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ABSTRACT

This document is designed to assist state and local program administrators in responding to the need for comprehensive care for children (specifically children under the age of 13) and child-rearing families affected by Human Immunodeficiency Virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS). The document is based on the premise that HIV infection in children must be seen as a family-based issue, involving parents, siblings, and extended family, and the premise that all families have strengths that professionals can build upon to empower and assist them in the care of their children. The document defines the scope of the problem; outlines the elements of comprehensive family-centered care (prevention, testing and counseling, integrated medical care, developmental and educational services, mental health assessments and interventions, basic support services, and social and legal services); describes how to organize these elements into a coordinated system; and suggests ways to finance community-based care programs through federal resources, state action, and private funding. Four case studies of state and local comprehensive care systems (from New Jersey, South Texas, Massachusetts, and Philadelphia) outline the way in which government, community, and private resources have been interwoven to make the system work. Appendices list many print and organizational resources. (JDD)

A GUIDE: FAMILY-CENTERED COMPREHENSIVE CARE FOR CHILDREN WITH HIV INFECTION

EC 300857

U.S DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Health Service
1991

A GUIDE:

FAMILY-CENTERED COMPREHENSIVE CARE FOR CHILDREN WITH HIV INFECTION

PANEL ON WOMEN,
ADOLESCENTS, AND
CHILDREN WITH
HIV INFECTION
AND AIDS

♥

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st 1991

Family-Centered Comprehensive Care for Children with HIV/AIDS

The Problem

- As of the end of June, 1991, 3,140 children under 13 with AIDS were reported to the CDC, *over half of them in the last 2 years alone.* Of these, 84 percent were infected perinatally, and 52.2 percent have died.

- AIDS in women and children is spreading beyond the large urban epicenters to smaller urban and even rural settings. The greatest increases in numbers of cases reported to the CDC were in the rural areas and in metropolitan areas with populations of under 100,000.

- Based on the National Survey of Childbearing Women, the CDC estimates that 5,000-6,000 HIV-infected women gave birth in the past year. Based on a 30 percent transmission rate, it is estimated that 1,800-2,000 infected infants were born.

- Children of minority families are disproportionately represented among children with HIV infection. For example, although only 15 percent of all children in the United States are African American, they are known to account for 51 percent of all AIDS cases, and although only 8 percent of all children in the United States are of Hispanic descent, they account for 26 percent of AIDS cases in children. By 1988 in New York State, HIV/AIDS was the first and second leading cause of death in Hispanic and black children 1-4 years old, accounting for 15 percent and 16 percent respectively of all deaths in these age-race groups.

Services Needed by Children with HIV/AIDS

- Families with HIV-infected children are frequently known to be poor, or minorities, with limited access to services, transportation, and housing; the vast majority may have a history of drug dependence or exposure to drug users; and generally, there is more than one family member infected or ill.

- Involving families with HIV-infected children from the start, as advisors and/or consultants to policy makers, will ensure that comprehensive systems are indeed comprehensive, and as such, responsive to the specific needs previously identified by these families.

- The document describes services, and in particular, 18 types of services that these children and their families may need. They range from primary prevention, education and behavior change, drug treatment, testing and counseling, to integrated medical care, developmental services, special and school-based education, mental health assessments and interventions, family-to-family support , nutrition assistance and support services. These support services include child and respite care, housing, transportation, legal services, foster care, adoption services, and group care.

- Services such as these are most likely accessible to families when offered in community-based settings.

Coordination: Creating a Comprehensive System of Care

- The many different kinds of services and providers needed by children and families with HIV infection require extraordinary coordination to operate as a system of care. Such a syatem of care must integrate highly specialized HIV-related medical care with basic primary care, and this integrated medical care must itself be integrated with developmental and social services. This variety of services must also be linked at the level of care provision to the family.

- Interdisciplinary and interagency partnerships at all levels will be required. A combination of personal, public, private, and corporate resources are necessary to create the system of care to answer the complex and multiple needs of children with HIV infection.

- Community support is of the utmost importance before anything else can occur. At the outset, careful and thorough consultation with families is critical in designing systems of care that will meet the true needs of these children and their families.

- A promising way to develop and instititionalize such needed coordination is the "transagency model"—a model in which services are coordinated by a board composed of staff from agencies whose services are part of the comprehensive care. Care coordination teams are also formed to develop a family care plan.

Financing Family-Centered Comprehensive Care for Children with HIV

- Given the scope and the range of services needed by HIV-infected children and their families, the financing of these services must be obtained from a wide variety of sources. Communities that have responded most vigorously to the HIV epidemic and the needs of the people have done so, not with Federal sources alone, but by integrating state, local government sources, foundation, businesses, and private and volunteer sources.

- It is important that program administrators charged with developing comprehensive care systems ensure that personnel from diverse funding sources articulate and work together toward a common goal. Administrators must also find or sustain such care or program funding once demonstration programs have expired.

- Available resources can be more effectively used when coordinated across agencies and disciplines; when directed toward the specific family needs; and when used to enhance or extend existing care systems, rather than creating new ones.

- Among the known Federal resources available for funding are: Medicaid, including optional waivers for home- and community-based care; U.S. Public Health Service programs, including Title V Maternal and Child Health block grant programs, pediatric AIDS model demonstration programs, Community and Migrant Health Centers, and substance abuse programs. Other Department of Health and Human Services programs are: Social Services block grants (Title XX), Head Start programs, the Abandoned Infants Assistance Act, and the Administration on Developmental Disabilities.

- The document provides four case studies of state and local comprehensive care systems—from New Jersey, South Texas, Massachusetts, and Philadelphia. They outline the way in which Federal resources have been interwoven with state and local resources, and with existing community and private and volunteer resources to make the system work. In addition, the document provides a summary of recent state activity on pediatric AIDS, a listing of several private sources of funding, and some national organizations that have funds and offer services for children with HIV infection and their families.

Conclusion

The needs of HIV-infected children and their families are complex. Specific initiatives to coordinate the full range of services required to address such comprehensive care are timely and necessary. For the most part, new comprehensive care systems should not be instituted; instead they should be interwoven within the broad capacities of existing programs. These include those care systems for adults with HIV infection and AIDS that have been previously established by the gay community, those of minority organizations, and others known to have been established to address the needs of children with HIV infection and their families in the past. ◆

August 1991

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Although it is impossible to mention them all by name, there are some, in addition to the Panel and its Subgroup, who contributed significant time and effort in helping us understand the dimensions of the problem and articulate the urgent need for family-centered comprehensive care for children with HIV infection. They are:

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Surgeon General Antonia C. Novello and an HIV-infected child.

INTRODUCTION

Communities throughout the United States are struggling to confront the diverse and compelling needs of families with children infected with the Human Immunodeficiency Virus (HIV). While these families have many of the same concerns as families of children with other chronic illnesses, they face additional challenges because of the circumstances surrounding HIV infection. Public fear and ignorance regarding the nature and transmission of HIV infection generate discrimination and isolation. Families with HIV-infected children frequently are poor and members of a minority community, with limited access to services, transportation, and housing; most have a history of drug dependence or exposure to drug users; and there is generally more than one family member who is infected or ill, often a mother too ill to care for her children. Efforts to respond effectively to pediatric HIV infection must address these problems through the delivery of a broad spectrum of multidisciplinary and coordinated medical and social services.

Experience and research have shown that these services are most likely to be accessible to families if they are offered in community-based settings. For purposes of this document, "community-based" implies geographically proximate, available services, delivered in and by a given community. In many communities, however, the necessary range of medical and social services may not be available. In others, needed services may exist, but they may not be accessible to those in greatest need or they may be seriously fragmented, with inadequate and/or ineffective coordination among agencies and providers. Further, specialized HIV-related services for children and families are, in many instances, being developed in isolation, apart from the service system for children with other special needs and out of touch with the daily life of the communities in which these children live.

Children with HIV infection are, above all, children. Effective, community-based programs for children with HIV infection should, therefore, embrace the dual goal of providing the known broad spectrum of medical and social services needed by these children, while at the same time ensuring that such interventions meet the basic need of all children to grow and develop in a nurturing, family-based environment.

For all of these reasons, comprehensive systems of care to serve children with HIV infection and their families are urgently required. These systems, to be successful, must be purposefully crafted to be coordinated, family-centered, and community-based. Currently, no single agency or program is equipped to provide the myriad services needed by children with HIV infection and their families. Therefore, when these comprehensive systems of care are being created, they should not be established de novo; instead, they should be interwoven with existing programs to take advantage of their broad experience and capacities. Many of these programs, including the care systems for adults with HIV infection and AIDS that have been established by the gay community, minority organizations, and others, have already begun to address the needs of children with HIV infection and their families. •

PURPOSE AND USE OF THIS DOCUMENT

This document is designed to assist state and local program administrators in responding to the need for comprehensive care for children in their communities, specifically children under the age of 13 and child-rearing families affected by HIV infection and AIDS. It is based on the premise that HIV infection in children must be seen as a family-based issue, involving parents, siblings, and extended family, spanning the transition from childhood into adult life. Although these recommendations are also relevant to adolescents with HIV, the complex needs of adolescents require additional specialized approaches and services that fall beyond the scope of this document.

This document defines the scope of the problem, outlines the elements of comprehensive family-centered care for these children, describes how to organize these elements into a coordinated system, and suggests ways to finance community-based care programs. It reflects the growing consensus that family-centered services should be the standard of care for all children with special health care needs and their families. Family-centered care is based on the premise that all families have strengths that professionals can build upon to empower and assist them in the care of their children, and it is achieved through family/professional collaboration. Only when families are involved from the start as advisors and consultants to policy makers and care providers will we be able to ensure that comprehensive care systems are responsive to family-identified needs.

The Ryan White Comprehensive AIDS Resource Emergency Act of 1990, Public Law 101-381, which calls for family-centered care for women, children and families with HIV infection, defines family-centered care as a "partnership among parents, professionals, and the community designed to ensure an integrated, coordinated, culturally-sensitive, and community-based continuum of care." Therefore, "family" needs to be defined broadly to include all types of families, including single-parent families, because temporary or ongoing responsibility for the care of infected children and their siblings is often assumed by extended family members (including grandparents, uncles/aunts), concerned friends and neighbors, or foster or adoptive parents.

This document was developed by the U.S. Public Health Service Panel on Women, Adolescents, and Children with HIV Infection and AIDS, chaired by the Surgeon General and co-chaired by the Director of the National AIDS Program Office, and is intended to build upon other reports and recommendations concerned with this issue. These include the 1988 report by the HHS Secretary's Work Group on Pediatric HIV Infection and Disease, which made recommendations for Federal and state policies regarding research, care, financing, and prevention. This current document seeks to extend these and other efforts by providing practical information to assist state and local program administrators in focusing the creative energies of local communities on the development of coordinated, comprehensive systems of care for children with HIV infection and their families. •

Defining the Scope of the Problem

Epidemiology

The first case of pediatric Acquired Immunodeficiency Syndrome (AIDS) was reported early in 1982. By June 1991, over 3,000 cases of AIDS (3,140) in children less than 13 years of age had been reported to the Centers for Disease Control (CDC). Between July 1989 and June 1990, 697 cases were reported, a 12 percent increase over the previous 12-month period and a 37 percent increase over the same period in 1987-1988. Because AIDS is usually the end stage of HIV infection, and the time from infection to the emergence of symptoms may take several years or more, only a portion of children infected with HIV are reported to have AIDS. Therefore, the figures regarding cases of pediatric AIDS do not reflect the entire scope of the problem. In some communities, as many as 2 percent of all newborns are born to women infected with HIV. It is estimated that in 1989 alone, between 1,500 and 2,000 HIV-infected children were born in the United States. Thus, even if transmission of HIV to children were to cease at once, clinical HIV disease would remain a pediatric concern for many years to come.

The large urban areas that were the original epicenters of the HIV epidemic continue to experience the largest social and economic toll from HIV infection. However, surveillance data have documented that the geographic distribution of HIV infection in children has become increasingly broad. Before 1985, 58 percent of the 565 children with AIDS who were infected at birth were reported from only three urban areas: New York City, Newark, and Miami. However, since 1985, only 36 percent of the 969 children with AIDS acquired in this same manner have come from these three cities.

Children of minority families are disproportionately represented among those with HIV infection. Although only 15 percent of all children in the United States are African American, and only 8 percent are Hispanic, these minorities have accounted for 51 and 26 percent, respectively, of reported AIDS cases in children.

The current prognosis for children infected with HIV is grim. Through June 1990, 53 percent of the children reported with AIDS cases were known to have died. Increasingly, HIV infection is changing the mortality patterns of children in the United States. In 1987, the most recent year for which national mortality statistics are available, AIDS was the ninth leading cause of death in children ages 1-4 years, and the twelfth leading cause of death in children ages 5-14 years.

Another serious repercussion of HIV infection for families is the fate of the 65 to 75 percent of the children born to HIV-infected women who will survive, uninfected. If the other biological parent is absent, these children, along with their uninfected siblings, will be orphaned. They will need ongoing social support services, and they will face significant psychological trauma and possible stigmatization. Adoption or options for adoption must be actively pursued for these children.

The Clinical Expression of HIV Infection and AIDS

Modes of Transmission: Children can be infected with HIV in several ways. Most common is transmission from an infected mother during pregnancy or delivery; 84 percent of all children with AIDS are infected in this way. Transmission of HIV through infected blood products has also occurred in a significant number of children. Very rarely, mother-to-infant transmission through breast feeding has been reported.

Although the precise mechanisms remain poorly understood, the perinatal or "vertical" mode of HIV transmission from mother-to- fetus appears to occur when the virus crosses the placenta or when the newborn is exposed to maternal blood during the birth process. Current information indicates that from 25 to 35 percent of children born to mothers with HIV infection will themselves become infected.

Children infected with HIV through the receipt of contaminated blood or blood products currently comprise approximately 15 percent of all pediatric AIDS cases. Most of these are children with hemophilia who, before adequate blood supply testing and blood factor product heat treatment was implemented, received blood products infected with HIV. With improved methods, this group represents an ever-smaller percentage of pediatric AIDS cases. These children tend to be school age or adolescents, and have a host of special needs related to their entry into the adult world and sexual activity.

Because mother-to-infant transmission represents the most frequent cause of pediatric HIV infection, the distribution of AIDS in children will be shaped largely by patterns of HIV infection in women. Here, injection drug use is of central concern. Of the 2,490 cases of perinatally acquired pediatric AIDS reported to the CDC through March of 1991, 1,228, or 49 percent of these mothers were infected as a result of their own injection drug use and another 581, or 23 percent, from sexual relations with an injection drug user infected with HIV. This means that most pediatric cases occur in a setting of profound social disruption. In addition to poverty and lack of familial or community support, the child's health care needs may be compromised by overriding concerns regarding adequate food, housing, and transportation. This transmission pattern also means that at least one, and often both of the parents must face the personal burden of illness that their own HIV infection implies.

Children of minority families are disproportionately represented among those with HIV infection.

Asymptomatic Infection and the "At-Risk" Child: The clinical manifestations of HIV infection and AIDS in children are preceded by a period in which the child, although infected, may not exhibit symptoms or illness. Early in life, infected children may appear totally normal. This period of "asymptomatic infection" varies in length, but appears to be shorter in children who acquire HIV perinatally. AIDS symptoms develop in an estimated 5 to 10 percent of HIV-infected children in the first year of life and in approximately 8 percent per year thereafter. By age five, therefore, about half of the perinatally infected children will have developed symptoms. However, changes in treatment regimens may extend the period an infected child is symptom-free; even now, some children may not exhibit symptoms until long after birth, perhaps ten years or more.

Another problem reflects a shortcoming in HIV testing methods. Standard tests, which look for antibodies to HIV, cannot identify whether an infant born to an infected wom[illegible] is truly infected. This is beca[illegible] mother's HIV antibodies c[illegible] the placenta, and may be found in the infant's bloodstream for 15 to 18 months after birth. Not until the maternal antibodies in the infant disappear can standard screening tests distinguish between infected and non-infected infants. During this period, the child is considered to be "at risk" for infection and requires careful monitoring for biochemical and physical evidence of illness, and their families' psychosocial needs deserve serious attention. The sooner the child can be diagnosed, the sooner he or she can begin to receive treatment, with an anticipated improvement in morbidity and mortality. As direct testing methods, such as HIV cultures, are developed, they must be made available to all seropositive infants. Therefore, while the majority of infants born to infected women will not ultimately be infected, specialized services are required to assess their infection and clinical status as well as to respond to the ongoing and profound needs associated with maternal illness.

