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KRISTINE M. GEBBIE, R.N., M.N., F.A.A.N.
NATIONAL AIDS POLICY COORDINATOR
DEPARTMENT OF HEALTH & HUMAN SERVICES
Room 729H Humphrey Building
200 Independence Ave., S.W.
Washington, D.C. 20201

DAY Thursday DATE August 6, 1993

TIME 11:00 a.m. LOCATION 750 17th St., N.W.

SUBJECT National Pediatric HIV Resource Center

PARTICIPANTS:

David Harvey, Mary Boland, Dorothy Mann and Karen Geney. One hour has been alloted for this meeting.

Kris Gebbe

1613 Harvard Street, NW, 315
Washington, DC 20009

June 28, 1993

Carol Rasco, Ph.D.
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

JUL - 1 1993

Dear Ms. Rasco:

I was honored to attend the White House press conference to announce the appointment of Kristine Gebbe, R.N., M.S.N., as Federal AIDS Policy Coordinator. For your review, I enclose my resume and curriculum vitae in consideration for a position on Ms. Gebbe's staff.

Since 1987, my career has been devoted to federal AIDS policy and legal issues on a full-time basis. In addition to my professional experience, I have held several volunteer HIV clinical and administrative positions with Whitman Walker Clinic, the largest provider of AIDS services to gay men in the Washington, D.C. metropolitan area. My curriculum vitae also includes a complete listing of chapters, periodicals and monograph publications on HIV and disability legal and policy issues. Finally, my experience working on Capitol Hill for U.S. Representative Samuel Gejdenson and in direct mental health services further adds to my qualifications.

I believe that I bring a high level of professionalism, dedication and energy to my career and would extend these qualities to a position on your staff. I would welcome the opportunity to discuss my qualifications with you at your convenience and may be reached during the day at 202-289-5970, or evenings at 202-332-3237.

Thank you for your consideration.

Sincerely,

David C. Harvey, M.S.W.

DAVID C. HARVEY
1613 Harvard Street, NW, Apt. 315
Washington, D.C. 20009
(202) 332-3237 (home)
(202) 289-5970 (work)

EXPERIENCE

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CURRICULUM VITAE

NAME David C. Harvey

HOME ADDRESS 1613 Harvard Street, NW, Apt. 315
Washington, DC 20009

WORK ADDRESS National Pediatric HIV Resource Center
900 Second Street, NE, 211
Washington, DC 20002

TELEPHONE 202-332-3237 (Home)
202-289-5970 (Office)
202-408-9520 (Fax)

EDUCATION

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PROFESSIONAL ACTIVITIES

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ORGANIZATIONS

National Association of Social Workers

PROFESSIONAL CREDENTIALS

Licensed Graduate Social Worker (L.G.S.W.) Washington, D.C. 1990

NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

900 Second Street, NE
Suite 211
Washington, DC 20002

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Carol Rasco, Ph.D.
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Roz - Call Mr. Harvey to ack. receipt of this - tell him we will forward to R. Gebbie. CHR

15 South Ninth Street
Newark, New Jersey 07107
201-268-8251
800-362-0071
201-485-2752 FAX

NATIONAL PEDIATRIC HIV RESOURCE CENTER

900 Second Street, NE
Suite 211
Washington, DC 20002
202-289-5970
202-408-9520 FAX

FAX COVER SHEET

Washington Office

TO: Carol Rasco

FIRM: The White House

FAX NUMBER: 456-2878

FROM: David C. Harvey, Policy Analyst

TOTAL NUMBER OF PAGES (INCLUDING COVER SHEET): 10

DATE: _____ **TIME:** _____

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Please call (202) 289-5970 if you do not receive all pages.

1613 Harvard Street, NW, 315
Washington, DC 20009

June 28, 1993

Carol Rasco, Ph.D.
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Ms. Rasco:

I was honored to attend the White House press conference to announce the appointment of Kristine Gebbe, R.N., M.S.N., as Federal AIDS Policy Coordinator. For your review, I enclose my resume and curriculum vitae in consideration for a position on Ms. Gebbe's staff.

Since 1987, my career has been devoted to federal AIDS policy and legal issues on a full-time basis. In addition to my professional experience, I have held several volunteer HIV clinical and administrative positions with Whitman Walker Clinic, the largest provider of AIDS services to gay men in the Washington, D.C. metropolitan area. My curriculum vitae also includes a complete listing of chapters, periodicals and monograph publications on HIV and disability legal and policy issues. Finally, my experience working on Capitol Hill for U.S. Representative Samuel Gejdenson and in direct mental health services further adds to my qualifications.

