

GAO

Report to the Chairman, Committee on
Finance, U.S. Senate

May 1989

PEDIATRIC AIDS

Health and Social Service Needs of Infants and Children



Human Resources Division

B-235379

May 5, 1989

The Honorable Lloyd Bentsen
Chairman, Committee on Finance
United States Senate

Dear Mr. Chairman:

Acquired immunodeficiency syndrome (AIDS) is rapidly becoming a major health threat to children. It is now the ninth leading cause of death among children 1 to 4 years old; within the next 3 to 4 years it could be among the top five leading causes of childhood death.¹ The Department of Health and Human Services (HHS) predicts that this epidemic among children will continue to spread to as yet unaffected communities.

In response to this growing problem, you asked us in December 1988, to provide information on services available to children infected with the human immunodeficiency virus (HIV), which causes AIDS. Pursuant to our March 9, 1989, briefing you specifically asked us to report on (1) whether children and adults are affected differently by HIV infection, (2) the health and social service needs of HIV-infected children, (3) how selected cities have responded to the service needs of these children, and (4) certain federal programs available to address these needs.

Background

As of February 28, 1989, the Centers for Disease Control (CDC) had identified 1,440 AIDS cases among children under 13 years old.² Of these children, 800 have died. Nearly 76 percent of the pediatric AIDS cases have been black and Hispanic. Appendix I provides a current profile of pediatric AIDS in the United States.

The Public Health Service predicts that by 1991, as many as 20,000 children will become HIV-infected and 3,000 will have contracted AIDS. In April 1987, the Surgeon General of the United States reported that as many as 2,000 more children may have symptoms of HIV infection, yet not fit specific AIDS diagnostic criteria. Moreover, for each reported case of pediatric AIDS, HHS officials estimate that 2 to 10 times more HIV-infected children may not manifest overt symptoms of the disease.

¹Final Report of the Secretary's Work Group on Pediatric HIV Infection and Disease, Department of Health and Human Services, Nov. 18, 1988.

²This estimate understates the pediatric AIDS problem because of underreporting and because the CDC surveillance definition for AIDS does not include all children with HIV infection.

Objectives, Scope, and Methodology

As agreed in discussions with your staff, we surveyed the status of health and social services for HIV-infected children in five communities: New York, New York; Newark, New Jersey; Los Angeles, California; Houston, Texas; and Cleveland, Ohio. We selected these cities to reflect differences in geographic location and pediatric caseloads. The distribution of AIDS cases in these five cities is shown in table 1.

Table 1: Cumulative Number of Pediatric AIDS Cases in Selected Cities (As of February 28, 1989)

Metropolitan area of residence	Number of pediatric AIDS cases	Percent of total pediatric AIDS
New York	391	27.2
Newark	85	5.9
Los Angeles	48	3.3
Houston	24	1.7
Cleveland	5	0.3
Total	553	38.4

Source: Centers for Disease Control, HIV/AIDS Surveillance Report, March 1989.

For these cities, we conducted telephone interviews about local services for HIV-infected children with state and local health departments, foster care agencies, Medicaid offices, and community-based health and child care providers. We also discussed federal programs that serve HIV-infected children and their families with HHS officials, including representatives of the Health Resources and Services Administration (HRSA), the Health Care Financing Administration (HCFA), and CDC. Finally, we reviewed the literature on pediatric AIDS (see bibliography).

Although we did not obtain written agency comments on this report, we verified specific sections with key state and local government officials and community-based providers for completeness and accuracy. We conducted our review between January and April 1989 in accordance with generally accepted government auditing standards.

HIV Infection Differs in Children

The HIV virus causes AIDS by damaging the human immune system. However, virus transmission, diagnosis, manifestation, and treatment differ between adults and children.

Mothers Transmit the Virus to Their Children

Adults are infected primarily through sexual contact or intravenous drug use; in contrast, nearly 80 percent of children with AIDS acquired the virus from their infected mothers. The vast majority of these women

contracted the disease through intravenous drug use or sexual contact with HIV-infected partners. Epidemiological evidence suggests that an infected mother transmits the virus to her infant either across the placenta during pregnancy or through blood contact during delivery. Recent data also indicate that HIV can be transmitted after birth by ingesting infected breast milk.