Clinical Manifestations: Children infected with HIV experience a variety of clinical problems. In the absence of definitive laboratory tests, these clinical manifestations may be the first sign of HIV infection. In general, clinical manifestations are due to the direct effects of HIV, as well as a number of secondary illnesses that occur as the child's ability to fight infection is impaired. The most common clinical problems are presented in *Table 1.*

Neurodevelopmental, Psychosocial, and Psychiatric Manifestations of HIV Infection and AIDS in Infants and Children: In general, children with chronic illnesses and their families may be at heightened risk for mental health problems because the strain of coping, added to the effects of poor physical health, may interact with other contributing factors to mental health problems, such as family disruption and

Table 1

Common Clinical Manifestations of Pediatric HIV Infection

Non-specific Syndromes: These include failure to thrive, wasting, enlarged lymph nodes (lymphadenopathy), enlarged liver and spleen (hepatosplenomegaly), persistent diarrhea, and recurrent fevers.

Neurologic Problems: These include brain disease, impaired capacity to learn, failure to neurologically develop at the expected rate, loss of certain functional capabilities once they are achieved, impaired motor functioning, delayed language, resultant severe impairments in social and emotional behavior, and other problems.

Impaired Lung Function: Lung function may be severely inhibited due to a syndrome known as lymphocytic interstitial pneumonia (LIP), which occurs in up to 40 percent of infected infants and children.

Recurrent Infections: Severe infections occur frequently, including bacterial, protozoal, and viral processes such as pneumonia and sepsis. Of special concern is pneumocystis carinii pneumonia (PCP) and infections that occur to impaired immune function (opportunistic infections).

Malignancies: Malignant blood disorders and tumors including lymphomas may also occur.

Multisystem Disorders: A variety of other syndromes affecting the heart, the kidneys, the skin and other body systems and functions are common.

Oral Conditions: Oral yeast infections (candidiasis), herpes simplex and herpes zoster infections, ulcerations, and parotid gland enlargement may occur.

poverty. For children with HIV infection or AIDS, the problems are even worse. Many HIV-infected children belong to single-parent families headed by HIV-infected mothers, women who may have limited social support and poor self-esteem, and who may be too ill to care for the child. If no one can assume the parental role, the child may face multiple disruptions in foster homes or institutional settings. Poverty, homelessness, drug abuse, and unemployment often exacerbate the problems associated with caring for seropositive children and their families.

Furthermore, the emotional impact of HIV infection and AIDS affects not only the children who are infected with HIV, but also their non-infected siblings. Additional threats to the family structure include multiple deaths, dissolution of the extended family, incarceration, additional illness, abandonment, court removal of children from home, and hospitalization of children or their parents.

Children with HIV infection may have serious neurodevelopmental disability, as evidenced by handicapping conditions such as language delays, motor impairments, and attention deficits. This disability appears early in the disease, frequently preceding other symptoms of the infection and often after a period of normal development. Since mother and child are often separated with one or the other or both hospitalized, these children also experience a range of psychiatric problems. Some infants and children develop signs of depression. Some, particularly the younger ones, exhibit symptoms that simulate autism. School-age HIV-infected children may display hyperactivity and attention difficulties.

Many HIV-infected children develop what appears to be an organic syndrome, with severely impaired social and emotional behavior. They show little or no affect, are unresponsive to social overtures from others, and demonstrate little purposeful behavior. Because these behaviors result in poor performance on a variety of cognitive tasks, it is difficult to determine whether their problems stem from impaired skills or represent an overall behavior disorder. ◆

Elements of Comprehensive Care for Children with HIV Infection

Some communities have developed comprehensive systems of care for children with HIV infection and their families. Their experience has made it clear that the services needed are many and diverse. Among such services, a high priority must be given to prevention activities that attempt to contain the spread of the HIV epidemic by changing high-risk behaviors, including drug abuse. Testing and counseling services for women and infants, in addition to augmenting prevention efforts, may facilitate early entry into appropriate medical care. In addition to basic medical care, children and families with HIV infection may benefit from special therapies to delay disease progression and prevent opportunistic infections. Innovative delivery strategies, such as coordinating a family's adult and pediatric care at the same facility, may improve the ability of infected family members to care for their own health.

A variety of developmental, educational, and support services may be necessary for children with HIV infection to develop to their full potential. Early intervention and Head Start programs can support children's development and enable them to participate fully in community life. Some children with HIV infection will require special education services as part of their public schooling while others will do well in regular education programs.

In-home support services are critical if families are to be able to care for their children at home. Nutrition and mental health services are also of special importance to children with HIV. Appropriately designed drug abuse treatment programs can be used to contribute to family stability and quality of care in families where illegal drug use is an issue. Families caring for children with HIV infection can help one another through support networks. Other families may need child care, housing, transportation, legal and advocacy services, foster care and adoption services, and/or group care.

Not every child and family will need every service. The particular constellation of services that will be needed by an individual child and family will depend on child and family strengths, needs, and resources, as well as the course of

Table 2

Elements of Comprehensive Care

Prevention
Education and Behavioral Change
Drug Abuse Treatment

Testing and Counseling

Integrated Medical Care
Basic Medical Care
Specific Therapies for HIV-Related Illness
Specialized Care for the Entire Family
Integrating Medical Care and Research

Developmental Services and Education Services
Early Intervention
Head Start
Special Education
Elementary and Secondary Education

Mental Health Assessments and Interventions

Basic Support Services
In-Home Support
Child Care Programs
Nutrition Services
Housing
Transportation

Social and Legal Services
Family-to-Family Support and Networking
Legal and Advocacy Services
Foster Care and Adoption Services
Group Care

the child's HIV infection. Nevertheless, the universe of integrated services for the child and family must include preventive, medical, developmental, social, and environmental support.

At a minimum, the kinds of services listed on the following table should be included in comprehensive, family-centered and coordinated care for these children and their families.

Prevention

Because vertical transmission is the most common route of childhood HIV infection, primary and secondary prevention goals include:

- reducing the prevalence of behaviors associated with acquisition of HIV infection by women of childbearing age;
- ensuring informed decision-making about pregnancy and pregnancy prevention by women already infected;
- enabling women who choose to continue to be sexually active to negotiate condom use to reduce the sexual transmission of HIV from injection drug users and other infected men; this should include the counseling of male partners;
- investigating strategies that attempt to interrupt the maternal transmission of HIV during pregnancy (chemoprophylaxis);
- identifying newborns at high risk for HIV infection in order to reduce the period of time between birth and the initiation of services; and
- preventing disease progression and opportunistic infections (i.e., early intervention).

No single approach to preventing HIV infection can be effective for all women, youth, and children. Prevention education must be individualized, tailored to the needs of the communities and groups that are most at risk of infection, and available in the areas where these individuals meet.

To be effective, prevention education must not shirk "tough" topics that many, including a number of professionals, may find difficult or embarrassing to discuss. Such topics include drug use and drug treatment; family violence; teenage sexuality; "safer" sexual activity, including the use of condoms; and birth control methods, including pregnancy prevention and counseling for already pregnant women. The link between HIV infection and poverty — the disproportionate infection rates in inner city communities — also necessitates prevention approaches that deal directly with issues of minorities, their culture, and their economic conditions.

Education and Behavioral Change: Preventive education programs can encourage people to adopt behaviors that reduce their risk of infection. Many women may believe erroneously that they are not at risk for HIV infection. Others may recognize the risk but not be able to negotiate safer behavior with their partner. Educational programs can help women and youth at high risk of infection develop a sense of power and control over their lives and their families' future.

The particular constellation of services that will be needed by an individual child and family will depend on child and family strengths, needs, and resources, as well as the course of the child's HIV infection.

Such an empowerment approach is particularly compelling when the educational interventions are conducted by members of the same high risk group. Speakers' bureaus that include adolescent mothers and other women who have given birth to HIV-infected children provide powerful advocates for prevention. Community-based outreach programs whose staffs include persons formerly at high risk, such as individuals who have traded sex for money or drugs, are effective means of reaching women at risk and helping them modify their risk behavior.

Drug Abuse Treatment: Drug abuse treatment for drug-dependent family members is an essential component of comprehensive, coordinated care because it allows families to continue to care for their infected children at home. Because injection drug use (IDU) is a major factor in the transmission of HIV to women, drug treatment is also a critical part of any prevention program. Of course, case management must ensure that drug treatment is coordinated with the other medical and social services provided to children with HIV infection and their families.

There are significant barriers, however, to drug treatment for most women, especially pregnant women and those women who are at highest risk of HIV infection—poor minority women. In many of the areas most affected by the HIV epidemic, treatment programs have long waiting lists. Most drug treatment programs are not geared to a woman's special needs and concerns as a woman and as a parent; many do not accept pregnant women at all.

However, a number of pioneering programs provide drug treatment designed for the special needs of women and their children. Among the common characteristics of such programs are the following:

- The staff acknowledge the influence of culture on drug-taking and help-seeking behavior. Staff include women from the same cultures and communities as the women seeking treatment.

- A variety of treatment options are available, including residential care that enables a woman to keep her children with her.

- The effects of violence against women and other family members are directly addressed as part of the treatment program.

- Support services for children of women in treatment include therapeutic child care, counseling, and peer support.

- Women are helped to find safe housing for themselves and their children, and are helped to build new support networks.

- Many follow-up services exist to support recovering women.

For more information on these types of programs, contact the Alcohol, Drug Abuse, and Mental Health Administration's (ADAMHA) Office for Treatment Improvement, (301)443-8802. For information on HIV outreach and counseling for drug-using women, contact ADAMHA's National Institute on Drug Abuse (Gloria Weissman, (301)443-6720) and its Drug Abuse Treatment and Referral Hotline 1(800)662-HELP; in Spanish, 1(800)66AYUDA.

Testing and Counseling

An important, though complex, prevention strategy involves counseling and HIV antibody testing. Such services can offer women important information regarding their health status, initiate specialized care if needed, and help them weigh reproductive planning considerations. Preventive health care for all women should routinely include assessment for behaviors that place women at risk for HIV infection, and education about sexually transmitted diseases, including HIV.

The nature of testing and counseling efforts in a particular community depends upon community structures and practices as well as the prevalence of HIV infection. The U.S. Public Health Service has recommended HIV counseling and testing for women at high risk for HIV infection and for all women in areas of high prevalence. Counseling and testing, or referral to counseling and testing, should be available in all settings where women routinely seek medical care, including family planning, gynecologic, prenatal, family or general medical, and primary care clinics, as well as inpatient settings.

Testing for HIV should include both an enzyme immunoassay (EIA, ELISA) and a supplemental, confirmatory test, such as the Western blot or immunofluorescence test. Using both these assays makes false positive results extremely unlikely. As noted earlier, in infants born to HIV-positive mothers, the antibody tests (both the EIA and Western blot) identify only a risk of HIV infection. Other tests and careful follow-up are needed for the actual diagnosis of HIV infection in a child.

Ideally, testing and counseling programs should be strongly linked with other service facilities and organizations to assure that the range of services required by women and children who test positive are accessible and of high quality. Financial and logistical barriers to care must be removed. A full range of medical, educational, social, and support services is needed to deliver the full benefits of testing — critical information on risk behaviors, partner notification services, and an opportunity for HIV-related discussion and education, as well as early medical intervention.

Confidentiality regarding the woman's and child's HIV status is essential to any testing program.

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Confidentiality regarding the woman's and the child's HIV status and protection of their rights is essential to any testing program. Disclosure of test results may cause infected individuals to lose their homes, their jobs, their insurance, and their social contacts. Children may encounter increased difficulty in finding school placement. These social issues, as well as the individual's emotional reaction to a diagnosis of seropositivity must be a central part of counseling and mental health services and should be addressed in any thorough and caring assessment of HIV testing policies.

Integrated Medical Care

Treatment of pediatric HIV infection requires a chronic-disease-oriented, multidisciplinary team approach that integrates primary care, including health maintenance, with specialist referrals and specialized hospital-based and home-based services (see *Table 2* on p.22). The goals of medical care for a child with HIV infection are as follows:

- to ensure that the child's basic health needs are met through comprehensive primary health care;

- to continuously assess the clinical impact of HIV infection on the child;

- to meet the child's medical needs through the purposeful integration of research and comprehensive care; and

- to help identify and coordinate psychosocial and support services for the child and family.

Basic Medical Care: Basic health care is critical for infants and children with HIV infection and should include standard pediatric care practices such as history and physical examinations; lead screening and other appropriate lab tests; growth and developmental evaluation; vision, hearing, and dental screening; nutritional and developmental guidance; and immunization. Because vaccine-preventable diseases can cause severe illness and death, immunization is especially important for HIV-infected children. Because of HIV-induced immune suppression in the children and their family members, the Advisory Committee on Immunization Practices (ACIP) has recommended some changes in routine vaccination and passive immunization following exposure to vaccine-preventable diseases. Poverty and possible drug use in the family place many children at high risk for other health problems that must be addressed as part of basic medical care. For further information, see *Guidelines for Health Supervision*, "Recommendations for Preventive Pediatric Health Care," published by the American Academy of Pediatrics, Chicago, Illinois, 1(800)443-9016.

Specific Therapies for HIV-Related Illness: Clinical research has demonstrated that the quality and duration of life for infants and children infected with HIV can be improved. Antiviral drugs are a significant component of medical therapy for these children. The use of the antiviral agent AZT (azidothymidine or zidovudine) may reduce AIDS-related neurological disease and improve immune function and growth. However, the use of AZT can cause serious toxic side effects, and it does not represent a cure. To the extent it delays disease progression, it provides hope that future antivirals will produce more effective and permanent solutions. New antiretroviral therapies are being used as single agents and in combinations with AZT. The combination approaches using multiple agents with different side effects have been designed to mitigate toxicity. Further, pharmacokinetic studies of the antivirals known as dideoxynucleosides have shown that it is important to monitor children to determine optimal drug dosing.

A host of illnesses caused by bacteria, viruses, and parasites also take advantage of the weakened immune system of HIV-infected children. These secondary, or opportunistic, infections not only interfere with a child's health and well-being, but also can accelerate the course of the HIV infection itself. The child's clinical status needs to be carefully monitored and the need for preventive medication regimens must be regularly assessed. Guidelines for preventing *Pneumocystis Carinii* pneumonia (PCP) initiated by the National Pediatric HIV Resource Center were published in CDC's *Mortality and Morbidity Weekly Report (MMWR)*, Volume 40, RR-2, March 15, 1991.

The National Institute of Child Health and Human Development (NICHD) of the National Institutes of Health (NIH) has recently completed a clinical trial examining the role of intravenous immunoglobulin (IVIG) in the prevention of serious bacterial infection in symptomatic HIV-infected children. This study demonstrated that IVIG (in a dose of 400 mg/kg every 28 days) delayed the occurrence of serious infections when given to children whose levels of CD4 white blood cells exceeded 200/mm3. It should be noted that there was no difference in survival between treated and untreated children. IVIG was also associated with a reduced rate of acute care hospitalizations for these children. Physicians caring for HIV-infected children will have to decide the utility of IVIG on a case-by-case basis. Additional information about this clinical trial may beobtained by calling 1(800)TRIALSA.

Specialized Care for the Entire Family: HIV infection can affect all members of the family, infected or not. Clinical centers treating children with HIV infection and their families have found that most infected women faced with conflicting demands on their time and energy will take care of the medical needs of their infected children at the expense of their own health. Ultimately, of course, the neglect of her own health reduces the mother's ability to care for her children. Therefore, "one-stop shopping" medical care, in which all family members (including fathers) receive coordinated care from the same source, is considered a particularly useful way to structure clinical practice for children with HIV infection and their families.

Integrating Medical Care and Research: Pediatric HIV infection has a poor prognosis, and many of its clinical manifestations are unique and only recently described. Certain clinical manifestations lack any approved therapies. For this reason, children need to have access to clinical trials, and they need to receive care that reflects the most current research. A multidisciplinary, clinical care/research team is therefore essential.

In general, the careful integration of clinical care and research protocols is best ensured by a strong family-centered, community-based approach. Serious ethical questions often emerge by integrating research and care. Families must fully understand their child's condition and the nature of available treatment options. Foster parents and state social service agencies may also play important roles in determining clinical care and participation in experimental protocols. Family-centered, community-based care provides the critical framework within which these difficult issues can best be addressed.

For more information on this aspect of research, see the upcoming publication by the U.S. PHS Panel on Women, Adolescents, and Children, *Points to Consider: Involving HIV Positive Children Who Are Wards of the State in HIV/AIDS Research*, to be available from the Office of Protection from Research Risks, National Institutes of Health, Bethesda, Maryland 20892.

Developmental and Educational Services

Developmental disability as a result of pediatric HIV infection is so widespread that in the next several years HIV infection will likely become the primary infectious cause of developmental disabilities and neurological impairment in children. The damage frequently produced by such neurological impairment includes progressive encephalopathy, loss of developmental milestones, impaired brain growth, weakness, and ataxia. In fact, an estimated 78 to 90 percent of children with symptomatic AIDS have accompanying central nervous system dysfunction.