I believe that I bring a high level of professionalism, dedication and energy to my career and would extend these qualities to a position on your staff. I would welcome the opportunity to discuss my qualifications with you at your convenience and may be reached during the day at 202-289-5970, or evenings at 202-332-3237.

Thank you for your consideration.

Sincerely,

David C. Harvey, M.S.W.

1613 Harvard Street, NW, 315
Washington, DC 20009

June 28, 1993

Kristine Gebbe, R.N., M.S.N.
Federal AIDS Policy Coordinator
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Ms. Gebbe:

I was honored to attend the White House press conference to announce your appointment as Federal AIDS Policy Coordinator last Friday, and enjoyed having the opportunity to meet you afterwards in the cabinet room. For your review, I enclose my resume and curriculum vitae in consideration for a position on your staff.

Since 1987, my career has been devoted to federal AIDS policy and legal issues on a full-time basis. In addition to my professional experience, I have held several volunteer HIV clinical and administrative positions with Whitman Walker Clinic, the largest provider of AIDS services to gay men in the Washington, D.C. metropolitan area. My curriculum vitae also includes a complete listing of chapters, periodicals and monograph publications on HIV and disability legal and policy issues. Finally, my experience working on Capitol Hill for U.S. Representative Samuel Gejdenson and in direct mental health services further adds to my qualifications.

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CURRICULUM VITAE

NAME	David C. Harvey
HOME ADDRESS	1613 Harvard Street, NW, Apt. 315 Washington, DC 20009
WORK ADDRESS	National Pediatric HIV Resource Center 900 Second Street, NE, 211 Washington, DC 20002
TELEPHONE	202-332-3237 (Home) 202-289-5970 (Office) 202-408-9520 (Fax)

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Who's Who Among Human Services Professionals, National Reference Institute. 1989

Assistant Fellow, Institute for Social Justice, Catholic University. 1987

A'Kempis Scholarship Award, Catholic University of America. 1987

Inducted Member, Alpha Delta Mu, National Social Work Honor Society. 1987

Member, Board of Trustees Student Affairs Committee, Clark University. 1984

ORGANIZATIONS

National Association of Social Workers

PROFESSIONAL CREDENTIALS

Licensed Graduate Social Worker (L.G.S.W.) Washington, D.C. 1990

Title
4
current $20
House added $2 mill for

goal $42 mill { $32 mil for existing
$10m for new areas —

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2 of CBO - base of [illegible] access to $s ?

Senate process —
Ryan White groups —
[illegible] Sears
Harkins

Pediatric AIDS Demonstrations

The recommendation does not include funding for the Pediatric AIDS demonstrations. The Committee concurs with the action of the House to transfer funding to the pediatric AIDS demonstrations supported under Title IV of the Ryan White AIDS CARE Act. This will enable these demonstration projects to continue and provide enhanced voluntary access for patients to clinical research.

Ryan White, Title IV

The Committee recommends $_____ for pediatric and adolescent AIDS demonstration projects for services and for enhanced access to HIV therapeutic trials. This is $_____ over the 1993 appropriation, and $_____ over the budget request, and $_____ over the recommendation of the House. The Committee expects that under Title IV the majority of the funds will support, without disruption, existing pediatric and adolescent AIDS demonstration projects. Title IV pediatric and adolescent projects will provide for comprehensive services and voluntary access to HIV therapeutic trials, include those existing demonstration projects developing the capacity to access clinical trials. The Committee understands that efforts to date to enroll and retain medically underserved HIV affected children, adolescents and pregnant women in trials are successful only when research is conducted within an established comprehensive system of family-centered, community-based, coordinated family services that includes providing or arranging for primary care. The Committee directs that MCHB continue to plan for, and administer, Title IV, and recognizes that it will be the primary means of delivering HIV family-centered care for children, adolescents and their families. Finally, established national projects that provide technical assistance and training on pediatric, adolescent and family HIV services and clinical trials should be continued under Title IV.

