is composed of a pediatrician, a research nurse, a social worker, an administrative assistant and the visiting nurse service liaison.

The Newark hospital has a major AIDS treatment grant from the NIH, which supports the staffing of the unit.

There is no HIV testing at the primary delivery hospital, University Hospital, thus children are made known to Children's Hospital, mainly when they become symptomatic. Although Children's has seen between 150 and 200 children with HIV infection since the epidemic began, they are currently managing 90 children and others are being managed by other facilities in the city. Five of the 90 children are HIV antibody positive and 85 have either ARC or AIDS and there have been 34 deaths (35 percent). Fifty-five of 60 children with ARC or AIDS were shown to have developmental disabilities.

The Children's Hospital Pediatric AIDS team has a very close working relationship with the Division of Youth and Family Services and the visiting nurse service, which allows for the coordination of medical and social services. In general children have rarely been abandoned (only 2-3 occasions), most stay with parent(s) or, if the parents are sick, then with extended family. There is need for an intermediate care facility, specifically a group home for mothers and their babies in need of medical care. In addition, the present pediatric facility at Children's Hospital is not large enough for the delivery of services.

The Community Health Care of North Jersey, the visiting nurse service, carries out an initial home visit with a hospital social worker to evaluate the status in the home. The Medicaid reimbursement for a home visit to pediatric patients is only $65 a visit. A non-AIDS home visit is usually of 30 minutes duration, but an AIDS visit can be 1.5 hours long. There is usually a need to offer services to the mother, but reimbursement can occur only under a separate referral mechanism and the parent and child home visits cannot be easily combined. Thus, there is need for a combined maternal and child health delivery approach. In addition, the visiting nurses require personal security because of the assault and robbery problems in the neighborhoods they visit. Further, hospital supply delivery services will not deliver to many sites without the visiting nurse's security guard accompanying them.

The City of Newark administration has until now virtually ignored the AIDS problem and the City Health Department has denied that there is a unique problem in Newark. These attitudes have a detrimental effect on the coordination and delivery of needed services to adults and children with AIDS. There is a new health commissioner, who has a community health background. The Health Department will be mounting a public education campaign which will be delivered with the water bill.

The AIDS Resource Foundation for Children is a Newark-based organization that carries on educational outreach in Newark, but has had to establish a transitional foster care residence for children with HIV in Elizabeth, Now Jersey. This residence, The St. Claire's Home for Children can handle up to five infants/children at any one time. There is always a waiting list. The Home receives moral and fiscal support form the St. Elizabeth Hospital, the New Jersey Department of Health and the Division of Youth and Family Services. Since the Home cannot increase above five children at any one time because of the prohibitive safety and alteration costs, there are plans to build several additional homes to handle children in Newark and in the Monmouth County section of New Jersey. It costs approximately $240/day/child ($60,000 per child per year). St. Claire's is not yet on a sound fiscal basis.

Jersey City Medical Center. Hudson County, the home of the Jersey City Medical Center is second to Essex County (Newark) in reported AIDS cases. The Jersey City Medical Center handles approximately 3,000 deliveries per year and has a diverse patient population which is 40 percent black, 40 percent Hispanic and the remainder Indian, korean, Arabic speaking and white. Fourteen to 15 percent of this population receives no prenatal care and 60-70 percent are high risk deliveries (teenage mother, no prenatal care, drug use, infected with an STD). A study, ongoing since July 1985, has found 53 HIV antibody positive neonates. The boarder baby problem is not severe. There have been two children who spent up to five months in the hospital for non medical reasons. One of the children was successfully placed with a male gay foster couple. In addition, a media campaign to search for foster parents led to 60 candidates.

Obtaining Medicaid coverage in Hudson County is a very complicated process. Three separate applications are needed and eligibility must be renewed every three

months. This leads to the finding that 47 out of 100 high risk parents do not have Medicaid coverage.

The medical center is involved in a gamma globulin therapy protocol for HIV positive children; however, it receives no special compensation or additional personal.

The staff of the Jersey City Medical Center felt that there was a lack of social service outreach activities, and transportation capabilities for their patient's' families.