Additionally, maternal HIV infection or illness and other indicators of family vulnerability, such as poverty and possible parental drug use, place both infected and noninfected children at high risk for developmental problems.

Early Intervention: Clearly, infants and young children with HIV infection are candidates for the kinds of developmental and family support services known as "early intervention." Under P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, states are developing statewide comprehensive systems of early intervention for children with developmental delays from birth to three years of age, and establishing early childhood special education services for children from three to six years of age. Each state is determining for itself, within certain guidelines, which children and families will be eligible for services and whether or not the state will choose to serve children identified as being "at risk."

Many states are including children with HIV infection and AIDS in their definitions of "developmental delay" and "at risk." Even in those states that do not explicitly include HIV infection and AIDS, infants and young children with HIV infection or AIDS and their families should be able to qualify for services under the general definitions provided.

For more information about eligibility for early intervention and early childhood special education in a specific state, contact the Governor's office for the name of the P.L. 99-457 "lead agency" in that state. For more information about effective models of developmental and family support for children with HIV infection, contact Dr. Merle M. McPherson, Maternal and Child Health Bureau, U.S. PHS Health Resources and Services Administration, (301)443-2350.

Head Start: Head Start is a national program for preschool age children from low income families. Head Start provides comprehensive developmental services based on the needs of an individual child, the child's family, and the community in which the family lives. Most young children with HIV infection and their families qualify for Head Start services based on family income.

At least 10 percent of Head Start's enrollment is reserved for children with special needs, and Head Start has been instrumental in developing models for support to children with HIV infection and their families.

For more information about Head Start opportunities for children with HIV infection, see the more detailed section on Head Start under "Financing Family-Based, Community-Based Care" on page 50.

Special Education: P.L. 94-142, the Education of the Handicapped Act, and Section 504 of the Rehabilitation Act of 1974, established the right of all children in the United States to a free public education, regardless of handicap or disability. These laws and the accompanying regulations also establish a child's right to an education in the "least restrictive environment." Therefore, no child with HIV infection can be denied access to public education or forced into segregated facilities. Children who are developmentally disabled as a result of HIV infection are entitled to special educational services and an Individualized Education Plan designed to meet their particular learning needs. Such support may include special instruction; physical, occupational, and speech and language therapy; and other related services necessary for the child to benefit from special education.

Each state has a Federally-funded Protection and Advocacy program that advocates for the rights of children and adults with disabilities. For more information about Federal and state laws ensuring free, appropriate public education for children who have special educational needs as a result of HIV infection, contact the *Protection and Advocacy Program* in the state in question or the National Association of Protection and Advocacy Systems, Inc., at (202)408-9514.

Elementary and Secondary Education: School attendance plays a critical role in a child's well-being. Children who are HIV-infected but not in need of special education services are entitled to the same public education as other children, and cannot be denied access to their neighborhood public schools. Section 504 of the Rehabilitation Act of 1973 and, more recently, the national Americans with Disabilities Act of 1990 require, among other things, that persons with disabilities be provided access to publicly-funded services and resources. Families caring for children with HIV infection may need legal and emotional support to help them ensure their child's access to public school.

Many state departments of education and local school boards have developed policies to ensure that children with HIV infection have access to their neighborhood public schools. For more information about this issue, see *Someone at School Has AIDS: A Guide to Developing Policies for Students and School Staff Members Who Are Infected with HIV* available from the National Association of State Boards of Education, 1989, 1012 Cameron Street, Alexandria, Virginia 22314.

Mental Health Assessments and Interventions

Assessment of the psychiatric and neurodevelopmental correlates of HIV infection and AIDS in infants and children is important in the evaluation of pharmacologic interventions, the efficacy of drug therapy, and the effects of other interventions such as physical therapy.

All aspects of normal child development, including psychosocial development, are threatened by the chronic condition of HIV infection and AIDS. Providing the opportunity for maximal psychological and social development involves minimizing hospitalization and special institutional care and enabling youngsters with AIDS to have normal contact with members of their family and community. Support given to children infected and affected by AIDS should emphasize developing independence, mobility, and self-care to enhance the child's sense of self. In all interventions, the wishes of the child and the family, the law, and appropriate confidentiality must be paramount considerations.

Psychosocial interventions should be ethnically, culturally, and gender-specific, and should be aimed at reducing stress and facilitating coping within family systems. A comprehensive model service delivery program must include mental health services that are coordinated with treatments for the whole spectrum of AIDS-related disorders as they occur in families. Psychosocial interventions, including social and community services, should support the family structure, strengthen the parental role, and maximize family involvement in decision-making.

The goals of mental health service programs for families with HIV infection are to: (1) monitor developmental delays; (2) reduce HIV-related distress and associated dysfunctions in the home, school, and interpersonal relationships; (3) increase adherence to medical treatments; (4) treat pre-existing or recently developed psychopathology, including depression, anxiety, maladjustment and organic mental disorders; and (5) provide family support. Mental health programs for pediatric AIDS should also foster acceptance of HIV-infected children in the home, school, and community settings.

See Appendix A for further information on neuropsychological assessment in children, Appendix B for further drug abuse information, and Appendix C for the characteristics of effective mental health services. For a comprehensive listing of mental health services in every state, see the *Mental Health Directory 1990*, publication number 017-024-01419-2, available from the U.S. Government Printing Office, Superintendent of Documents, Washington, D.C. 20402.

Basic Support Services

In-Home Support: Caring for children with HIV infection at home is demonstrably more humane and cost-effective than hospitalization. Support services that enable families to care for their children at home are urgently needed by both foster and birth families, yet in-home services are often least available in the inner-city communities most affected by the HIV crisis. Developing options for in-home support in all communities is essential in the development of comprehensive, coordinated care.

In-home care includes home health services; nutritional support and homemaker services; nursing services to monitor medication and to provide direct patient care; respite care; social work support and counseling; and hospice care. In-home care providers can also teach family members and friends the skills they need to care for children with HIV infection at home. The success of in-home care depends, as does all pediatric HIV care, on care coordination, or case management, that links in-home care with medical, developmental, and social services.

In some states, certain Medicaid requirements have been waived in order to cover in-home care, beyond room and board, that is not otherwise available under the State

Medicaid Plan. A written plan of care and evidence of cost-effectiveness are necessary to obtain such waivers. Children covered by these Home and Community-Based Services (HCBS) waivers must be Medicaid-eligible and must otherwise require an institutional level of care. For example, the New Jersey HCBS waiver furnishes private duty nursing, case management, intensive foster care, and other services to Medicaid-eligible asymptomatic infants. In California, however, the Medicaid HCBS waiver serves only children with an AIDS/ARC (advanced HIV) diagnosis. For information about waivers and how to apply for them, contact the Health Care Financing Administration regional office with Medicaid oversight responsibility for your state. See listing of Associate Regional Administrators for Medicaid (HCFA) in Appendix D.

Child Care Programs: Child care that provides a safe and supportive environment for children while their parents and other family members address their own health care and support needs is essential to enabling children with HIV infection to live at home rather than in hospitals or other institutions. It should be available for all children in families affected by HIV infection, including foster and adoptive families.

Child care can consist of a variety of options and arrangements, including babysitting, respite care, family-home child care, center-based child care, and emergency residential care for short periods when family members become temporarily unable to care for children at home. Medical day care is also needed for children in the advanced stages of disease.

Nutrition Services: For children with HIV infection, nutrition may be jeopardized by poverty, illness, loss of appetite, and increased metabolic demands. In addition, parental illness may make the regular preparation of well-balanced meals difficult. Nutritional support services to address these problems should build on existing nutrition programs such as Women, Infants, and Children Nutritional Supplementation Program (WIC) and breakfast and lunch programs at schools and various child care centers. For information and a contact for WIC programs, see a more detailed description on page 53.

Caring for children with HIV infection at home is demonstrably more humane and cost effective than hospitalization.

Housing: Housing often is one of the most critical needs of women and children with HIV infection. Most HIV-infected women are poor and may suffer from related social problems, such as family violence, drug abuse, and/or social isolation resulting from community fear and ignorance about HIV. As parents and other caretaking adults with HIV infection become increasingly ill, they may need housing arrangements that provide significant supervision and homemaker services. Others with HIV infection, however, may be homeless and live on the street. State Medicaid agencies are required to provide cards verifying Medicaid eligibility of individuals who lack a permanent dwelling, fixed home, or mailing address, to assure their access to Medicaid benefits.

The Federal Government is responding to these needs in a variety of ways. For information on Federal housing initiatives that address problems of HIV-infected individuals such as the McKinney Assistance Act program, contact the non-Federal organization, AIDS Action Council, 2033 M St. NW, Suite 801, Washington, D.C. 20036, and the Office for Housing for Handicapped People, U.S. Department of Housing and Urban Development (HUD), 451 7th St. SW, Washington, D.C. 20410.

Transportation: Transportation is a key concern for many families caring for children with HIV infection. Many do not have cars; others cannot afford to operate them; and many are no longer well enough to drive them. HIV-related weakness, illness, or disability also limits the viability of buses and subways as transportation options, yet taxicabs are prohibitively expensive for most families. Therefore, providing or subsidizing transportation to and from medical, educational, developmental, and social services is a necessary component of comprehensive care. Bus and subway tokens, taxi vouchers, and special mass transit vans for persons with disabilities have all been successfully used to enable families to participate in HIV services and other community programs. Volunteers using their own cars have also been an effective resource for children and families with HIV infection.

Social and Legal Services

Family-to-Family Support and Networking: Families caring for children with HIV infection can be a significant source of mutual support and friendship by sharing feelings, common experiences, and expertise through group meetings, parent-to-parent visitation programs, and telephone networking. These support systems can ease frustration, overcome loneliness, and end social isolation. Such networks also provide a non-threatening, supportive setting that encourages families to help others, establishing a two-way process that is itself therapeutic and empowering. Family-to-family support is essentially a volunteer effort, but professionals can help by putting families in touch with other families, by providing space for meetings and get-togethers, and by helping defray copying, telephone, transportation, and other incidental costs.

Legal and Advocacy Services: Families caring for children with HIV infection may have a broad range of legal and advocacy needs. Parents who are themselves infected often need help preparing wills and medical powers-of-attorney and legal arrangements for custody in case they become too ill to make decisions for their own care and the care of their children. They also may need legal advice on child custody issues or drug-related legal problems. Finally, as long as fear and uncertainty cloud efforts to diagnose, treat, and live with HIV infection, families will need legal assistance to invoke anti-discrimination protections.

These protections apply to finding jobs, getting or keeping health insurance, ensuring informed consent and confidentiality, gaining access to public and private housing, and ensuring children's access to early intervention, day care, preschool, or public school. Discrimination in furnishing health care services to Medicaid- or Medicare-eligible persons with HIV infection or AIDS violates Federal civil rights laws and can be a basis for terminating provider participation in these programs. Complaints alleging such discrimination should be reported to the appropriate Office of Civil Rights and HCFA regional offices for investigation.

State Protection and Advocacy agencies can provide a variety of legal services to protect the rights of developmentally disabled persons with HIV infection. In addition, state bar associations, legal aid societies, and many law schools encourage *pro bono* services by both practicing attorneys and law students. For more information about legal issues for persons with developmental disabilities and HIV infection, contact the American Bar Association, AIDS and

Developmental Disabilities Project, 1800 M St., NW, Washington, D.C. 20036 for their legal publication, *AIDS and Persons with Developmental Disabilities: The Legal Perspective.*

Foster Care and Adoption Services: Although most children with HIV infection live at home with parents or extended family members, current estimates indicate that 10 to 30 percent of these children are in foster care. As of June, 1989, approximately 800 children with HIV infection were in foster care across the Nation. Family foster care is intended to provide a safe, nurturing, and loving home for children when birth families are temporarily or permanently unable to care for them. When parents or other family members are permanently unable to care for their children, adoption gives children with HIV infection — and their uninfected sisters and brothers — an opportunity to have a permanent home and family.

Foster and adoptive parents of children with HIV infection need a variety of support services to help them care for these children at home. Many of these services are the same ones that birth families need; others are specifically related to foster care. Based on the experience of many states and programs, the following services will enable foster parents to care for children with HIV infection:

- higher board rates for HIV infected and medically fragile children;
- training and support on issues related to HIV infection, including transmission, infection control procedures, medical and developmental complications, confidentiality, participation in research, and grief, loss, and bereavement;
- regular consultation with medical and child welfare staff;
- in-home nursing care, homemaker services, and respite care; early intervention and day care; and
- support groups and other networking opportunities for foster parents.

State Medicaid agencies are required to provide Medicaid to children for whom adoption or foster care maintenance payments are made under title IV-E of the Social Security Act.

A number of specialized HIV foster care programs are under development across the country. Leake and Watts, a child welfare agency in New York City, established such a program in 1985 and now operates a Pediatric AIDS Foster Care Training and Technical Assistance Project. For information and resources, including the *Pediatric AIDS Foster Care Network Bulletin,* contact the project at Leake and Watts, 487 South Broadway, Suite 201, Yonkers, New York 10705.

Group Care: Like all children, children with HIV infection deserve to live in a permanent home with a loving family, whether it is a birth family, a foster family or an adoptive family. However, group care may sometimes be necessary for children awaiting foster or adoptive homes or reunification with their families. It is essential that group care be considered only as a temporary arrangement, be developmentally supportive, be staffed with appropriately trained personnel, and welcome and encourage the involvement of the child's family.

CREATING A COMPREHENSIVE SYSTEM OF CARE

A wide range of services is necessary but not sufficient for the creation of a comprehensive system of care for children with HIV infection and their families. A system of care will not exist until these individual services are linked together to form a whole. Coordination is the key to these linkages, both at the level of system and program design and at the level of care coordination for an individual child and family.

Creating a coordinated system of care requires that everyone involved — state and local policy makers, professionals, families, and the community — commit themselves to interdisciplinary and interagency partnerships. Personal, public, private, and corporate resources are all necessary to meet the complex needs of these children and families. The Pediatric Oncology Program of the National Cancer Institute at the National Institutes of Health is one such example. This Federally-funded effort provides total comprehensive care for children and, acting in concert with the Adult Medicine Branch of the Clinical Oncology Program, is actively implementing comprehensive family-based care. The contact person is: Dr. Philip A. Pizzo, National Cancer Institute, Building 10, Room 13N240, Bethesda, Maryland 20892, (301)496-4256.

Fostering Community Support

Community support is one of the single most important factors in determining the success of a program for children with HIV infection and their families. Such support is essential if the necessary mix of public, private, and corporate resources is to be realized.

Many communities are fostering support for HIV programs through task forces or other consortia made up of public policy makers, health care providers, educators, social service providers, civic leaders, and families. Such consortia can shape public opinion and develop support for services through community education to promote HIV awareness, media interviews and public service announcements, meetings with local and state legislators, and fundraising events.

Assessing Community Needs

Community needs should be assessed concurrently with, and as a part of the process for, developing community support for programs to serve children with HIV infection and their families. The purpose of this needs assessment is to identify available resources, both HIV-related and non-HIV-related; to identify current gaps in services; to increase awareness of the need for comprehensive care programs to close these gaps; and to identify local agencies, providers, and community members who are willing and able to provide services and supports to children and families with HIV infection.

Among the kinds of programs and services that should be reviewed in the needs assessment are primary, secondary, and tertiary medical facilities; universities and other research institutions, including University Affiliated Programs (UAPs); local, state and Federal government agencies and programs, including, for example, Medicaid, child welfare, and health care programs; community social service and child welfare agencies; child care centers and Head Start programs; early intervention, family support, and family resource programs; local education agencies and public and private schools; organizations for persons living with AIDS/HIV and minority community-based organizations; private insurers and health care providers; adult AIDS organizations; gay and lesbian organizations involved in AIDS issues; volunteer clearinghouses; neighborhood development and civic organizations; and churches, synagogues, mosques, and other spiritual institutions.

Consulting with Families

To be effective, comprehensive care systems and programs must be designed to meet the real needs of children and families, as perceived by the families themselves, rather than identified only by professionals. In recent years, families of children with special health care needs have increasingly come to be recognized as vital consultants and advisors to program planners and care providers. In a 1988 meeting with Federal health policy makers for instance, a variety of birth, foster, and adoptive parents and extended family members demonstrated that families caring for children with HIV infection are able and willing to help plan services for their own children and, given proper support and assistance, to advise about and advocate for services for other children as well.

It is essential that family consultants and advisors reflect the culture, language, race, ethnicity, socioeconomic status, and routes of transmission of the families in the communities to be served by the program. Because child and parental illness, family drug dependence, and poverty are often factors in the lives of these families, it is important that programs rely on a variety of families for consultation to avoid overburdening any particular families at times of crisis.