Senator Kohl

Ryan White, Title IV

The Committee is concerned about rapidly rising rates of HIV infection among adolescent girls and young women. With additional funds, the Committee expects that prevention services will be emphasized within the context of comprehensive care and that projects will collaborate with CDC funded prevention projects to prevent HIV infection to newborns in pregnant women as well as prevention of HIV infection in adolescent girls and young women.

COMMITTEES
LABOR AND HUMAN RESOURCES
JUDICIARY
FOREIGN RELATIONS
BUDGET
INDIAN AFFAIRS

United States Senate

WASHINGTON, DC 20510-1302

July 29, 1993

The Honorable Tom Harkin
Chairman Labor, Health and Human Services, Education, and Related Subcommittee
SD-186 Dirksen Senate Office Building
Washington, D.C., 20510

Dear Tom:

We are writing to request your support for consolidating the $20.9 million allocated for the Pediatric/Family AIDS Demonstration Program into Title IV of the Ryan White CARE Act. In addition, Title IV is in need of additional funding.

As you know, the Administration has requested $6 million in start-up funds for Title IV of the CARE Act and $20.9 million for Pediatric/Family AIDS Demonstration projects. Given the importance of making the most efficient use of limited resources, consolidating this funding in Title IV will result in enhanced HIV services and access to HIV clinical trials for children, adolescents, pregnant women and families with HIV and AIDS.

While consolidating these two programs maximizes the limited resources available, it does not diminish the need for substantial new funding for the demonstration programs. We are hopeful that the Committee will expand funding for Title IV to $42 million so that services for a rapidly growing population of women and children with AIDS may be expanded.

There are currently 33 demonstration projects that provide vital services to this group. Two of those are in Illinois. Despite the fact that demand for these services have increased overall by 50 percent, these programs have received level funding for the past three years.

We appreciate your consideration of this request.

Sincerely,

Paul Simon
U. S. Senator

Carol Moseley-Braun
U. S. Senator

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THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES ACT OF 1990

Title IV Background Summary

Section 2671 Statutory Title

Demonstration Grants for Research and Services for Pediatric Patients Regarding Acquired Immune Deficiency Syndrome

Intent of Statutory Language

The purpose of these grants is to support the development of infrastructure to provide outpatient care to patients and their families and to facilitate the linkages between comprehensive care and clinical trial sites as well as increase the participation of HIV infected children, adolescents, pregnant women and families in clinical research trials.

Background

How did Title IV get established?

Section 2671 of Title IV was authorized in 1990 as part of the overall Ryan White CARE Act bill. However, Congress never appropriated funds for Title IV under fiscal year 1994.

How did funding get started for Title IV?

The President's Economic Stimulus Package of 1993 included $200 million for the Ryan White CARE Act. Of this amount, $5 million was requested for the first time for Title IV. The Economic Stimulus Bill was not passed by Congress. The President's budget request for 1994 again included funds for Title IV at $6 million. In addition, in a separate line item, $20.9 million was requested for pediatric/family AIDS demonstrations (essentially level funded for three years).

A PROJECT OF THE UNIVERSITY OF MEDICINE & DENTISTRY OF NEW JERSEY-NEW JERSEY MEDICAL SCHOOL AND CHILDREN'S HOSPITAL OF NEW JERSEY.

What is the current funding situation as of July 1993?

The House of Representatives in June of 1993, approved a consolidation of the $20.9 million funding for the Pediatric/Family AIDS Demonstration Program and $6 million for Title IV. However, in the end, the House only approved a total of $22 million for Title IV. Senate action is now pending.

Why was funding consolidated for the Pediatric/Family AIDS Demonstration Program and Title IV?

Through policy development work of the National Pediatric HIV Resource Center, the Pediatric/Family AIDS Demonstration projects and the Pediatric AIDS Coalition in Washington, D.C., a formal policy position was adopted that called for consolidation of funding for services and access to clinical trials for children, adolescents, pregnant women and families under Title IV. The rationale for this decision included the fact that (1) the demonstration program was not a permanently authorized program; (2) that funding increases had not been granted by Congress for three years despite a rapidly growing population; (3) the infrastructure already created by the demonstrations was important to preserve as health care reform is considered; and (4) funding should be consolidated within a larger statutory framework to ensure increases.

How will Title IV be implemented by the field?