C. Miami/Dade County

The site visit took place on November 17-19, 1987. The site visit team included Dr. J. William Flynt, Dr. Stephen Margolis, and Ms. Lela Baughman of Macro, and Ms. Ann Segal of ASPE.

1. Organizations Visited

The AIDS Program Manager for Dade County and the Executive Director of the primary community-based AIDS organization, "Health Crisis Network" were interviewed because of their involvement in community outreach programs. The Florida State Contracts Office and the South Florida AIDS Network were interviewed because of their involvement in the funding and management of AIDS programs for Dade County and South Florida. The primary health care facility, Jackson Memorial Hospital, and the primary child care/placement organization, Children's Home Society were visited to review the status of service delivery to children with HIV infection, ARC and/or AIDS. In addition, during the site visit, the team became aware of the activities of the Health Council of South Florida, and a special visit was arranged.

2. Magnitude of the Problem

Florida ranks third in the United States in officially reported pediatric AIDS cases. Although the official number of pediatric cases was 82 (of which 32 have died) as of November 1987, the primary health care facility of South Florida has dealt with 190 HIV antibody positive, ARC or AIDS children, of which 60 have died. This primary hospital has approximately 14,000 births per year and a projection of one to two percent HIV antibody positivity among pregnant women. AIDS boarder babies are not a major problem--there have been five, but one has been in the hospital for 2.5 years.

The vast majority of pediatric AIDS cases are among women of Haitian descent, living in Miami. There is very little AIDS related outreach and education taking place in the Haitian areas of Miami and many women do not understand, or refuse to appreciate their risk for AIDS virus infection and the potential for transfer to their offspring. This will have significant impact on the number of pediatric AIDS cases in Miami in the future. In addition, today, there does not appear to be a significant problem of pediatric AIDS where the parent is a drug abuser, or sexual partner of an IV drug abusers. Of the total

caseload seen at Jackson Memorial, 25 percent are born to IV drug abusing women. This finding is somewhat surprising considering that 79 percent of the cases in New York are related to IV drug abuse and that Miami is reported to have a large IV drug abusing population.

3. Description and Response of the System

Jackson Memorial Hospital is the primary medical facility for managing children with HIV infection, ARC or AIDS. There is a separate inpatient and a shared outpatient facility for the management of this patient population. Staffing is not a problem, partially because of the funds available from the many research studies which have been awarded to Jackson Memorial and its affiliated medical school, the University of Miami. There are 15 active projects underway, four of which are related to the pediatric AIDS population. Approximately 100 Miami high risk families are followed through one of the studies, and one family per week is entered into these studies. A social worker and nurse routinely make home visits for recruitment and support purposes. Hospital social work staff report significant problems in applying for Aid For Dependent Children.

The South Florida AIDS Network is the primary funding and coordinating unit for AIDS in South Florida and is responsible for (1) care and management of patients; (2) education and training; (3) research management; and (4) legal and ethical issues. Funds are funneled through the South Florida AIDS Network and include: a Robert Wood Johnson Foundation grant ($400,000), a HRSA Clinical Demonstration Site grant ($600,000), and funds from the State of Florida ($6,800,000). The Network is housed at Jackson Memorial Hospital, which facilitates close coordination between the funding management source and the service delivery facility.

The South Florida AIDS Network handles all subcontracts for services, including foster care and child care. A foster parent is paid $2,700 per month for foster care for an AIDS/ARC child. This amount includes all activities and is not supplemented, as is the case in other jurisdictions. A foster parent is paid the regular foster care rates directly from the State and receives an enhanced rate from the South Florida AIDS Network. The State is approximately four months behind in issuance of checks to foster parents. There is general belief that the success of the Miami pediatric and adult AIDS service activities is based upon the planning activity undertaken by the Health Council of South Florida. This group facilitated the development and accomplishment of a six month planning process which included the input from more than 150 people with varied interest in the AIDS problem.