Coordinating the Care System

The many different kinds of services and providers needed by children and families with HIV infection require extraordinary coordination to operate as a system of care. Such a system of care must integrate highly specialized HIV-related medical care with basic primary care, and this integrated medical care must itself be integrated with developmental and social services. All this must be done within a framework that allows close communication and coordinated decision-making by families and professionals from many disciplines and agencies.

Linking Medical Services: The existence of primary, secondary, and tertiary medical care within a geographic area does not guarantee that an integrated system exists. Particularly critical is the coordination between clinical out-patient care and in-hospital care (for example, follow-up and monitoring). Arrangements such as the following are necessary to develop and maintain an integrated system:

- integrated clinical care protocols to guide coordination of primary care, referrals, and in-hospital management;
- communication guidelines and mechanisms to ensure that providers at all levels of care have up-to-date information on a child's medical status; and
- joint educational programs to facilitate timely dissemination of important clinical care recommendations and to stimulate discussion and exchange among care providers.

Federal, state, county, and local financial and reimbursement policies also must be examined to ensure to minimize financial disincentives that hamper coordinated care.

Linking Medical Services with Developmental and Social Services: The survival of many children with HIV infection and AIDS and their families depends on the linkage of existing medical, developmental, and social service systems; collaboration among these systems and personnel must be institutionalized. At a minimum, regular meetings must take place between medical care providers, child welfare and other social service workers, and developmental specialists and educators.

The survival of many children with HIV infection and AIDS and their families depends on the linkage of existing medical, developmental, and social service systems.

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There are numerous approaches to developing and institutionalizing such links. One of the most promising may be the "transagency" model. This model applies the principles of transdisciplinary team-based service delivery to community service systems. In this model, services are coordinated by a board made up of staff from relevant agencies. Care coordination teams are formed across participating agencies to develop and implement, with the family, a family care plan.

For more information about this approach or how to receive training in the transagency service delivery model, contact Projects WIN and STAR, 1800 Columbus Avenue, Roxbury, Massachusetts 02119.

Coordinating Care for the Child and the Family

Just as the system of care must be coordinated, so too must be the services that an individual child and family receive. Care coordination, or case management, is the vehicle for coordinating the services that make up child and family careplans. Care coordinators ensure that children and families have access to all needed services; promote integrated care by linking medical, developmental, and social service providers; follow-up to ensure that these families receive the services and that the services are acceptable; advocate for and act as liaison between the family and other members of the care team; and empower families in the care of their children and themselves.

All of the current pediatric AIDS demonstration projects funded by the Health Resources and Services Administration (HRSA) have a care coordination component, usually called case management. The locus of care coordination varies among projects. In some, care coordination is based in a tertiary care center; in others, it is located in a community-based service organization. The New Jersey Statewide Health Services Network for Children with HIV Infection and Their Families, for example, is built upon the state's 30-year-old system of case management for children with special health care needs through the Title V program.

The Boston Pediatric AIDS Demonstration Project features a Family Support Team that includes a case manager, social worker, and outreach worker based in a community health center to work with families to develop and implement a service and referral plan. The Case Management Demonstration Program in Los Angeles County uses an automated case management system for care planning and coordination. Alabama, Maryland, Pennsylvania, and Washington State Medicaid programs use targeted case management services to link eligible persons with AIDS to medical social, educational and other services.

Other HRSA-supported activities which provide case-management activities for HIV-infected children and their families include the Primary Care and HIV Initiative and Health Care for the Homeless Program supported by HRSA's Bureau of Health Care Delivery Assistance (BHCDA), as well as the Primary Care and Substance Abuse Linkage Program, jointly sponsored by ADAMHA and HRSA. For more information, contact Ms. Joan Holloway, Division of Special Populations, HRSA/BCHDA, (301)443-8134.

Recruiting, Training, and Supporting Care Providers

To a great extent, a comprehensive system of care for children with HIV infection and their families depends on the existence of well-trained and willing care providers who are committed to working across agencies and across disciplinary boundaries.

Preferably, program staff should reflect the culture and ethnic background of the children and families that the program is serving. Traditional methods of recruitment must be supplemented by creative non-traditional methods such as speaking to community and church groups, utilizing the media, and others. Incentives in terms of salary, vacation, insurance, and personal time policies must attract qualified and dedicated candidates.

Depending on its structure (whether staff for a coordinating body, a hospital-based program, or a home- and community-based effort), a comprehensive care delivery system will require a team of medical and social service workers, including medical and allied health professionals, social workers, mental health specialists, developmental specialists, physical and speech therapists, and educators. At all times, staff should have access to medical and nursing staff for medical updates and client health monitoring. Formal and informal pre-service and ongoing staff training is essential. The caregivers will need emotional support to reduce stress and to pace themselves when faced with difficult family issues. Such support comes not only from staff support sessions, but also from rituals that help staff acknowledge and express their emotions — attending funerals and memorial services, or holding ceremonies to celebrate life and growth, such as a child returning to school after hospitalization.

For information on Federally-sponsored HIV training for health care professionals, contact Ms. Cherry Tsutsumida of HRSA's Educational and Training Center Program at (301)443-6817. In addition, WIN Outreach, a project operated by Project STAR, provides training and technical assistance geared to the needs of staff providing comprehensive care to children with HIV and their families. WIN training ranges from hour-long to five-day workshops, tailored to meet the needs of each site. For information, contact Project STAR at (617)442-7442.

Coordinating Volunteer Efforts

Volunteers and voluntary organizations are essential contributors to a comprehensive system of care. To be most effective, voluntary efforts must be fully integrated with the other elements of the care system. The cost of expanding the volunteer community committed to pediatric HIV infection is usually quite modest and may be limited to training volunteers on pediatric HIV issues; to coordinating and supervising volunteer providers; to training volunteers to train other volunteers and families: and to providing emotional support and counseling for volunteers around issues of grief and loss. State Medicaid agencies are required to train and make use of volunteers in providing Medicaid services; volunteers may be reimbursed only for actual expenses incurred in rendering such services.

Although there are many differences between pediatric and adult HIV infection, the massive volunteer efforts that have been essential to fighting the adult epidemic offer important lessons for programs concerned with children and families. These adult efforts, led for the most part by community-based gay men's organizations, can be a substantial resource for the pediatric community, organizing, for example, "buddy programs" to provide respite care for families, or operating residences for HIV-infected families.

The massive volunteer efforts that have been essential to fighting the adult epidemic offer important lessons for programs concerned with children and families.

Families of children with HIV infection can be a valuable resource to the pediatric HIV care system. Many families are interested in supporting other families and sharing expertise on caring for infected family members. Many parents who are themselves infected seek to help others; such reciprocal help-giving opportunities help families recognize and build on their family and community strengths. Time spent recruiting, training, and supporting families in such roles will be amply repaid by the development of a cadre of committed, experienced volunteers. •

Estimated Cost of Direct Medical Care

The limited data available suggest that the lifetime cost of direct medical care for pediatric HIV/AIDS totals about $50,000 per child. Most of the cost is attributable to inpatient hospitalizations, which are somewhat more frequent for infected children than for adults and are concentrated in the final stage of illness (AIDS). The U.S. Health Care Financing Administration (HCFA) estimates that, nationally, Medicaid serves at least 40 percent of all AIDS patients and up to 90 percent of all children with AIDS.

The medical costs associated with pediatric HIV infection are changing rapidly. Many of the strategies and drugs used in treating pediatric HIV are experimental, and their costs have not been reflected in past studies. If these strategies succeed in reducing morbidity and extending survival, it is difficult to assess what overall impact they will have on the lifetime cost of care. Whatever that impact, community-based care can help to contain costs by reducing unnecessary hospitalizations. It can also make a major contribution to the quality of life for children with HIV infection.

Locating and Integrating Funding Streams

Given the scope of services needed by HIV-infected children and their families, it is not surprising that financing for these services must be obtained from a variety of sources. Integrating Federal funding streams is complicated by the fact that local program administrators have somewhat limited opportunity to combine Federal entitlement programs, block grants, and discretionary grants. Those communities that have responded most vigorously to the HIV epidemic have been able to support services from not only Federal but also state and local government sources, foundations, businesses, other private sources, and volunteer efforts.

As this document shows, a wide variety of services is required from cooperating agencies and providers to help create family-centered, comprehensive, coordinated systems of care. Because these agencies all have their own languages and ways of operating, it is important for program administrators to help them articulate common interests and identify mutual tasks.

This shared process of articulating common interests and identifying tasks results in a political and management coalition that can then develop its own strengths and program directions. Successful relationships in such a coalition are based on detailed planning, clearly identified roles and responsibilities, program monitoring, periodic evaluation and revision, and constant cooperation. Written agreements can provide a framework for effective collaboration and shared use of resources.

Often administrators have to be flexible in finding ways to sustain community-based care programs, both financially and politically. Some of the programs developed with government and foundation support have begun as time-limited demonstration projects; when these expire, ongoing sources of funding must be in place.

Over the course of a time-limited demonstration project, Federal, state, and local policymakers can help program administrators identify additional funding sources to provide continuity in client services. It is critical that program administrators and those whom the programs serve make these programs well-known to legislators and policymakers. Program administrators should make these contacts early in the life of the program and should provide progress reports as the program matures. In this way, when continuation or bridge funding is sought, dialogue will already be established and the program will be familiar. Also, in discussions with policymakers, program administrators should identify barriers to effective utilization of existing resources.

The types of services covered by any particular entitlement program are often subject to administrative constraints. If local programs are to be comprehensive, program administrators will need to not only highlight such constraints, but also identify complementary sources of funding to fill coverage gaps. For example, although good housing and nutrition are crucial to community-based care programs, many medical entitlement programs do not cover them. Funds may be available for these purposes, however, from social service programs.

Similarly, there may be restrictions upon the levels of reimbursement available through entitlement programs. For example, because medical care for HIV is often more intensive and comprehensive than that required for other diseases, ceilings on provider fees may threaten to limit services. In a number of states, reimbursement programs have been redesigned to accommodate the needs of people with HIV. Thus, for instance, some state Medicaid agencies have established special rates and/or have developed special diagnosis-related groups (DRGs) to enhance reimbursement for hospitals for the care of HIV-infected patients. Medicaid waivers have been obtained by over a dozen states to allow for the reimbursement of home- and community-based services; and payments made to foster parents of children with HIV have been increased above previous ceilings.

Because of wide variations in state and local resources, as well as in the way states structure their use of Federal entitlement and grant programs, it is impossible to draw up a universally satisfactory manual for the financing of HIV care. While programs developed in some states may serve to inspire efforts in other states, adapting them to meet local needs may be difficult. However, some strategic advice can be offered to help in the development of local family-centered, community-based programs:

- Resources, regardless of amount, can be used more effectively when they are coordinated across agencies and disciplines, when they are directed toward the specific, expressed needs of the family, and when they enhance or extend existing care systems rather than create new ones.

- Needs assessment can provide information to help with program advocacy, planning, and management.

- Local consortia and task forces may be effective in developing integrated community-wide programs.

- Families currently receiving services are an invaluable source of information about barriers to care and, thus, the need for program enhancements.
- For children and mothers with HIV, many benefits are available through existing programs for maternal and child health.
- Private donors are often willing to make capital outlays to develop facilities, especially when there is assurance of a continuing funding stream to provide services in these facilities.
- Potential donors are particularly supportive of programs that have incentives to use resources efficiently, such as those that emphasize preventive and out patient care.
- It is wise to seek support from local employers that have particular interests in helping children, for example, public utilities or companies that provide services or health products.
- From the moment time-limited programs begin, administrators must plan for and seek new sources of support.
- Revenues can be increased through effective coordination of benefits. For example, several states have found it cost-effective to pay for extensions of clients' insurance coverage, relieving the burden on Medicaid.

Given below are descriptions of several specific funding streams that have been used in the financing of family-centered, community-based care for children with HIV and their families. Among the Federal resources of funding available are Medicaid, including optional waivers for home- and community-based services care; U.S. Public Health Service programs, including model health care programs such as Title V Maternal and Child Health block grant programs and pediatric AIDS model demonstration programs, Community and Migrant Health Centers, and substance abuse programs; and other Department of Health and Human Services programs, including Social Services block grants (Title XX), Head Start programs, the Abandoned Infants Assistance Act, and the Administration on Developmental Disabilities.

In addition, a summary of state activity on pediatric AIDS is provided, as well as a listing of several private sources of funding and national organizations that fund services for children with HIV infection and AIDS.

Table 3

Federal Resources

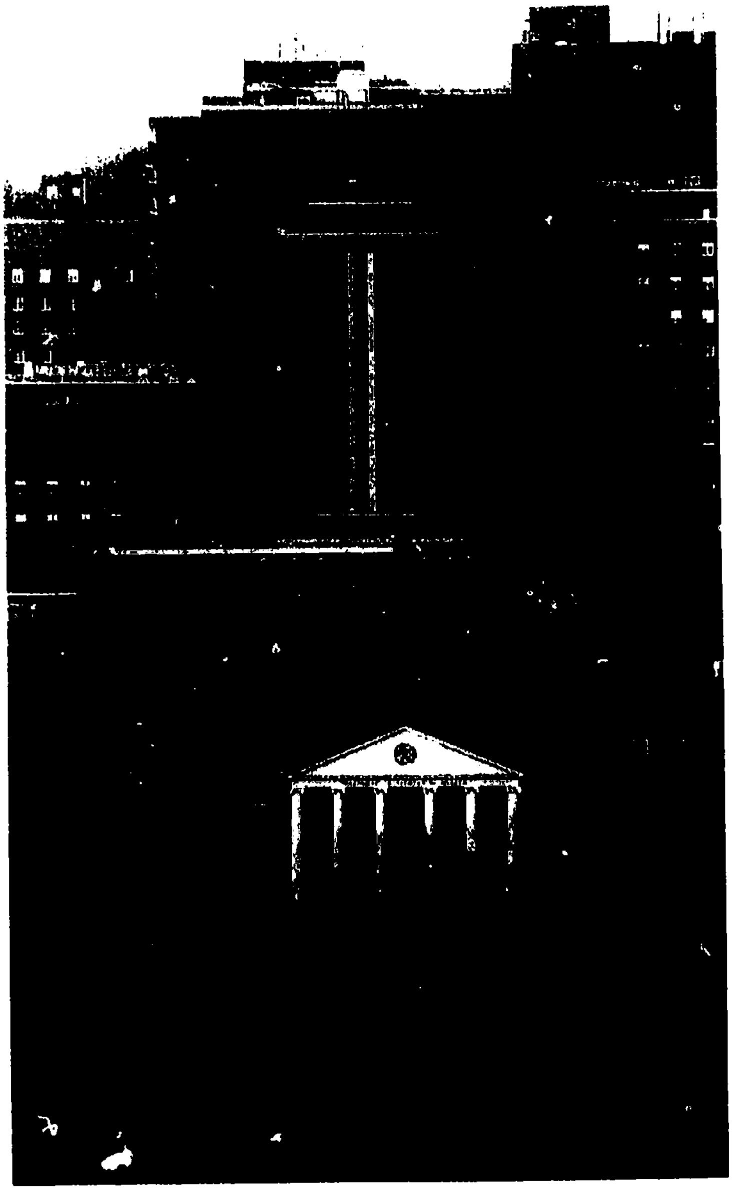
Health Care Financing Administration
Medicaid

U.S. Public Health Services
Perinatal HIV/AIDS Prevention Programs
Model Health Care Programs
Substance Abuse Treatment Programs
HIV/AIDS Research

Federal Human Services, Education, and Nutrition Programs
Social Services Block Grant (Title XX)
Head Start
Abandoned Infants Assistance Act
Administration on Developmental Disabilities
Early Intervention Program for Infants and Toddlers with Handicaps (P.L. 99-457)
National Institute on Disability and Rehabilitation Research Programs (NIDRR)
Early Education Program for Children with Disabilities (EEPCD)
Special Supplemental Food Program for Women, Infants, and Children (WIC)

Federal Resources

States exert significant authority over the disposition of most of the relevant Federal resources, notably Medicaid (Title XIX) and block grants for maternal and child health (Title V) and social services (Title XX). The Omnibus Budget Reconciliation Act (OBRA) 1989 amendments to the Maternal and Child Health block grant (Title V) redefined the mission of the state programs for maternal and child health and for children with special health care needs. Under these amendments, Congress directed the programs to develop systems of services that are "family-centered, community-based and coordinated." A statewide needs assessment and plan are required to include children and families with or at risk for HIV infection. Program managers should begin efforts to develop comprehensive pediatric HIV care programs by contacting the various state offices responsible for these programs to determine the extent to which they can be utilized in putting together a comprehensive pediatric HIV care program.