The majority of the remaining pediatric AIDS cases (about 18 percent of all cases) acquired the virus through transfusion of contaminated blood or blood products. (About one-third of these children are hemophiliacs.) However, the screening of donated blood for HIV antibodies since March 1985, and the heat treatment of blood plasma products to kill the virus have virtually eliminated this mode of HIV transmission. The route of transmission for the remaining cases is undetermined.

Diagnosis in Children Is Difficult

Unlike adults, the presence of HIV antibodies in newborns does not always indicate that the child is actually infected with HIV. During pregnancy, HIV-infected women transmit their own HIV antibodies to their unborn babies. During this time, they may also transmit the virus to the fetus. For as long as 15 months after birth, infants can test positive for antibodies, although they may not be HIV-infected. Between 20 to 60 percent of those infants are actually infected with the virus and at risk of eventually contracting the disease.

Recent studies show that some children without HIV antibodies may carry the virus. Therefore, laboratory tests to detect the virus as well as antibodies may be needed to diagnose HIV infection in children.

Clinical Manifestations Differ in Children

In 1987, CDC revised its surveillance definition to highlight clinical and diagnostic differences between adult and pediatric AIDS. Unlike adults, children with AIDS can develop lymphoid interstitial pneumonitis (a form of lung inflammation), but rarely develop Kaposi's sarcoma (an invasive skin cancer). Moreover, many infected children are low birth weight babies and fail to grow according to norms for their chronological age. Over half of the infected children have central nervous system deficiencies, resulting in developmental delays and neurological abnormalities.

The typical life span for children with AIDS ranges from 12 to 18 months, but may be longer. Survival times are shorter for infants and longer for children who are infected later in life. The life span of children who

acquired AIDS before or at birth does not appear to differ significantly, however, from the life span of children with transfusion-acquired AIDS.

Treatment for Children Lags Behind Adults

Clinical specialists acknowledge that drug therapy research for HIV-infected children has lagged behind that for adults due to cultural and ethical concerns. Moreover, in certain states HIV-infected children who are wards of the state may be barred from participating in clinical trials because of legal restrictions.

The National Institutes of Health is expanding its pediatric clinical trials (see app. II) to develop treatment therapies for various infections associated with HIV infection. Current therapies have been shown to reduce the incidence of infections likely to affect HIV-infected children.

HIV-Infected Children Need Many Health and Social Services

Children with HIV infection experience a wide range of illnesses requiring different levels of care. Specifically, in acute stages, these children need inpatient hospital care, often in intensive care units. When symptoms subside, these children can be cared for in the home, with varying levels of medical support and social services.

The literature we reviewed showed that most HIV-infected children are born to families who are already facing poverty, drug abuse, parental HIV infection, and educational problems. As a result, their complex social and medical needs strain the resources and energies of families and of health and social services systems. Without home-based care, foster care, and support services, these children are at risk of extended and costly hospital care, most of which is provided by public hospitals and paid for by the Medicaid program.

Home-Based Care

Health experts agree that, whenever possible, health services for HIV-infected children should be delivered at home to promote maternal bonding and to provide adequate environmental stimulation for the child's development. Because the HIV-infected child requires considerably more specialized in-home medical care than a normal healthy child, parents and caretakers need special training.³

³CDC recommends that parents and caretakers should follow infection control measures, such as hand washing and the use of gloves, when the potential exists for exposure to the infected child's blood and other bodily fluids.

In many instances, the child's medical needs require the help of home health care nurses. These specialists can provide medical monitoring, oxygen, supplemental nutrition, intravenous drug therapy, and intravenous nutrition. In addition, home health aides can help parents with the child's daily care and homemakers with managing the household.

Foster Care Families and Group Homes

When the parents or relatives of HIV-infected children are unable or unwilling to care for such children, health care experts believe that foster care families or group homes are better alternatives than inpatient hospital care. Foster care for these children may be difficult to find, however, because the foster care systems in some communities are already overburdened.

Some studies indicate that foster parents may be less willing to take these children into their homes because of the psychological stress or the stigma that caring for an AIDS child brings with it; at the same time, they may not be able to obtain respite care that they occasionally need to ease these burdens. Other studies cite the foster care parents' fear of infection as a major constraint in recruiting foster care families.

Foster families need to be aware of the HIV antibody status of children to provide appropriate health care. In 1985, CDC recommended that adoption and foster care agencies consider screening children who are at increased risk of HIV infection as part of their routine medical evaluations before placing the child in a foster or adoptive home. CDC specifically advised close medical monitoring for HIV-infected children because they are more susceptible to frequent infections and may react adversely to childhood immunizations.