The Health Crisis Network is a community-based outreach organization that began its activities in 1983. Its original focus was to the Miami gay community, but it has expanded its counseling and outreach activities to the heterosexual communities of Miami, specifically to women and to Haitians. It receives some of its funding through the South Florida AIDS Network. The organization operates a hotline, including a Creole speaking operator, and funds a community outreach nurse for a half day per week at a local community center in the Haitian part of Miami. A primary concern of the

organization is the need for counseling and outreach to siblings of HIV infected children. The problem of AIDS so devastates a family's structure and functioning that multiple social services outreach is needed. The organization operates a support group for 28 high risk women, but does not have the staff for psychosocial outreach to families with AIDS.

The Dade County AIDS Unit is primarily focused upon providing voluntary and confidential testing and counseling. Although the County operates six health clinics, any HIV seropositive/ARC/AIDS child coming to these facilities is sent to Jackson Memorial Hospital for management. The staffs of these clinics do not perceive the black communities to be at risk for AIDS, and this has affected their prevention and education activities. There is very little AIDS prevention outreach occurring, especially in the Haitian community.

A system is being developed that would link by computer the County community health centers to the Jackson Memorial Hospital. This would allow better tracking and management of patients.

There have been a variety of foster care approaches in Miami. Foster care placement of HIV positive children was initially handled by the State, but now the South Florida AIDS Network has contracted with the Children's Home Society to handle the foster care placement for this population. As of the site visit, no children had actually been placed with foster parents by this agency. However, two nurses from Jackson Memorial Hospital have left their nursing positions to become foster parents to HIV/ARC/AIDS infants and children, and each has several placements living with them. The Society also operates a shelter for children and will be handling HIV positive/ARC and AIDS clients. The Society is worried about the problem of infected teenagers and how they will be handled in the future.

APPENDIX J. FOLLOW-UP STUDY AREAS

ASPE STUDY OBSERVATION: A difference was observed between the officially reported pediatric AIDS cases, according to the CDC case definition, and the number of children being managed by medical and social service personnel at studied sites.

POTENTIAL STUDY:

1. How many HIV infected, ARC and AIDS infants, babies and children are there? What impact does an expanded case definition have?

   A. How do they compare to official AIDS case numbers?

   B. What are the service delivery needs for each?

      HIV Infected: day care, foster care, congregate care, medical followup, family social services

      ARC: day care, foster care, congregate care, respite care, medical care, family social services

      AIDS: medical care, hospice care, foster care, day care, respite care, family social services

   FOCUS POINT: For every AIDS infant, baby, child, there are _____ more who require services. The services include _____, _____and _____ and the cost for each category of service for HIV infected, ARC and AIDS child are _____, _____, _____, and _____, _____, _____ and _____, _____, _____. The needs for additional services are _____, _____, _____, and _____.

ASPE STUDY OBSERVATION: HIV antibody testing of pregnant women and neonates was very variable. Most sites are not testing for suspected pediatric AIDS, some are planning for testing and one site has tested pregnant women in its catchment area.

POTENTIAL STUDY:

2. Identification of where testing related to pediatric AIDS is occurring and not occurring and a differential analysis of the issues and impact.

   A. Where is testing occurring and not occurring.

B. Who is being tested?
   - Women of child-bearing age?
   - Neonates
   - Women of child-bearing age and neonates?

C. What is the impact of testing on the health, social service and welfare delivery systems and their costs?

D. How are AIDS children being brought into the system in sites with no formal testing program?

E. What are the comparative differences relating to pediatric AIDS in testing versus non-testing sites?

ASPE STUDY OBSERVATION: The number of HIV+, ARC and AIDS neonates, infants and children being managed at study sites is 3 to 15 fold greater than the officially reported AIDS cases.

POTENTIAL STUDY:

3. What is the impact of testing for AIDS suspected babies (HIV+, HIV-, ARC, AIDS) on the health, social service and child welfare system?

   A. What is/are the most effective, efficient and cost-effective methods for defining the problem?

   B. How will test results be utilized?

   C. What are the legal implications to testing?

ASPE STUDY OBSERVATION: The multiple child care systems are in the process of "gearing up" for managing the Pediatric HIV/ARC/AIDS problem. The desire to maintain family structure and to utilize extended family members, especially grandmothers, is the focus of social service activity.