Health Care Financing Administration

Medicaid: To be eligible for Medicaid, persons must meet certain financial requirements and categorical tests. Medicaid eligibility for women and children may derive from the Aid to Families with Dependent Children (AFDC) program status of the children's mothers for cash assistance, by virtue of their disability under the Supplemental Security Income (SSI) program of the Social Security Administration (SSA), or from their status as a poverty-related pregnant woman or child or as a low income person whose Consolidated Omnibus Budget Reconciliation Act (COBRA) private health insurance premiums are paid by Medicaid. Some states offer a medically needy program, for which individuals "spend down," incurring medical costs that deplete their resources for medical expenses. Most children with perinatally-acquired HIV are eligible for and have their medical care covered by Medicaid.

Available Medicaid funding streams are being successfully used by some states to put together comprehensive pediatric AIDS care programs. State Medicaid programs must cover a core of essential services, including: inpatient and outpatient care, early and periodic screening, diagnostic and treatment program (EPSDT), and physician care. States may also opt to cover other services, such as case management, prescribed drugs, home health care, and hospice care. EPSDT, the preventive and comprehensive health program for Medicaid-eligible individuals under 21, is a significant base for building comprehensive care systems for children with HIV infection and AIDS.

State Medicaid agencies must seek out eligible children and families, inform them of the benefits of prevention and about available services, furnish assistance with scheduling and transportation, and encourage their enrollment. States must also assure that health needs are assessed through periodic screenings. Screening services include comprehensive health and developmental history, physical examinations, appropriate immunizations, blood lead level and other laboratory tests, health education and guidance, and vision, dental and hearing services. To correct or ameliorate any health problems found, states must provide any medically necessary health care, diagnostic services and treatment available under Medicaid, whether or not they are covered under the state's Medicaid plan. Care coordination or case management is integral to successful EPSDT programs.

Alabama, Maryland, Pennsylvania, and Washington State have added targeted case management services as an optional Medicaid service for eligible persons with HIV infection or AIDS. For example, Maryland pays providers $150 a month per patient for case management. In addition, all states provide Medicaid coverage of prescribed drugs as a state option, each state deciding which drugs they will pay for. HCFA, based on FDA approval, has specifically encouraged states to cover AIDS therapies such as zidovudine (AZT), aerosolized pentamidine, and gancyclovir.

Waivers enable states to pay for home- and community-based services for children and families with HIV infection and AIDS who otherwise would require institutional care. As of February, 1991, HCFA has approved AIDS-specific waiver for 15 States: California, Colorado, Delaware, Florida, Hawaii, Illinois, Iowa, Missouri, New Jersey, New Mexico, Ohio, Pennsylvania, South Carolina, Virginia, and Washington. Illinois and North Carolina also include persons with AIDS under similar waivers for broader populations. Some of the services covered include: case management, foster care, private duty nursing service, and personal care. Twenty-four states now offer hospice benefits under their Medicaid programs, providing eligible individuals with terminal illnesses a comprehensive home program including physician services, nursing, medical appliances and supplies, and counseling.

States can also opt to enhance Mec[illegible]' access to services by increasing payments to providers. Massachusetts, for example, allows payment for specialized nursing units (SNUs) for AIDS and ARC patients, and requires that facilities reserve 60 percent of SNUs for Medicaid recipients. Twelve states offer enhanced payment to nursing homes for AIDS-related care. New York has developed a system of designated care centers providing or arranging for a full range of care, including housing, home health care, and hospice services for persons with AIDS. Covered services provided by these centers qualify for higher Medicaid reimbursement. Although originally developed to serve adult AIDS populations, 21 New York hospital programs have been designated pediatric and maternal care centers. New York and New Jersey have developed specific DRGs for hospital inpatient AIDS care, and the New York Medicaid program has encouraged the Visiting Nurse Association to provide a comprehensive package of home care services.

For further information, contact the appropriate regional office of HCFA, the state Medicaid agency, or Christine Nye, Director of the Medicaid Bureau, HCFA, Baltimore, Maryland, (301)966-3870.

U.S. Public Health Service Programs

Through its eight agencies, the U.S. Public Health Service (U.S. PHS) currently devotes $1.9 billion to address all aspects of AIDS. From brochures sent to every U.S. household about HIV infection, to extensive and ground-breaking AIDS research programs, to expedited AIDS drug development and studies of the impact of HIV/AIDS on U.S. health care, many of the dollars spent on HIV/AIDS by the U.S. PHS benefit children with HIV infection and their families.

With regard to pediatric AIDS, the U.S. PHS provides funding for perinatal AIDS prevention activities, for the development of model health care programs, for substance abuse services, and for clinical trials of HIV therapeutics throughout the country. In its provision of comprehensive health care to American Indians and Alaska Natives, the Indian Health Service, an agency of the U.S. PHS, provides direct care for HIV-infected individuals.

Perinatal HIV/AIDS Prevention Programs: CDC's Perinatal AIDS Prevention Projects implement and evaluate approaches to preventing perinatal transmission of HIV infection (see Appendix E). Continuation funding, totaling over $5 million in FY 1990, was awarded to seven ongoing projects. Six of these projects were initially funded in FY 1988; a New Jersey project was funded in 1987.

Successful perinatal prevention programs limit the spread of HIV infection among women of childbearing age and encourage the effective use of contraception by both HIV-infected women and women at high risk of becoming infected who wish to avoid pregnancy. These projects have four main objectives:

- to identify and remove barriers to effective use of contraception among target populations of women at high risk of HIV infection or HIV-infected women;
- to facilitate the use of family planning services by the target populations;
- to evaluate psychosocial factors related to use of contraception; and
- to encourage behavioral change to reduce risk of acquisition and transmission of HIV.

Three prevention models are currently being tested following preliminary research and interviews with women at high risk:

- enhanced services provision/increased accessibility of services (Philadelphia, New Jersey, San Francisco, Harlem Hospital, and New York City);
- group-based education/skills-building sessions (New York City and Florida); and
- community-based risk reduction (Baltimore).

The U.S. PHS provides funding for perinatal AIDS prevention activities, for the development of model health care programs, for substance abuse services, and for clinical trials of HIV therapeutics throughout the country.

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Each project uses a common set of questionnaire items and a longitudinal study design to assess the impact of these programs on access to services, contraceptive use, and risk behavior change among cohorts of pregnant and non-pregnant high risk or HIV-infected women.

For more information contact Christine Galavotti, CDC, at (404) 639-0848.

During FY 1990, CDC also distributed approximately $146 million to state and local prevention programs in 50 states, seven municipalities, and eight territories through HIV/AIDS Prevention and Surveillance Cooperative Agreements to support:

- continuation of HIV antibody testing, counseling, and partner notification services in STD clinics, drug treatment centers, and women's health clinics;
- health education/risk reduction (HE/RR) efforts targeting persons at high risk;
- a program of financial and technical assistance to community-based organizations through state and local governments for the prevention of HIV in minority populations; and
- continuation of state and local public information programs that address local needs and situations based on the findings of locally conducted surveys of HIV-related knowledge, attitudes, and beliefs. This includes a local and/or statewide hotline in all cooperative agreement areas.

Model Health Care Programs: Under the Maternal and Child Health block grants, states can use 85 percent of these funds as they choose to provide quality maternal and child health services and to promote family-centered, community-based, coordinated care. Innovative use of these funds can, for example, allow for one-stop family shopping for health services, reducing transportation and scheduling disincentives associated with separate care delivery systems for mothers and children. Fifteen percent of the funds are retained by the HRSA's Federal program office to carry out discretionary projects in research, training, genetic disease testing and counseling, hemophilia, and other special projects of regional and national significance (SPRANS). Funding under SPRANS supports a national network of comprehensive diagnostic and treatment centers that provide services to children with hemophilia (including those with HIV infection and AIDS) and their families.

For further information, contact Dr. Merle M. McPherson, HRSA/MCHB, (301)443-2350.

In addition, the Maternal and Child Health Bureau (MCHB) of HRSA administers the Pediatric AIDS Demonstration program which has developed strategies and innovative models for comprehensive services to HIV-infected children, adolescents, and families.

MCHB currently supports 23 demonstration projects that provide interventions in pediatric AIDS and coordinated services for children, youth, and women of childbearing age with HIV infection, AIDS, or other related conditions, or for those at risk of developing HIV infection. The projects (1) demonstrate effective ways to prevent infection, especially by reducing perinatal transmission;

(2) develop community-based, family-centered, coordinated services for infected women, infants, children, youth, and families; and (3) develop programs to reduce the spread of HIV infection to vulnerable populations of young people.

Two projects, in New York City and in Philadelphia (see page 65 for a more detailed description of this program), have developed a coordinating entity or "consortium" using formal contracts and agreements to link medical and social service providers within a local area. Institutionalization of the consortium is fostered by requiring each participant to garner private support for a specified portion of coordinating costs. Also in New York, at Harlem Hospital, the Pediatric Demonstration program is funding comprehensive pediatric care to HIV-infected children, as well as counseling, testing, and social services for high risk mothers who have received little or no prenatal care.

The fifteen MCHB National Resource Centers, including the National Pediatric HIV Resource Center at Children's Hospital in Newark, New Jersey, provide information on family-centered community-based care, and focus on HIV education and training and AIDS policy development and community planning.

For further information, contact Dr. Merle M. McPherson, HRSA/MCHB, (301)443-2350.

HRSA also supports 550 Community Health Centers (CHCs) that provide direct comprehensive primary care services to the medically underserved, and that offer linkages to other providers. Currently, special funds are earmarked for HIV/AIDS and Early Intervention Services in Migrant and Community Health Centers and other community-based primary care centers. The 1991 budget increased such funds to $44.9 million, up from just over $10 million in 1990. HRSA's Health Care for the Homeless Program and Comprehensive Perinatal Care Program (CPCP) also offer HIV-related care to children. In addition, programs addressing health care provision for migrants and the homeless offer services to children with HIV/AIDS.

Substance Abuse Treatment Programs: Given the interrelationships among drug abuse, risky sexual behaviors, and HIV infection, a comprehensive approach to pediatric HIV/AIDS care must address drug abuse treatment and prevention for women of childbearing age. The drug abuse prevention and treatment context offers the opportunity for intervention strategies aimed not only at drug use, but also directly at prevention of HIV infection (e.g., safer sex practices education, self-esteem development, empowerment training). Additional special efforts may be necessary to reach women who themselves are not injection drug users, but who are the sexual partners of injection drug users.

Over 100 Federally-supported demonstration and research projects are in the process of implementing and examining intervention strategies to prevent and reduce drug abuse by pregnant and postpartum women and, more generally, by all women of childbearing age.

Numerous offices in the U.S. PHS's Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) fund research and demonstration projects on substance abuse treatment and prevention in women of childbearing age. For information on these programs, contact the following agencies and individuals: the National Institute on Drug Abuse, Elizabeth Rahdert, (301)443-4060; the Office for Substance Abuse Prevention (OSAP), Dr. Bernard McColgan, (301)443-9110 and Marilyn Rice (301)443-4564 jointly with HRSA's Maternal and Child Health Bureau, Ellen Hutchins, (301)443-5720; and the Office for Treatment Improvement (301)443-8802.

Other U.S. PHS efforts addressing substance abuse in women and children include NIDA's Outreach Demonstration Projects, Barry Brown, (301)443-6720 and HRSA's Community and Migrant Health Center Program, Joan Holloway, (301)443-8134.

Finally, the National Association of State Alcohol and Drug Abuse Treatment Directors (NASADAD) is knowledgeable about Federal and state efforts on substance abuse, women, and children. Contact William Butynski, (202)783-6868.

In addition, ADAMHA/NIDA and HRSA have provided $9 million to 21 grantees to provide community-based drug treatment and primary health care along with a wide spectrum of services for sexual partners and families. Nine of these sites are community health centers (CHC's). CHC's are also receiving funding from the Centers for Disease Control (CDC) for community education and risk assessment/prevention activities. CHCs in Miami, New Jersey, and New York are demonstrating comprehensive systems of care for persons with HIV/AIDS, with CDC funding for prevention activities and ADAMHA funding for drug abuse treatment linked to primary care for HIV.

HIV/AIDS Research: HIV infection and AIDS have been the focus of an unprecedented research effort by the U.S. PHS. An array of basic and applied scientific investigations has been directed at virtually all aspects of the disease, its determinants, and its treatment. In addition, studies of its societal impact, financial costs, and ethical challenges have also been undertaken in the hope of assessing the full scope of HIV's meaning to American society.

The Federal research agenda on HIV and AIDS has been implemented within the Federal Government's own laboratories and clinical centers as well as through an intense collaboration with a range of state, municipal, and private organizations, including many leading universities and research institutions. There is significant coordination and joint effort among the involved U.S. PHS agencies, and a general outl ie of their mutual responsibilities is on *Table 4*.

Table 4

U.S. Public Health Service Research Programs on HIV and AIDS

Basic Biomedical Research:
National Institutes of Health
Alcohol, Drug Abuse, and
Mental Health Administration

Clinical Trials of New Treatments:
National Institutes of Health

Product Evaluation and Monitoring:
Food and Drug Administration

Epidemiologic Research on HIV
Alcohol, Drug Abuse, and Mental
Health Administration
Centers for Disease Control
National Institutes of Health

Transmission and Illness:
Alcohol, Drug Abuse, and
Mental Health Administration
Centers for Disease Control
National Institutes of Health

Drug Use Research:
Alcohol, Drug Abuse, and
Mental Health Administration
Centers for Disease Control
National Institutes of Health

Children with HIV infection and AIDS and their families may derive significant resources and support by participating in AIDS research underway throughout the country. The AIDS Clinical Trials Group (ACTG) is a cooperative group of clinical trials established by NIH's National Institute on Allergy and Infectious Diseases (NIAID). (See Appendix F for a list of ACTG sites and units.)

Beginning in 1990, the National Institute of Child Health and Human Development (NICHD) and NIAID joined forces to extend access to clinical trials to HIV-infected pregnant women and children in the United States and Puerto Rico. Together, these two Institutes fund 48 maternal and pediatric clinical trials. These clinical trials include research on the use of antiretrovirals, including zidovudine (AZT), in infants and children, treatment of opportunistic infections, and the timing and prevention of perinatal transmission of HIV infection. In addition to the 48 trials in the ACTG, the National Cancer Institute (NCI) is conducting 13 pediatric trials, and the NICHD is conducting another three.

With regard to comprehensive pediatric AIDS care, coordinated delivery of services will also be fostered by linkages between, for example, the CHC's and NIH's Community Program for Clinical Research in AIDS (CPCRA, funded by NIAID). This program broadens access to clinical trials through support of 18 institutions where community-based physicians enroll their patients into clinical trials of new HIV/AIDS therapies. (See Appendix G for the entities participating in CPCRA.)

The U.S. PHS also gathers information to more accurately estimate the number of HIV-infected infants born each year. The CDC, in collaboration with state and local health departments and NIH, conducts surveillance for HIV antibody among childbearing women through "blinded" testing (with no means of identifying the infected person) of blood specimens collected on filter paper from newborns for routine metabolic (PKU) testing. To date, 44 states and territories are participating in these surveys. Other blinded seroprevalence surveys are being conducted in women attending clinics in several geographic areas, applying to the military, Job Corps, and blood donation programs.

For information on these surveillance programs, contact the National AIDS Information Clearinghouse, Rockville, Maryland, 1(800)458-5231.

Federal Human Service, Education, and Nutrition Programs

In addition to the U.S. PHS, other parts of the Department of Health and Human Services (HHS) and the Department of Education provide relatively unrestricted funding to states for the types of social and educational services needed by children with HIV infection and AIDS and their families.

<u>*Social Services Block Grant (Title XX):*</u> HHS' new agency, the Administration for Children and Families (ACF), provides funding in a block grant to states for social services. In its tenth year, the Social Services Block Grant (Title XX) allows states to provide social services that increase self-support and self-sufficiency, that prevent or remedy neglect, abuse, or exploitation of children or adults, that pre-

vent or reduce inappropriate institutionalization, and that secure referral for institutional care, where appropriate.

States show great variation in the design of their social services programs. Despite their variety, all the state social services programs fund services that address the problems of children with HIV infection and AIDS and their families. In FY 1989, for example, the most frequently provided services were day care for children, home-based services, special services for the disabled, and protective services for children. In 42 states, AFDC and SSI recipients are eligible to receive all these services and, in 13, Medicaid recipients can receive certain services. In addition, several states transferred funds from this block grant to the Maternal and Child Health block grant and to the block grant for substance abuse services.

For further information, contact William Schambra, HHS's Administration for Children and Families, at (202)245-7027.