Human services agencies can identify high-risk children to determine the need for HIV screening. However, these agencies must also deal with the need for confidentiality of test results. Furthermore, they may be liable for either breaching confidentiality of test results or failing to inform foster families about potential exposure to HIV. The cities in our review follow their state's screening policy. Only New Jersey routinely tests all high-risk foster care children. The other four states require HIV screening of high-risk children only when it is medically indicated.

When natural or foster families are not available, small group homes providing congregate care for HIV-infected children are considered to be a more appropriate setting than inpatient hospital care. Group homes hire staff or recruit volunteers to care for foster children. By law, they

serve no more than 25 children. These homes can be temporary residences for children waiting to return to their parents or awaiting foster care placement.

Group homes can also be used as permanent placements to provide higher levels of care, including intermediate or hospice care, for HIV-infected children. Health experts agree that intermediate care facilities are appropriate for HIV-infected children who need subacute medical services, such as oxygen, catheterization, or physical rehabilitation. Also, hospice care provides pain relief to the terminally ill child with AIDS and supportive services to both the child and family.

Support Services

Families with an HIV-infected child also require social support, such as transportation to health services and legal guidance to arrange for custody in the event of the parent's death. In addition, specialized day care programs for HIV-infected children who cannot be integrated into regular day care can provide medical, social, and educational supervision of the child and respite care for their parents. Parents, siblings, and relatives of AIDS children may also need extensive mental health and psychosocial counseling services to cope with terminal illness in the family. This counseling may concern the illness of the child and other family members. Often the diagnosis of a child's HIV infection is the first indication that the mother, and possibly the father and siblings, are infected.

Cities' Response to the Needs of HIV-Infected Children

Health and social services providers in our review have established certain community-based services to prevent unnecessary hospital care for HIV-infected children. Despite their efforts, some services in these cities are limited or nonexistent. Communities who face large pediatric AIDS cases may have to expand their health and social service systems.

Home-Based Care

Providers in all cities reported that home health care for HIV-infected children and their families was available, but more was needed. Providers in New York and Los Angeles also told us that they believe that home health providers were not adequately trained and skilled to care for these children.

Foster Care Families and Group Homes

Los Angeles, Houston, and Cleveland do not have large numbers of HIV-infected children in foster care. However, providers in Los Angeles and Houston report that they will need more foster families and group homes in the future. On the other hand, New York and Newark currently face a shortage of foster families willing to care for HIV-infected children. These two cities use strategies to improve recruiting of foster care families that include contracting with private child placement agencies and setting higher reimbursement rates for HIV-infected children.

New York City's child welfare agency (the New York City Human Resources Administration) contracts with private agencies to recruit foster care parents. Two private agencies, Leake and Watts Children's Home and Project Hope of the New York Foundling Hospital, specialize in locating homes for HIV-infected children. According to the clinical director at Mount Sinai Medical Center in New York City, the city's active recruitment of foster homes for HIV-infected children has reduced the number of babies unnecessarily hospitalized.

As incentives to recruit foster families to care for HIV-infected children, New York and New Jersey have set high foster care rates for such children. New York pays \$1,177 per month for foster care for an HIV-infected child, compared to \$355 to \$483 per month for care of a non-HIV-infected child. In New Jersey, the enhanced rate for HIV-infected children is \$950 to \$1,200 per month, depending on the stage of illness, compared to \$266 per month for non-HIV-infected children. Although Texas, California, and Ohio do not have specific rates for these children, they have set higher maintenance rates for all foster care children who have been determined to have special needs. These include HIV-infected children.

Four cities in our review—New York, Newark, Houston, and Cleveland—provide transitional or permanent group homes for HIV-infected children. The AIDS Resource Foundation established St. Clare's Home near Newark as a transitional group home for a maximum of five HIV-infected children. The Hale House for Infants, Inc., is a group home in New York City that serves seven HIV-infected children in addition to drug-dependent children. In Los Angeles, a group home for HIV-infected children has been incorporated, but has not yet obtained initial funding to become operational.

Providers in New York, Newark, and Houston identified the need for more permanent homes for HIV-infected children who require extra medical attention. The Children's Center operated by Herbert G. Birch Community Services, Inc., is a permanent group home offering comprehensive residential services, including medical surveillance for HIV-infected developmentally disabled children in New York City. The Children's Home in Houston provides hospice care and the Collette Marie Infant Home in Avon, Ohio cares for terminally ill children with AIDS.