POTENTIAL STUDY:

4. Analysis of the pediatric AIDS problem on the child care system.

   A. Utilization of extended families for child care. The grandmother issue.

   B. The feasibility of short and long term congregate care.

C. Role of the day care system and need for new approaches.

D. Availability of hospice care for AIDS children.

E. Utilization of foster care for HIV infected, ARC and AIDS children.

ASPE STUDY OBSERVATION: Every HIV seropositive child has a seropositive, ARC or AIDS mother and possibly a sick father. Agencies caring for the child face significant obstacles in also dealing with the mother, father and other family members.

POTENTIAL STUDY:

5. AIDS in children is AIDS in families.

   A. What is the impact on the health, social service and welfare systems of the problem of both mother and child who are HIV+, ARC and/or AIDS victims?

   B. What are the needs of parents, siblings, extended family and community?

   C. What other deficits in the area of health, financial and welfare may be superimposed on a family with AIDS and what are their impacts?

   D. What systems are available to maintain family structure for those affected with AIDS and what systems are available to prevent the disintegration of affected families?

   E. How can needed services be delivered efficiently, effectively and in a cost-effective manner?

ASPE STUDY OBSERVATION: Selected foster care agencies are beginning to deal with HIV+, ARC and AIDS children. The selection and training of potential foster care parents is a significant problem. The utilization of extended family members for child care and foster care is also a significant problem.

POTENTIAL STUDY:

6. Impact of AIDS in children on the foster care system.

   A. The effect of AIDS knowledge and attitude changes on foster parents and the recruiting of foster parents.

   B. Models and strategies for foster care placement.

C. Recruitment and processing of foster parents.

D. Barriers to the effective use of the foster care system.

ASPE STUDY OBSERVATION: Communities vary in the type of control and level of management of children with AIDS. One site has created a unified management office which controls all finances and contracts for services. Another site has created a State level management committee and other sites are depending on ongoing systems for handling the pediatric AIDS problem.

POTENTIAL STUDY:

7. Identification and analysis of models of coordinated community-based programs and services for children with AIDS and families with AIDS.

   A. Exemplary practices and the transportability of those practices.
   B. Coordination of planning, service delivery and financing.
   C. Relationship of size of childhood AIDS problem to service delivery approaches.

ASPE STUDY OBSERVATION: There are a variety of approaches being utilized to manage HIV+, ARC and AIDS neonates, infants and children and their families. There are also a variety of service funding approaches being utilized. Some of these approaches are unique to their site of origin, other approaches may be transportable.

POTENTIAL STUDY:

8. The creation of a "Technical Assistance" manual for planning and management of AIDS in children.

   A. Methodologies for planning and issues to be dealt with.

   B. Alternative approaches to service delivery.

   C. Financing of medical, social and child welfare services.

   D. Social service approaches to case management.

   E. Resources for managing AIDS in children.

   F. Issues surrounding families of children with AIDS:
      - Infected and uninfected sibling
      - Parents with infection, ARC, AIDS
      - Death in families with AIDS
      - Role of extended family members in care

ASPE STUDY OBSERVATION: Many medical, governmental and social service organizations are planning or carrying out pediatric AIDS initiatives. There should be a uniformity of approaches and activities for increased efficiency and cost-effectiveness.

POTENTIAL STUDY:

9. What plans, programs and activities are other groups carrying out out concerning AIDS in children?

    A. American Academy of Pediatrics

    B. Child Welfare League of America

    C. World Health Organization

    D. State pediatric AIDS planning groups

    E. Other Federal agencies

ASPE STUDY OBSERVATION: In 1986, PHS held the Coolfont AIDS meeting, which did not deal with pediatric AIDS. The only major meeting related to pediatric AIDS was held at the request of the Surgeon General. The issues surrounding pediatric AIDS have increased significantly and deserve broad-based attention.

POTENTIAL STUDY:

10. Planning and facilitating a Federal government meeting on pediatric AIDS issues.

    A. Define the critical issues to be presented.

    B. Catalogue the potential presenters (Federal, State, local, university, community groups, AIDS and minority organizations.

    C. Handle logistics of meeting

    D. Prepare meeting report for dissemination.