Head Start: HHS' Administration on Children, Youth and Families (ACYF) administers the Head Start Program, which provides comprehensive development services for low-income children and their families through a nationwide network of 1,290 Head Start grantees serving 2,000 communities. Its four major program components — education, health, parental involvement, and social services — provide a net of human services that can be a vital part of a comprehensive pediatric AIDS care program.

Head Start programs provide preschool children with medical screenings, dental exams, immunizations, special services, and needs assessments. Beyond these basic health care services, the Head Start Program also funds five pediatric AIDS demonstration programs, as well as 37 parent and child center programs (PCC) for pregnant and postpartum women and infants.

One project, in Alaska, provides AIDS information and education to Alaska Natives. The other projects, in Boston, Baltimore, Los Angeles, and Newark, are developing comprehensive family-based services for children with HIV infection and their families. The Boston and Baltimore projects utilize transagency or multidisciplinary case management systems to provide comprehensive services for young children with HIV infection and their families. Through its Parent and Child Center, the Newark project operates a program specifically for children with HIV infection and their families; it provides parent education, parental support, foster parent education and support, and nutrition services to children under the age of three with HIV infection and their families.

For further information, contact Dr. Wade Horn, Commissioner, ACYF, (202)245-0347.

Abandoned Infants Assistance Act: HHS/ACYF also administers the Abandoned Infants Assistance Act, which provides grants to develop and operate services for "abandoned infants and young children, particularly drug-exposed infants and those with AIDS." Approximately 50 grants were awarded in September, 1990, ranging from $75,000 to $300,000.

The types of projects funded include Model Community Service Projects, designed to prevent the occurrence of "boarder babies"; support of HRSA's pediatric AIDS demonstration projects to expand services to include drug-exposed infants; and state/local coordination models, supporting innovative models to target state and local resources to communities experiencing problems related to babies with HIV and drug exposure.

For further information, contact Dr. Wade Horn, Commissioner, ACYF, (202)245-0347.

Administration on Developmental Disabilities (ADD): This HHS program serves persons whose severe and chronic disabilities began before age 22. Through funding programs for protection and advocacy, model service delivery, university research and training, and efforts of "national significance," ADD stresses independence, productivity, integration into the community, and keeping families intact.

Through its Projects of National Significance, ADD funds a number of demonstration projects related to Pediatric AIDS. For example, a collaborative project at Boston Children's Hospital has produced a set of *Guidelines on Developmental Services for Children with HIV Infection,* to be periodically updated, that provide resource information and recommendations for programmatic efforts for persons with HIV infection and developmental disabilities. It has also produced several technical reports, including reports on model service delivery for program planners, and has conducted a national conference on HIV infection and developmental disabilities.

ADD also funds a project with the American Bar Association (ABA) intended to help overcome barriers to services for persons with HIV/AIDS and developmental disabilities, and to provide guidance on appropriate procedures for handling confidentiality issues. Its publications include *AIDS and Persons with Developmental Disabilities: The Legal Perspective,* which addresses the major legal issues confronting persons with HIV infection and developmental disabilities, including access to child welfare, education, housing, employment, and health care, as well as the service and advocacy organizations devoted to helping persons with developmental disabilities. Another is a 1991 report, *Guidelines and Model Procedures on Confidentiality,* specifically for service providers.

ADD also funds projects to develop AIDS information and education for persons with mental retardation, to develop coordinated, comprehensive early intervention services for HIV-infected children at risk for developmental disabilities, to provide specialized foster care for children with HIV infection, and to inform agencies and families about the special developmental needs of young children with HIV infection.

For further information on ADD and how to obtain their publications, contact Deborah McFadden, Commissioner, ADD, Washington, D.C., (202)245-2890.

Early Intervention Program for Infants and Toddlers with Handicaps: This program, part H of Public Law 99-457, directs participating states to establish a statewide, comprehensive system of early intervention services for infants and toddlers with handicaps and their families. Under the provisions of the law, the Governor of each state appoints a lead agency and an interagency coordinating council to be responsible for developing a statewide system of early intervention based on the 14 minimum components included in the law.

Some states are explicitly including HIV infection in their definition of developmental delay...[by which the child can receive] a broad array of developmental... and support services.

❦

Eligible children and families receive services based on an Individualized Family Service Plan (IFSP) developed jointly by the family and early intervention service providers. Early intervention services under this law include a broad array of developmental services for the child and support services for the child and family.

Under the provisions of the law, each state will determine, within certain guidelines, how it will define "developmental delay" and, therefore, determine eligibility for early intervention services. Included in this definition is the degree or level of delay that qualifies a child for services. Individual states also have the option to decide whether or not to serve children "at risk" for developmental delay. Thus, infants and toddlers with HIV infection and their families can become eligible for these services in a variety of ways, depending on how individual states define "developmental delay," on whether or not they decide to serve children at risk, and on how "at risk" is defined. Some states are explicitly including HIV infection in their definition of developmental delay. Others are specifying HIV infection as a risk factor. Any child with HIV infection who demonstrates a level of developmental delay consistent with the state definition is eligible for and cannot be denied these early intervention services.

For more information, contact the Governor's office in each state for the name of the lead agency dealing with developmental delay or the National Early Childhood Technical Assistance System, (919)962-2001.

National Institute on Disability and Rehabilitation Research Programs (NIDRR): NIDRR is part of the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS). NIDDR contributes to the independence of persons of all ages who have disabilities by seeking improved systems, products, and practices in the rehabilitation process. It does this through grants, contracts, and cooperative agreements with universities, Indian tribes, research groups, nonprofit organizations, some profit-making companies, and individuals.

Through its Innovation Grants, NIDRR supports inventive approaches to old and newly identified problems. In 1989, NIDRR funded the development and publication of *Community-Based Services for Children with HIV Infection and Their Families: A Manual for Planners, Service Providers, Families and Advocates* by Geneva Woodruff, Ph.D. and Christopher Hanson, Ph.D. Manuals may be purchased from South Shore Mental Health Center, 6 Fort Street, Quincy, Massachusetts 02169, (617)847-1950.

In 1990, NIDRR approved funding for a national training institute for 100 planners, professionals, and advocates who are serving or planning to serve children with HIV infection and their families. This week-long training institute, scheduled for the summer of 1991 in Boston, will address community-based services for children with HIV infection and their families. Specific topics of the training will include: "Characteristics, Issues and Needs of Children with HIV Infection and Their Families: Family-Centered Principles for Community-based Programs Serving Children with HIV Infection and Their Families;

Developing a Transagency Case Management System; and Helping the Helpers: Strategies for Professionals Working with Families Affected by AIDS." For more information about the training institute, contact Tasha Davidson, 77B Warren Street, Brighton, Massachusetts 02135, (617)783-7300.

For further information about NIDRR's programs, contact NIDRR's Grant Information Line at (202)732-1207.

Early Education Program for Children with Disabilities: Part of the U.S. Department of Education, Office of Special Education and Rehabilitative Services. EEPCD (formerly known as the Handicapped Children's Early Education Program, or HCEEP) supports model demonstration projects, outreach projects, experimental projects, research projects and research institutes, in-service training projects, and technical assistance with the goal of improving and expanding services to young children with disabilities and their families.

HCEEP funded Project WIN from 1986 to 1989 to provide services to 30 children a year who were at risk for or diagnosed with HIV infection and their substance-using parents. WIN utilized a transdisciplinary team model to provide home-based services to the children and a transagency model of case management to coordinate services in the community. Services were overseen by a transagency board comprised of representatives from 31 agencies serving children, adults, and families.

For further information about WIN, contact James Hamilton at (202)732-1084.

Special Supplemental Food Program for Women, Infants, and Children (WIC): This is jointly administered by the Food and Nutrition Service of the U.S. Department of Agriculture at the Federal level and by the state health department at the state level. WIC provides monthly infant formula or basic food packages (milk, juice, cereal, beans, cheese, peanut butter) to pregnant, postpartum, and breast-feeding women, infants, and children under the age of five, meeting state-specified income and nutritional need requirements. In most states, the income requirement is 185 percent of U.S. Poverty Income Guidelines. Also, in Federal guidelines and in most state programs, nutritional risk includes medically-based risks such as anemia, being underweight, and poor pregnancy outcomes, including HIV infection and AIDS.

Most infants and children at high risk for HIV or with HIV infection will qualify for WIC. In addition to receiving these nutritional supplements, WIC participants are referred as needed to health and social services agencies for assistance. Thus, WIC can serve as an important coordinating tool in developing comprehensive care for children with HIV infection and AIDS and their families. State Medicaid agencies are required to refer certain pregnant, postpartum, and breast-feeding women, as well as children under age five to local WIC programs.

For further information about WIC, contact Ronald J. Vogel, Director, Supplemental Food Programs Division, Food and Nutrition Service, USDA, 3101 Park Center Drive, Alexandria, Virginia 22302, (703)756-3746.

State Action to Address Pediatric HIV Infection and AIDS

States are taking action in a number of areas to address pediatric HIV and AIDS. The extent and type of activity frequently depends on the number of cases of pediatric AIDS in the state. The following is a description of some state activities.

Coordination: States often initiate or facilitate the coordinated planning and delivery of services to children with HIV infection and AIDS and their families. The task force is a common mechanism for bringing together providers, families, advocates, social workers, and government officials to share information and determine how to best meet needs and develop plans.

Innovative Use of Federal Resources: Although only a limited number of states have Medicaid waivers for home and community-based care for AIDS patients, many envision using "Katie Beckett" waivers to provide care at home. At least half of the states offer case management services for children, not necessarily specific for HIV, either through the Maternal and Child Health program or the Medicaid program. A number of other states are considering case management programs. In many of the low-incidence states, most of the medical care for HIV-infected children has been provided in pediatric medical centers.

AIDS Information and Education: States collect information about pediatric AIDS, and often operate or sponsor AIDS clearinghouses that distribute pertinent information. Many states have their own hot lines, and most states are expanding their AIDS information-programs targeting minorities, women, jail inmates, and youth. The need for HIV education at the local school level is a major concern of public health and education agencies in every state. Currently, every state and several local departments of education receive Federal funding to help develop HIV prevention education programs for youth. HIV education is mandated in many states, although it is not necessarily linked to school funding. In fact, most states have rejected the idea of requiring HIV education as a condition of funding for schools. The grade at which the education is offered may vary, from elementary to high school. Because a high proportion of New Jersey's AIDS cases are injection drug-related, HIV/AIDS education in that state is closely linked with the drug and alcohol education program.

Communities are frequently and directly involved in planning and providing HIV/AIDS education. For example, to make sure that HIV infection prevention is addressed, Indiana requires the development of an HIV/AIDS advisory committee in each school to provide input to school administration and school boards. The Michigan Department of Public Health has devoted considerable effort to the school population, including training for school personnel and development and distribution of suggested AIDS curricula for grades K-12, and the Department's cooperation with the Department of Education has been hailed as a model across the country.

Targeted Outreach and Prevention: Almost all states appear to give priority to expanding outreach to hard-to-reach groups, and expanding counseling and testing sites. California's AIDS plan includes a recommendation for routine testing and counseling of all women of child-bearing age in areas where HIV infection rates among that group exceed 1/1,000.

Foster Care Issues: Policies vary among states as to whether wards of the state can participate in HIV/AIDS clinical trials. At least 15 states have policies that allow participation, and a number of other states have such policies under consideration. Other states, however, do not allow wards of the state to participate in clinical trials. For further information, see the upcoming report of the U.S. PHS Panel on Women, Adolescents and Children with HIV Infection and AIDS, *Points to Consider: Involving HIV Positive Children Who Are Wards of the State in HIV/AIDS Research,* to be available from NIH's Office of Protection from Research Risks, Bethesda, Maryland, (301)496-7005.

States recognize relatives as appropriate sources of foster care, and relatives are usually the first choice. Using relatives can be difficult in high-incidence areas, however, because the relatives themselves may have AIDS. Relatives of children needing care are informed of the services and benefits available to them as foster parents. As a result of an experiment called the Boston Blitz, Massachusetts expects to provide timely training and quick placement in families willing to take drug-exposed and HIV-infected children. Other areas too, are accelerating certification programs for foster parents and making them more flexible, and also providing training for potential foster parents for HIV-infected children.

Placement for the few children needing foster care has not posed a significant problem for low-prevalence states. However, states with areas of high prevalence are addressing the need for congregate care in a variety of ways.

Connecticut is considering means by which congregate care could be arranged and financed if the need arises. In Massachusetts, there is a widely-perceived need for newmodels of congregate care that can serve mothers and children together, and some thought has been given as to how such facilities might be developed on an experimental basis. Although Pennsylvania places priority on family placement for HIV-infected children, projects for four- to six-bed programs are being developed as interim steps in the cities of Philadelphia and Pittsburgh. Associated Catholic Charities of Maryland has recently opened a community-based residential program for infants with AIDS. Georgia and Florida have temporary residences for HIV-infected children.

For more information about foster or congregate care, contact the appropriate state child welfare agency.

Private Support and Funding

The private sector can and does contribute significantly to the provision of services for children with HIV/AIDS and their families. Collaboration among the public sector, private foundations, and community-based organizations may be the only way to build a comprehensive, integrated system of care for children with HIV/AIDS and their families.

National Foundations and Organizations

According to the Foundation Center, over 150 private foundations have made AIDS-related grants. Since 1985, the Robert Wood Johnson Foundation (RWJ) has awarded 127 grants totaling more than $50 million to existing health care facilities and community-based organizations to improve AIDS care and accessibility and to support HIV prevention efforts. Under its AIDS Prevention and Services Program, RWJ has awarded 54 grants to geographically and organizationally diverse AIDS prevention and service projects; the AIDS RWJ Health Services Program awarded grants serving 11 high-incidence areas for comprehensive community-based systems of care. Six grants totalling $4.2 million have been awarded to support programs specifically serving the pediatric population.

RWJ also funds the Healthy Children and Healthy Futures programs, specifically designed to assist communities in developing health care services for children. These programs may enable existing funding to be utilized for services to children with HIV/AIDS. For further information on RWJ funding, contact RWJ at (609)243-5937.

National Pediatric HIV/AIDS Organizations
Since the mid-1980s, numerous organizations have been formed to provide advocacy and support for persons with AIDS. Organizations that specifically address pediatric AIDS include:

- The Pediatric AIDS Coalition is a coalition of 21 national organizations that serves as advocates for children, adolescents, families, and caregivers whose lives are affected by HIV infection and AIDS. Staffed by personnel from the American Academy of Pediatrics, the Coalition serves as the pediatric task force for the National Organizations Responding to AIDS (NORA) and lobbies before Congress for better laws and appropriations of funds. Appendix H provides a list of national organizations that belong to the National Pediatric AIDS Coalition. For further information, contact the Pediatric AIDS Coalition at (202)662-7460.

- The Pediatric AIDS Foundation promotes biomedical research on pediatric AIDS. It works closely with the American Foundation for AIDS Research (AmFAR), the Pediatric AIDS Consortium of Los Angeles, and pediatric AIDS units in hospitals around the world to improve and increase pediatric AIDS research. It also has provided funds to a model community program in Los Angeles for emergency assistance and public education. For further information, contact the Pediatric AIDS Foundation at (213)395-9051.

- The Foundation for Children with AIDS, Inc. provides a network for professionals working with drug-exposed and HIV-infected children and their families. The purposes of the Foundation are to advocate quality services for drug-exposed and HIV-infected chidren and their families; to promote and provide innovative, comprehensive, family-centered and community-based services; to provide a network for professionals; and to disseminate state-of-the-art information about the issues, needs, and services for drug-exposed and HIV-infected children and their families to professionals, family members, decision and policy makers, and the public.

Six times a year, the Foundation publishes a newsletter, entitled *Children with AIDS*, that reaches a national readership of 3,800 people. The newsletter carries articles about children and families, programs from across the country, job openings, updates on research, funding sources, and resources. The Foundation is engaged in a campaign with the Junior League of Boston to increase public awareness about the needs of children with HIV infection and their families through presentations made to corporations and businesses. The Foundation sponsors conferences, lectures, and workshops for professionals, including intensive training institutes for community service providers. It receives funding from the Samuel Jared Kushnick Foundation, the U.S. Maternal and Child Health Bureau, the JDM Foundation, the Shappell Foundation, and also from private donations.

For more information, contact the Foundation for Children with AIDS at (617)442-7442.

Non-AIDS Public Interest/Advocacy Organizations
Numerous organizations that are not AIDS-specific provide advocacy for children's health and welfare. Such organizations include the Child Welfare League, the National Foster Parent Association, and the Association for Care of Children's Health. These organizations provide the public advocacy that can often stimulate the increased public awareness, funding, and volunteerism so critical in addressing pediatric AIDS/HIV care issues. See Appendix I for a selected listing of these organizations.