Support Services

Providers in New York, Los Angeles, Houston, and Newark told us of the need for more mental health and counseling services or social support groups for families who care for HIV-infected children. In addition, providers in all cities noted that transportation to and from physician offices is needed. Providers in Los Angeles and Newark stated that legal support for HIV-infected children is also needed.

Therapeutic day care centers with respite care for parents at the Bronx Municipal Hospital Center in New York City served 25 HIV-infected children and Babyland Nursery, Inc., in Newark served 10 such children. Despite these specialized day care facilities for HIV-infected children, providers in these two cities reported the need for more day care. In addition, providers in New York, Los Angeles, Cleveland, and Newark reported that respite care was an unmet need.

Federal Programs Available to Address the Service Needs of HIV-Infected Children

Certain federal programs are available to fund health and social services for HIV-infected children and their families. The objective of two of these programs—the Medicaid Home and Community-Based Waiver and the HRSA Pediatric AIDS Demonstrations—is to allow these children to continue to live in the community in a more cost-effective setting.

Medicaid Home and Community-Based Waiver

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 established what are referred to as home and community-based waivers. These waivers, designed by the state and submitted to HCFA for approval, expand Medicaid eligibility and the range of allowable services.

HCFA granted waivers to New Jersey, California, and Ohio to provide targeted health care and related services—such as case management, home care, and nursing—to persons with AIDS or AIDS-related complex

(ARC), which can also be debilitating or fatal. Texas submitted a waiver application in 1988, which HCFA rejected because all program requirements were not met. The state is planning to resubmit its waiver application in June 1989. Of the cities in our review, only Newark was affected because New Jersey had implemented its waiver and as of December 1988 was providing targeted services to 31 HIV-infected children under 5 years old and children with AIDS or ARC of any age in Essex County (Newark).

The Medicare Catastrophic Coverage Act of 1988 added a new Medicaid Home and Community-Based Services Waiver authority under section 1915(e) of the Social Security Act. Under this provision, states could use these new waivers to provide services for children who are HIV-infected or drug-dependent at birth. The waiver program targets children under 5 years old who are or will be placed in foster or adoptive homes. According to an HCFA official, no state has yet applied for this waiver.

Pediatric AIDS Health Care Demonstrations

To improve coordination between services, HRSA funded Pediatric AIDS Health Care Demonstration projects for children, youth, and women of childbearing age who are HIV-infected or at risk. These projects support comprehensive ambulatory and community-based services for HIV-infected children to minimize health care costs.

In fiscal year 1988, the program awarded 13 grants for about \$4.8 million. Organizations in three of the cities we reviewed—New York, Newark, and Los Angeles—received funding from these grants. HRSA expected to spend about \$7.8 million in fiscal year 1989, and requested another \$7.9 million to fund these projects for fiscal year 1990.

Title IV-E Foster Care Maintenance

Title IV-E of the Social Security Act authorizes funds for foster care of children who are eligible for Aid to Families With Dependent Children. Under this title, the federal government provides matching funds to the states for both the maintenance and administrative costs of foster care. All cities we reviewed used title IV-E funds to pay a higher reimbursement rate for foster children with special needs, including HIV-infection. In addition, New York State supports foster group homes with title IV-E funds.

CDC AIDS Information
Clearinghouse

CDC's National AIDS Information Clearinghouse, established in 1987, is developing data bases of available resource organizations and materials and is already responding to professional inquiries. According to a CDC official, the clearinghouse is expanding its data bases on AIDS and the demand for clearinghouse services to assist localities in developing information networks is overwhelming.

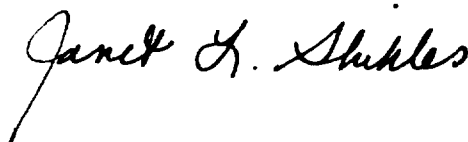
Summary

Most HIV-infected children are from low-income and disadvantaged families who have limited access to adequate health care services. As a result, these children and their families rely on public health and social services systems. In some communities, these systems are already overburdened. Consequently, these children are at risk of long and costly hospital stays that tend to reduce the overall quality of life compared to a home environment.

In communities we reviewed, foster care, home health care, and support services have been developed or expanded to help reduce the time HIV-infected children spend in the hospital and the resultant health care costs. All communities reported, however, inadequate current capacity to meet the demand for certain services, such as day care, group homes that provide intermediate level care, respite care, mental health counseling, and transportation. Some federal support is available to fund these services.