Community Organizations, Including Churches
Other non-AIDS organizations that operate at the community level are potential resources for services and support. For example, the American Cancer Society (ACS) pays a certain amount for home attendant services, depending on local funding. ACS may pay family members and friends for providing care, as well as furnish transportation to and from the hospital, clinic, or doctor's office. Meals on Wheels and similar programs deliver two meals a day to the homes of sick or disabled persons. Churches or civic groups may provide companions or aides who will help with household chores, pick up medications, provide respite care, and other services. For more information on the American Cancer Society, contact 1(800)4- CANCER. For more information on Meals on Wheels programs, contact (202)547-6157.

The National Community AIDS Partnership, a partnership of 19 cities, awards funds on a competitive basis to local community groups for various AIDS activities, including pediatric AIDS efforts. For more information, contact any of the 19 locally-based organizations forming the partnership listed in Appendix J.

The National Association of Community Health Centers (NACHC) is also involved in pediatric HIV issues. It provides clinical, management, and capacity development training concerning HIV to its members, Federally-funded community and Migrant Health Centers and Health Care for the Homeless Projects. Thirty percent of the 5.8 million patients in care at these 2,000 clinic sites are children under the age of 15. It is estimated that health centers will see 247,000 HIV positive individuals in 1991. For further information, contact David Cavenaugh, (202)659-8008. ◆

New Jersey

One of the first areas in the United States where the HIV epidemic took root among injecting drug users was in the urban northeastern part of New Jersey adjacent to New York City. By the mid-1980s, hospitals in that area and health officials in the state government were aware that growing numbers of drug users, women, and children — most of whom were uninsured or relied upon public entitlements to fund their health care — were becoming infected. Because the state reimbursed hospitals for uncompensated care, many of these people first sought care for HIV symptoms at acute care hospital emergency rooms. For those who were admitted and treated, getting discharged was often a problem because there were so few services and support mechanisms to assure them continuing appropriate care.

By 1986, having recognized the scope of the epidemic, state health and human services officials had made application to foundations and federal sources to develop programs for HIV-infected people. The New Jersey State Department of Human Services applied to Medicaid for a home- and community-based service waiver. The waiver, implemented early in 1987, set up two case management systems — one for adults and one for children — to assure the cost-effective delivery of care to people with HIV in local facilities. The Medicaid case management program for children with HIV was combined with an existing case management program for children with special health needs, under the aegis of the Special Child Health Services program.

Also in 1986, the Department of Health applied to the Robert Wood Johnson (RWJ) Foundation's AIDS Health Service Program to develop a case management system in the areas most seriously hit by the epidemic. Representatives of many major health and social service organizations in Newark and Jersey City were brought together to help plan the care system. When the RWJ grant was awarded, this same consortium of providers set about to implement it. The case management system, administered centrally by the State Department of Health, was funded at six hospitals, including Children's Hospital of Newark, because the hospitals were the points of entry to the health care system for the majority of HIV-infected people. With additional funding from the Federal Health Resources and Services Administration, the program was expanded in 1988 from six to ten hospitals.

[In New Jersey], representatives of many major health and social service organizations in Newark and Jersey City were brought together to help plan the care system.

RWJ program case managers and other providers came to be strong advocates for the broad range of services needed by HIV-infected people. And, seeing the program's success, several participating hospitals elected to fund additional case management positions.
Currently, both the RWJ and the Federal grants supporting this project are for demonstration programs; with their expiration in 1991, the state plans to use Federal HIV block grant funds to maintain the project.

A case management program can succeed only to the extent to which there are community-based services to which clients can be referred. In New Jersey, some of these services already existed, although in some cases, case managers had to intervene to make them available to people with HIV. In other instances, services had to be created. For example, subacute facilities were needed for children no longer requiring hospitalization but not yet ready to go home (or to a foster home). The first such facility in New Jersey was financed by a newly created foundation, and much of the work to prepare the physical plant was donated. Several additional such facilities have since opened throughout the state.

Recognizing the need for broad cooperation among providers serving children with HIV, the State Department of Health and Children's Hospital applied to the Federal Department of Health and Human Services for a pediatric AIDS demonstration grant to establish a network of regional pediatric HIV centers. The experience of Children's Hospital indicated that such centers should plan care for HIV-infected children with input from their mothers and other family members. This input was sought through various agencies serving these populations, including the state's Maternal and Child Health Care unit and its child protective agency, the Division of Youth and Family Services.

Most of the facilities that became the five regional centers were already experienced in dealing with HIV-infected children. Experienced personnel from Children's Hospital were already serving as consultants to other facilities throughout the country. In 1989, this service was institutionalized as the National Pediatric HIV Resource Center, and received Federal funding in 1990.

During 1990, New Jersey also instituted a Treatment Assessment Program to extend monitoring, evaluation, and care to asymptomatic people with HIV infection. This program enables women and children to receive antiviral and prophylactic treatment as appropriate. These services are being financed to the greatest possible extent out of existing funding streams. Private payers are beginning to recognize that timely reimbursement for ambulatory care often reduces the costs of acute care down the road. State health authorities, who have already adopted DRGs for the reimbursement of in-hospital HIV care, have been negotiating changes in reimbursement for outpatient care, to include case management and pharmaceuticals. Since many clients receive health care through Federal entitlement programs, appropriate changes will need to be made in those reimbursement policies as well.

To ensure broad professional and public input into its programs, in 1986 the New Jersey Department of Health formed several statewide task forces to make recommendations on public policy. A task force on education brought together community leaders in education with representatives of both the Department of Health and the Department of Education to develop HIV curriculum guidelines for schools. To carry prevention messages to children and adolescents not in schools, the Department of Health worked with the New Jersey Health Products Council, representing the pharmaceutical industry. One product of their collaboration was a series of "Bands to Beat AIDS" posters featuring popular entertainers.

Another statewide task force was the Pediatric AIDS Advisory Committee. In 1989, this committee obtained funds from the

Department of Health to prepare a final report. Called *Generations in Jeopardy: Responding to HIV Infection in Children, Women, and Adolescents in New Jersey,* the report identifies priority issues in shaping care delivery and prevention efforts for children, women, and adolescents at risk.

To procure copies of this report and for general information about New Jersey's efforts, contact the National Pediatric HIV Resource Center at Children's Hospital, 89 Park Avenue, Newark, New Jersey 07104, (201)268-8251.

South Texas Children's AIDS Center

South Texas is a region with intermediate prevalence of HIV infection. Recent studies of the Texas Department of Health place this prevalence at about 1/1000 among pregnant women and at about 2/100 among students of colleges and universities. Prevalence is three times higher among blacks than among Hispanics and Anglos. The South Texas Children's AIDS Center is a program of the Department of Pediatrics of The University of Texas Health Science Center at San Antonio in collaboration with many community-based organizations and clinics. Because of the relatively low prevalence of HIV infection in this region, the faculty and staff of the Center had the opportunity to develop strong programs in prevention of HIV infection and professional and community education in addition to programs of care for infants, children, and their families.

The three stated objectives of the Center have been to provide:

- comprehensive care of HIV-infected infants and children and their parents through case management;
- prevention of the spread of HIV infection through education; and
- education of health professionals on the diagnosis and management of HIV infection in infants, children, and their parents.

Comprehensive Care: In 1985, testing of patients with hemophilia revealed 67 who were seropositive for HIV. Of these, 43 were under 18 years of age. The Hemophilia/HIV Surveillance Clinic was organized by the faculty and staff of the Department of Pediatrics at the Santa Rosa Children's Hospital. Because increasing referrals of non-hemophilic, HIV-infected pediatric patients to that clinic strained the resources designated for patients with hemophilia, in early 1988, the Department of Pediatrics committed faculty and staff to create a separate clinic, the *San Antonio Pediatric AIDS Clinic,* which was housed at the Brady/Green Community Health Center in downtown San Antonio. With a Pediatric AIDS Health Care Demonstration Grant from the Maternal and Child Health Bureau of the DHHS, in August of 1988 the two clinics were merged into South Texas Children's AIDS Center. Early in 1989, a monthly clinic was begun in the border town of McAllen, Texas, to provide care for infants, children, and their families in the rural Rio Grande Valley.

The characteristics of the comprehensive care provided at the Center are as follows: The faculty and staff of the multidisciplinary care team are mostly bilingual in English and Spanish. The care team provides primary, secondary, and tertiary care to outpatients and inpatients; subspecialty care is provided by the AIDS Center's 75 faculty members from the Department of Pediatrics in the University Clinics. While outpatient care is provided without regard to financial eligibility, all patients needing inpatient care have so far qualified for coverage by insurance, Medicaid, or the Texas Crippled Children's Program (Chronically Ill and Disabled Children) of the Texas Department of Health.

Case management is provided to all patients and their families. Moreover, the care team is assisted by 90 volunteers trained in the handling of pediatric HIV-infected patients. Care includes developmental assessment and support of the HIV-infected children and their families. To care for abandoned babies with HIV-infection awaiting foster home placement or to provide respite care to needy families, the Center, in collaboration with the Sisters of the Divine Providence, has built and now operates the Providence Home for Infants with HIV Infection/AIDS, a special care facility licensed by the Texas Department of Health on the grounds of the Stella Maris Clinic.

The fiscal support for the Center is derived from the University of Texas Health Science Center, the Maternal and Child Health Bureau of the DHHS, the Hemophilia Foundation, local charitable organizations, the United Way of San Antonio, and numerous donors of monies from the private sector. The development of this special care delivery system has been accomplished through the support of existing agencies and institutions without the need to invest in new facilities. The Center faculty is comprised of physicians, psychologists, nursing and social work coordinators, research nurses and a developmentalist; it recently acquired the services of an internist to care for parents in the same setting and at the same time care is provided to their children. Care is available 24 hours a day. An Advisory Committee, comprised of "consumers," representatives of collaborating organizations, hospital administrators, and Center faculty, meets quarterly to review the evolution and effectiveness of the Center programs.

Prevention: The Center has developed a multifaceted system for preventing the spread of HIV infection among women and through them to their offspring, as well as among youths engaging in high-risk activities. Some of the prevention programs include:

- reproductive counseling of injection drug abusers referred to the Center;
- AIDS prevention classes (5 hours per week) for the approximately 1,500 youths (ages 10-17 years) detained for acts of delinquency at the Juvenile Detention Center of Bexar County. This program, through a grant from HRSA, has been expanded to provide integrated primary care, drug abuse rehabilitation, AIDS prevention education, and vocational/educational rehabilitation to these youths during detention and during the year of probation that follows;
- AIDS prevention education to administrators, PTA presidents, school nurses and teachers of three San Antonio school districts;
- AIDS education to churches and synagogues in collaboration with the Regional AIDS Interfaith Network;

- AIDS prevention classes for drug-abusing pregnant adolescents; and
- Numerous print, radio, and television interviews on pediatric AIDS.

Professional Education: The Center has been active in the education of health professionals, increasing their understanding of the epidemiology and pathophysiology of HIV infection and developing their skills in diagnosing and treating (or referring) pediatric patients with this disease. Some of the highlights of these activities include:

- familiarizing all pediatric residents and medical students with the principles of diagnosis, treatment, and prevention of HIV infection;
- presenting in-service training to medical, nursing, and other staff of hospitals and clinics in the region;
- publishing articles on pediatric AIDS in eight consecutive issues of *Texas Medicine*, the official journal of the Texas Medical Association, which is distributed to 28,000 physicians monthly;
- accepting graduate students from nursing, social work, counseling, and psychology program of various colleges and universities for clinical training in pediatric AIDS;
- providing care in five community clinics, which removes the fear of handling HIV-infected infants and children; and
- working with the judicial staff of the Juvenile Probation System and providing correct information about pediatric AIDS.

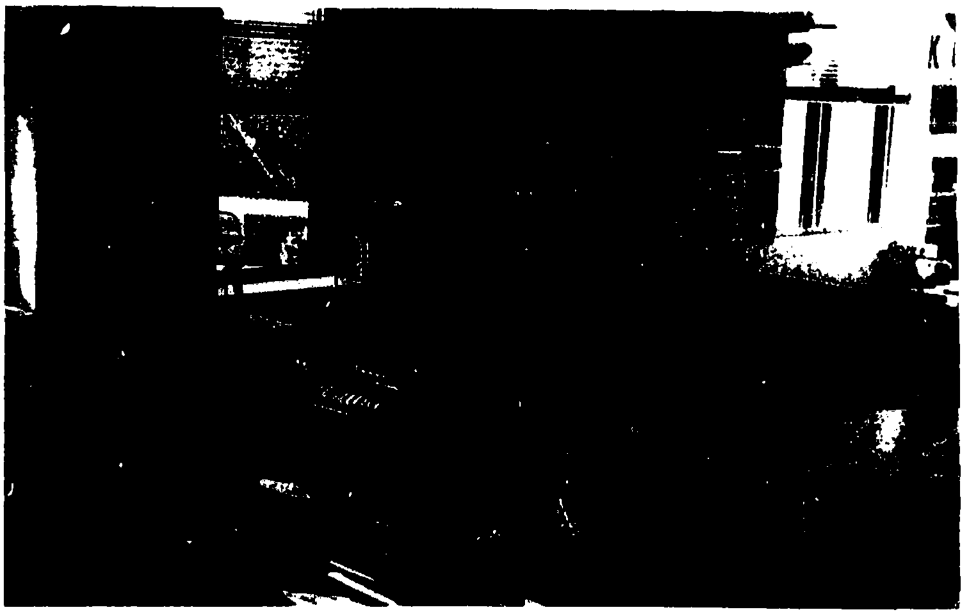
The model system represented by this Center has worked well in this region with an intermediate prevalence of HIV infection. It has made crisis interventions unnecessary and allowed time to prepare, interweaving existing resources into an effective multifaceted system. It has marked a new era in the practice of pediatrics by an academic group; it has opened the doors of community clinics and health organizations to the pediatric faculty of the University and demonstrated that such interactions can be mutually beneficial. It has shown that, as the HIV epidemic gains momentum in our country, all segments of our health care delivery systems and the public must work together to successfully meet the challenges of this disease, difficult as they are. It has shown the immense value of public and professional education in the prevention of pediatric AIDS. It has shown what pediatric practice should and could be in the year 2000.

> *The South Texas Children's AIDS Center has shown the immense value of public and professional education in the prevention of pediatric AIDS.*

For more information, contact the South Texas Children's AIDS Center, Department of Pediatrics, University of Texas Health Science Center at San Antonio, 7703 Floyd Curl Drive, San Antonio, Texas 78284, (512)692-3641.

Project STAR

Project STAR is a community-based program providing a range of services to Boston area children with HIV infection and their families. Most of the children served by STAR live with their biological families; all have at least one parent who is infected. Funded until 1993 by a grant from the Robert Wood Johnson Foundation, the program aims primarily to help families continue caring for their HIV-infected children at home for as long as possible. To this end, STAR defines



the family as the client, and staff work with all family members to promote and support family functioning.

STAR services are monitored by a transagency board of 31 representatives from hospitals and agencies serving women, children, substance users, families, and those affected by AIDS. Transagency board members and staff from their affiliate agencies refer families for STAR services. At monthly board meetings, the transagency board members recommend services and strategies for families, monitor case management, and advocate for services.

STAR employs a 20-member multicultural and multilingual staff. A four-member outreach team works on Boston streets and in the Massachusetts women's prison to educate adults and youth engaging in high-risk behaviors about preventing HIV transmission. They also identify families in need of STAR services and engage them in the program.

At present, early intervention and day care staff work with 46 children under age five who are HIV-infected and 140 members of their families. Services begin with an exploration with the family about their perception of service needs, and an assessment of the child's developmental strengths and needs. The staff and family then develop an Individualized Family Service Plan that will govern the delivery of STAR services. In addition to working directly with the family, the early intervention team member also serves as the family's case manager and coordinates STAR services with those provided by direct service providers from other agencies who also serve the family, such as the Massachusetts Association of Visiting Nurses, the family's physicians at clinics and health centers, legal aid staff or other community-based AIDS programs. At the Star Project, all of the families receive services from at least five outside agencies.

STAR staff work with the families in their homes, providing counseling and developmental intervention, and at a center located on the grounds of a community health center. Children with HIV infec-

[Project] STAR defines the family as client, and staff work with all family members to promote and support family functioning.

tion under age five are transported by bus to the STAR early intervention groups and therapeutic day care programs each day. Parents, siblings, and other family members also come to the center for education, support groups, and recreational activities. The STAR center is designed to be a happy, comfortable, and safe haven where families can openly share their thoughts and feelings, support one another, and feel at home.

The case management activities of STAR staff are critical to helping the children live at home and the families function effectively. Many of the families are involved with as many as 15 different practitioners and agencies. Careful coordination of the medical, social, and other family services helps to ensure that the children and families not only receive, but also utilize, necessary services.