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies to interested parties and make copies available to others on request. A list of major contributors is in appendix III.

Sincerely yours,



Janet L. Shikles
Director of National and
Public Health Issues

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Abbreviations

AIDS	acquired immunodeficiency syndrome
ARC	AIDS-related complex
AZT	azidothymidine
CDC	Centers for Disease Control
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
IVIG	intravenous gamma globulin
NCI	National Cancer Institute
NIAID	National Institute of Allergy and Infectious Diseases
NICHD	National Institute of Child Health and Human Development
NIH	National Institutes of Health

Number and Characteristics of Pediatric AIDS in the United States (As of February 28, 1989)

Transmission categories	Cases	Percent	Race	Cases	Percent
Perinatal	1,126	78.2	White	339	23.5
Blood transfusion			Black	759	52.7
(including hemophilia)	261	18.1	Hispanic	330	22.9
Undetermined	53	3.7	Other/Unknown	12	0.8
Cumulative Total	1,440			1,440	

Note: Percentages may not add to 100 percent due to rounding.

Source: Centers for Disease Control, HIV/AIDS Surveillance Report, March 1989.

National Institutes of Health AIDS Pediatric Clinical Trials

As of April 14, 1989, three institutes at the National Institutes of Health (NIH)—the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), and the National Institute of Child Health and Human Development (NICHD)—have treated over 500 pediatric patients in protocols designed to test the efficacy of drug treatments for HIV infection. Five more protocols are currently under development at NIH.

The drugs under study or about to be studied, alone or in various combinations, are

- azidothymidine (AZT),
- dideoxycytidine (ddC),
- dideoxyinosine (ddI),
- soluble CD4,
- immune system stimulator Human Macrophage Colony Stimulating Factor (rH-GM-CSF), and
- intravenous gamma globulin (IVIG).

The Office of AIDS Research at NIH provided information on the protocols underway as of April 14, 1989. Specifically, NIAID protocols include

- phase I evaluation of AZT in children with AIDS or ARC,
- a multicenter trial to evaluate oral AZT in the treatment of children with symptomatic HIV infection,
- clinical trial of the efficacy of IVIG in the treatment of symptomatic children infected with HIV,¹
- a multicenter phase I trial to evaluate the safety and pharmacokinetics of intravenous and oral AZT in infants with perinatal HIV exposure, and
- a double-blind placebo controlled trial to evaluate IVIG in children with symptomatic HIV infection receiving AZT.

The NCI protocols include

- evaluation of AZT by intravenous infusion of delivery in children with symptomatic HIV infection;
- evaluation of AZT by Bolus infusion and/or intravenous infusion;
- phase I evaluation of ddC;
- phase II evaluation of oral AZT;
- evaluation of continuous intravenous infusion AZT administered together with rH-GM-CSF to overcome bone marrow suppression;

¹This protocol is sponsored by NICHD.

**Appendix II
National Institutes of Health AIDS Pediatric
Clinical Trials**

- phase I evaluation of ddI in children with symptomatic HIV infection;
- evaluation of alternating AZT and ddC in children with HIV infection;
- randomized clinical trial comparing continuous intravenous infusion of AZT to oral sustained release as oral intermittent therapy; and
- evaluation of recombinant soluble CD4 for children with symptomatic HIV infection, including newborns and pregnant women.

Table II.1 shows the locations of the AIDS pediatric clinical trials units.

Table II.1: NIAID AIDS Pediatric Clinical Trials Units

Trials Unit	City
University of California at San Diego Medical Center	San Diego, CA
University of California at San Francisco	San Francisco, CA
University of California/ L.A. Center for Health Sciences	Los Angeles, CA
University of Miami School of Medicine	Miami, FL
Children's Memorial Medical Center	Chicago, IL
The Johns Hopkins University	Baltimore, MD
Children's Hospital Corporation	Boston, MA
Boston City Hospital	Boston, MA
New Jersey Medical School	Newark, NJ
Bellevue Hospital Center	New York, NY
Mount Sinai School of Medicine	New York, NY
The Presbyterian Hospital/ Columbia-Presbyterian Medical Center	New York, NY
Baylor College of Medicine	Houston, TX

Source: National Institutes of Health, Office of AIDS Research, April 1989.

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