In addition to the grant from the Robert Wood Johnson Foundation, operating support to STAR is provided by the fundraising activities of the Foundation for Children with AIDS. Funds raised from private foundations in the Boston area were used to renovate and equip the STAR Child and Family Center. Medicaid reimburses some of the services provided by the early intervention team. The program is exploring ways to integrate STAR services into the state early intervention and education systems in order to ensure continuation of the program when Foundation funds are no longer available.

For more information about Project STAR, contact the Project at 1800 Columbus Avenue, Roxbury, Massachusetts 02119, (617)442-7442.

Circle of Care

The Circle of Care, established in 1990, is a family-centered program designed to meet the needs of HIV-affected families and help prevent the spread of HIV among women, children, and adolescents living in Philadelphia. This project employs an integrated system to deliver health care, case management, centralized support services, community education programs, and prevention efforts. Public and private organizations have come together to provide an extraordinary array of services.

The participating programs are ActionAIDS, Bethanna, Blacks Educating Blacks About Sexual Health Issues (BEBASHI), Children's Hospital of Philadelphia, Congreso de Latinos Unidos, Family Planning Council of Southeastern Pennsylvania, Pennsylvania Department of Health, Philadelphia Community Health Alternatives (PCHA), Philadelphia Department of Human Services, Philadelphia Department of Health, and St. Christopher's Hospital for Children.

The spirit of collaboration extends to the funding of this project. The Pew Charitable trusts is supporting the Circle of Care with an $800,000 two-year grant and the Rhone-Poulenc Rorer corporation is partially underwriting the family health clinics with a $1 million five-year grant. The Commonwealth of Pennsylvania is funding the case management program with a $350,000 18-month grant through the Philadelphia AIDS Consortium. The U.S. Department of Health and Human Services (through HRSA's MCHB) is providing a three-year grant with funding of $600,000 in the first year.

The Circle of Care is guided by a vision of the future, a vision that is simultaneously bleak and heartening. The number of families affected by HIV and in need of services is rising and will continue to rise for the foreseeable future. This tragic situation is offset by the fact that treatment methods for HIV are rapidly improving, and state-of-the-art medical and social interventions are helping people to live longer, more productive lives.

Services Provided: In Philadelphia, the system of services for HIV-affected families has been over-extended, under-financed, and totally uncoordinated. Until now, almost no public funding existed to meet the needs of HIV-affected women, children and families. The Circle of Care provides a coordinated, comprehensive ongoing response. Approximately 430 HIV-affected families representing an estimated 1,940 individuals will be enrolled in the program over the next three years.

All services provided by the Circle of Care are available to children under the age of 19, their siblings, HIV-infected parents, other family members and foster families. Services are provided to family members who are symptomatic or asymptomatic. The components of the Circle of Care are:

- *Health Care:* Out-patient primary care for HIV- affected parents and children is provided under one roof. For the first time in Philadelphia, adult clinicians are providing care at two pediatric hospitals, creating family clinics for HIV families. These family-centered clinics are at St. Christopher's Hospital for Children and the Children's Hospital of Philadelphia.

- *Case Management:* Case management services are being provided by ActionAIDS, and every family enrolled in the program has a case manager. Supplementing the case managers are trained home visitors who provide support and assistance to the families.

- *Other Support Services:* Non-reimbursable goods and services are available to families through the Resources to Families Fund. Bethanna, a foster care agency, promotes positive, interactive relationships between foster and biological families.

- *Outreach and Case Identification:* Philadelphia Community Health Alternatives (PCHA) provides education on HIV prevention geared toward homeless youth. Counseling and testing services are available to at–risk teenagers.

- *Prevention and Community Education:* Blacks Educating Blacks About Sexual Health Issues (BEBASHI) and Congreso de Latinos Unidos provide community-based prevention education to minority youth. The Family Planning Council of Southeastern Pennsylvania coordinates HIV risk assessment and counseling at teen family planning clinics. Sexuality education and referrals for services will be provided to at-risk teenagers.

- *Linkages with Existing Services:* The Philadelphia Department of Public Health insures that its HIV-funded services are appropriate and sensitive to the needs of women, children, and families. The Philadelphia Department of Human Services insures that children of HIV-affected families receive appropriate protective services. The Pennsylvania Department of Health, Division of Maternal and Child Health, provides linkages with existing Maternal and Child Health-funded services throughout Philadelphia.

For more information about the Circle of Care, contact the Family Planning Council of Southeastern Pennsylvania,
260 South Broad Street, Suite 1900,
Philadelphia, Pennsylvania 19102,
(215)790-4638. •

[Through the Circle of Care], public and private programs have come together to provide an extraordinary array of services...[and] the spirit of collaboration extends to funding as well.

RECOMMENDED READING

Allbritten, D.J. (1990). *Children with HIV/AIDS: A Sourcebook for Caring.* National Association of Children's Hospitals and Related Institutions, Alexandria, Virginia.

Association for the Care of Children's Health. (1990). *A Checklist for Communities.* Washington, D.C.

Dokecki, P.R., Baumeister, A.A. and Kupstas, F.D. (1989). Biomedical and Social Aspects of Pediatric AIDS. *Journal of Early Intervention, 13*(2), 99-113.

Fraser, K. (1989). *Someone at School has AIDS: A Guide to Developing Policies for Students and School Staff Members who are Infected with HIV.* National Association of State Boards of Education, Alexandria, Virginia.

McGonigel, M. (1989). *Family Meeting on Pediatric AIDS.* Association for the Care of Children's Health, Washington, D.C.

Woodruff, G., Hanson, C.R., McGonigel, M., and Sterzin, E.D. (1990). *Community-Based Service for Children with HIV Infection and Their Families: A Manual for Planners, Service Providers, Families, and Advocates.* South Shore Mental Health Center, Brighton, Massachusetts.

APPENDIX A

Neuropsychological Assessment

Domains - Birth to 3 years old. In assessing infants and young children from birth to 3 years old, the following construct domains are essential (Fletcher, Francis, Bronstein, Brouwers, Pequegnat, Raudenbush, Schmitt, & Stover, 1990): (1) receptive vocabulary, (2) temperament, (3) motor development, (4) information processing, and (5) social interaction which can be obtained using naturalistic methods complemented with psychometric assessments and caretaker reports. These assessments can be used to evaluate the efficacy of drug therapy and other behavioral preventive interventions and educational programs, and to design rehabilitation programs to improve the quality of life of HIV-infected infants and young children.

Domains - 3 to 13 years old. In assessing children from 3 to 13 years old, the following domains may need to be assessed (Wilson, Pequegnat, Belman, Brouwers, et al., 1990). The essential construct domains are: (1) attention, (2) memory, (3) motor, (4) constructional, and (5) general intellectual ability. The desirable construct domains are: (1) language and (2) conceptualization. The optional construct domains are: (1) academic achievement, (2) affective processing, and (3) learning.

APPENDIX B

Information Sources: Substance Abuse, Women, and HIV

Publications:

<u>Substance Abuse Treatment and Prevention in Women of Childbearing Age</u>

Brown, S.S. (Ed.) **Children and Parental Illicit Drug Use: Research, Clinical, and Policy Issues.** Institute of Medicine, National Academy Press, Washington, D.C., 1991.

U. S. Government General Accounting Office. **Drug-Exposed Infants: A Generation At Risk.** Washington, D.C., 1990.

American Bar Association. **Drug-Exposed Infants and Their Families: Coordinating Responses of the Legal, Medical, and Child Protection System.** Washington, D.C., 1990.

Miller, H.G., Turner, C.F., & Moses, L.E. (Eds.). **AIDS: The Second Decade.** National Academy Press, Washington, D.C., 1990.

Office of Inspector General, U. S. Department of Health and Human Services. **Crack Babies.** Washington, D.C., 1990.

Feig, L. **Drug Exposed Infants and Children: Service Needs and Policy Questions.** Office of Social Services Policy, Division of Children, Youth, and Family Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Washington, D.C., 1990.

Hutchins, E., & Alexander, G. **Substance Use During Pregnancy and Its Effect on the Infant.** PIC-III TRS 90-01, Department of Maternal and Child Health, The Johns Hopkins School of Hygiene and Public Health, Baltimore, Maryland, 1990.

National Center for Clinical Infant Programs. **Zero to Three.** Washington, D.C., 1989 (Vol IX, No. 5).

Chasnoff, I.J. (Ed.). **Alcohol, Pregnancy and Parenting.** Kluwer Academic Publishers, Hingham, Massachusetts, 1988.

Chasnoff, I.J. (Ed.). **Drug Use in Pregnancy: Mother and Child.** Kluwer Academic Publishers, Hingham, Massachusetts, 1986.

Preparation for Hospitalization and Medical Procedures

Wells, N., Anderson, B. **Preparing Children for Medical Tests: Guidelines for Parents and Professionals.** Federation for Children with Special Needs, Boston, 1986.

Residential and Foster Care

American Academy of Pediatrics, Task Force on Pediatric AIDS. **Infants and Children with Acquired Immunodeficiency Syndrome: Placement in Adoption and Foster Care.** *Pediatrics, 83*, 609-612, 1989.

Gitelson, P., & Emery, L. J. **Serving HIV-infected Children, Youth, and Their Families: A Guide for Residential Group Care Providers.** Child Welfare League of America, Washington, D.C., 1989.

Programs that Address Substance Abuse Treatment and Prevention in Women of Childbearing Age. *(See section on Federal Resources for more comprehensive listing.)*

National Institute on Drug Abuse (NIDA) Research Demonstration Projects on Drug Abuse Treatment for Women of Childbearing Age. NIDA, ADAMHA. Contact Person: Elizabeth Rahdert, (301)443-4060.

Office for Substance Abuse Prevention (OSAP) and Maternal and Child Health Bureau (MCHB) Demonstration Projects for Pregnant and Postpartum Women and Their Infants. OSAP, ADAMHA, and MCHB, HRSA. Contact Persons: Marilyn Rice, (301)443-4564; Ellen Hutchins, (301)443-5720.

Office for Treatment Improvement (OTI) Demonstration Projects for Women of Childbearing Age. OTI, ADAMHA. Contact Person: Loretta Finnegan, (301)443-8802.

National Institute on Drug Abuse (NIDA) Outreach Demonstration Projects. NIDA, ADAMHA. Contact Person: Barry Brown, (301)443-6720.

Bureau of Health Care Delivery Assistance (BHCDA) Community and Migrant Health Center Program. BHCDA, HRSA. Contact Person: Joan Holloway, (301)443-8134.

Administration for Children, Youth, and Families (ACYF) Abandoned Infants Assistance Program. ACYF, OHDS. Contact Person: Dr. Wade Horn, (202)245-0347.

National Association of State Alcohol and Drug Abuse Treatment Directors (NASADAD). Contact Person: William Butynski, (202)783-6868.

APPENDIX C

Characteristics of Effective Mental Health Services

The goals of mental health interventions include:

- decreasing health risks and increasing compliance with medical regimens (through cognitive-behavioral interventions and combinations of social learning, educational, behavior modification, and face-to-face modeling approaches);
- decreasing psychologic symptoms such as depression and fatigue;
- improving coping and social supports;
- improving school performance and peer relationships; and
- improving the quality of life (Pequegnat, 1990).

Additionally, mental health service programs must demonstrate:

- commitment to meeting the child and family needs;
- multidisciplinary professional expertise in the treatment of children with administrative policies and procedures to facilitate integration of health and mental health care;
- physical, financial, and cultural accessibility with adequate space, personnel, and supplies;
- a plan to minimize institutional barriers to the services provided;
- policies and procedures to support program staff and prevent burn-out";
- access to consultation with medical specialists, ethicists, religious personnel, advocacy groups, and legal experts;
- systematic methods of evaluation.

Essential resources (whether internal or available through referral) would include:

- an intake and diagnostic evaluation service, including individual and family assessment;
- crisis intervention and emergency services;
- in/outpatient medical and psychiatric services;
- aggressive outreach for less accessible populations (e.g., the homeless); and
- mobile services for home care (National Institute of Mental Health, 1989).

APPENDIX D

Associate Regional Administrators for Medicaid, Health Care Financing Administration, Regional Offices

Boston (I):Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont
Contact: Alfred G. Fuoroli
(617) 565-1223

New York (II): New Jersey, New York, Puerto Rico, Virgin Islands
Contact: Arthur J. O'Leary
(212) 264-2504

Philadelphia (III):Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia
Contact: Robert J. Taylor
(215) 596-1378

Atlanta (IV): Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee
Contact: William R. Lyons
(835) 841-2418

Chicago (V): Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin
Contact: Charles W. Hazlett
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Dallas (VI): Arkansas, Louisiana, New Mexico, Oklahoma, Texas
Contact: James L. Reed
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Kansas City (VII): Iowa, Kansas, Missouri, Nebraska
Contact: Richard P. Brummel
(816) 426-5925

Denver (VIII):Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming
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San Francisco (IX):American Samoa, Arizona, California, Guam, Hawaii, Nevada
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Seattle (X): Alaska, Idaho, Oregon, Washington
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APPENDIX E

CDC's Perinatal HIV Reduction and Education Demonstration Activities (PHREDA)

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APPENDIX F

NIH AIDS Clinical Trials Group (ACTG) Mailing List

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APPENDIX G

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AIDS Research of Atlanta, Inc. (ARCA) Unit 15	131 Ponce de Leon Avenue Suite 220 Atlanta, Georgia 30308 (404)876-2317 FAX: (404)872-1701 Atlanta, GA 30308 E-Mail: 407-3316	Principal Investigator: Melanie A. Thompson, M.D. Project Coordinator: Amy Morris Education & Training Preceptor: Barbara Blake, R.N., M.S. ODB Coordinator: Amy Morris
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APPENDIX 1

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(202) 544-1076

American Academy of Pediatrics
141 NW Point Boulevard
P.O. Box 927
Elk Grove Village, Illinois 60007
(708)427-1205

American College of Obstetricians and
Gynecologists
409 12th Street, SW
Washington, D.C. 20024-2188
(202)638-5577

Association of Black Social Workers
MetropolitanWashington Chapter
P.O. Box 2126
Washington, D.C. 20013
(202) 529-6127

Child Welfare League of America
440 1st Street, NW, Suite 310
Washington, D.C. 20001
(202) 638-2952

Healthy Mothers, Healthy Babies National Coalition
409 12th Street, NW
Washington, D.C. 20024-2188
(202) 863-2458

National Association of Children's Hospitals and
Related Institutions
401 Wythe Street
Alexandria, Virginia 22314
(703) 684-1355

National Black Nurses'Association, Inc.
1012 10th Street, NW
Washington, D.C. 20001
(202) 393-6870

National Institute of Child Health and Human
Development (NICHD), NIH
9000 Rockville Pike
Room 2A32
Bethesda, Maryland 20892
(301) 496-5133

APPENDIX J

NATIONAL COMMUNITY AIDS PARTNERSHIPS
LOCAL PARTNERS

Hartford Foundation for Public Giving
85 Gillett Street
Hartford, Connecticut 06105

New York Community Trust Foundation
2 Park Avenue, 24th Floor
New York, New York 10016

The Minneapolis Foundation
1400 16th Street, Suite 360
Washington, D.C. 20036

California Community Foundation
3580 Wilshire Boulevard, Suite 1660
Los Angeles, California 90010

Jacksonville Community Foundation
112 West Adams Street, Suite 902
Jacksonville, Florida 32202-3828

Arizona Community Foundation
4350 East Camelback Road, Suite 216C
Phoenix, Arizona 85018

Foundation for the Carolinas
301 South Brevard Street
Charlotte, North Carolina 28202

San Diego Community Foundation
525 B Street, Suite 410
San Diego, California 92101

Greater Richmond Community Foundation
4001 Fitzhugh Avenue, P.O. Box 11553
Richmond, Virginia 23230

Dade Community Foundation
200 South Biscayne Boulevard, Suite 4970
Miami, Florida 33131-2343

The Saint Paul Foundation
1400 Hanna Building
Cleveland, Ohio 44115

Metropolitan Atlanta
The Hurt Building, Suite 449
Atlanta, Georgia 30303

Eugene & Agnes E. Meyer Foundation
500 Foshay Tower
Minneapolis, Minnesota 55402

Northern California Grantmakers
AIDS Task Force
731 Hillgirt Circle
Oakland, California 94610

Community Foundation of Metropolitan
306 West 7th Street, Suite 702
Ft. Worth, Texas 76102

Council of Michigan Foundations
One South Harbor Avenue, Suite 3
P.O. Box 599
Grand Haven, Michigan 49417

Community Foundation of New Jersey
Knox Hill Road
P.O. Box 317
Morristown, New Jersey 07960

Heart of America United Way
605 West 47th Street, Suite 201
Kansas City, Missouri 64112