Title IV will be implemented through the existing care infrastructure created by the Pediatric/Family AIDS Demonstration Program. Congress started the Pediatric/Family AIDS demonstration program in 1988 to serve children, adolescents, women and families under general authority of the Public Health Service Act. Between 1988 and 1993, the Pediatric/Family AIDS Demonstration Program expanded to 35 direct service lead sites in 20 states, Washington D.C. and Puerto Rico.

The projects have been highly successful in providing and organizing services for needy children, adolescents and their families affected by HIV and AIDS where no service infrastructure has existed. Almost all projects include as elements of comprehensive care, access to clinical research trials for their patients.

How was planning for Title IV initiated within the Federal government?

From 1990 until 1992, the Maternal & Child Health Bureau of Health Resources Services Administration and the National Institutes of Health formulated a plan for the implementation of Ryan White Title IV. This planning included meetings with researchers and community providers and focused on identifying barriers to the linkage of care and research. In 1992 supplemental awards were made to grantees in order to further identify barriers.

Administration

What federal agency administers Title IV?

Congress has indicated that the Maternal Child Health Bureau (MCHB) should administer Title IV in consultation with The National Institutes of Health (NIH) to coordinate services and access to clinical trials.

What are the legislative requirements for grantees?

The applicant must arrange for or provide primary care for a significant number of pediatric, adolescent, and pregnant women patients with HIV disease. The application must have an agreement with a biomedical or other institution administering clinical trials to provide voluntary access for patients. Other elements of comprehensive services must be provided in a family-centered, community based, coordinated and culturally competent environment and includes such services as mental health, substance abuse, inpatient hospitalization, social support services and other incidental services such as transportation and child care. Evaluations and training and technical assistance must be offered to projects.

What other intent has been given by Congress related to Title IV?

Congress has indicated an intent that current grant recipients should be "grandfathered" in to Title IV so that current services are not disrupted. This includes projects are that in the process of developing access to clinical trials for their patients.

Philosophy of Care

What is the philosophy of care to be provided through Title IV?

Title IV will provide funds for comprehensive services that are family-centered, community-based, coordinated, and culturally competent that will provide as one element of care, the capacity to offer voluntary access to clinical trials. Congress also states that clinical trials for medically underserved HIV affected children, adolescents, pregnant women and families are only successful when research is conducted within an established comprehensive care system that supports the entire family.

Are there other expectations?

National training and technical assistance on pediatric, adolescent and family HIV services and clinical trials should be offered to projects. Congress also recognizes that Title IV will be the primary means of delivering HIV family-centered HIV care for children, adolescents, and families affected by HIV and AIDS.

Funding Categories

What is the Appropriations Committee report language state for funding Title IV in 1994?

The majority of funds are expected to be granted to existing Pediatric/Family AIDS Demonstration Projects. Other funds will be granted for planning and technical assistance to geographic areas where no comprehensive care system or clinical trials is organized.

Barrier to Participation in Trials

What were found to be the major barriers to participation in clinical trials during the planning for implementing Title IV?

Lack of access, resources and information as well as cultural and institutional barriers were the major issues that prevented participation in clinical HIV clinical trials. Children, adolescents, and women lack uniform access to comprehensive HIV services. Other barriers include lack of transportation and day care, and protocols have not been specifically designed for women or adolescents.

A lack of resources at community based facilities was also identified. Physical constraints such as not enough space and pharmacy inadequacies were compounded with staff members who had not been trained in research protocol requirements and procedures. A need for support services and outreach workers was also identified.

What strategies have been proposed to overcome these barriers?

In order to increase access, care systems with linkages to research must be in place. Support services should include transportation and day care as well as food during the hospital visit. The community site should have input when the protocol is being designed so that the needs of the potential participants can be included.

Resources at community sites will be augmented by funding for additional staff members such as a research nurse and laboratory technician as well as for community outreach workers and a research liaison. Funds are to be subunit in order to assure adequate resources at the community sites. "Gypsy teams" as well as outplacement of research personnel are expected. Institutional/Cultural differences will be address via new training strategies as well as cultural sensitivity training. The use of AIDS ETCs is expected.

Informational barriers will be addresses through the development of materials for participants and prospective participants that are culturally, linguistically and developmentally appropriate. Providers will participate in information sharing and training will be offered for community Primary Care Providers about the available trails.

Date Prepared:	July 7, 1993
Updated:	
Prepared by:	David C. Harvey, M.S.W. Coordinator of Public Policy
	Karin Cadwell, R.N., M.N. Policy Intern

US Public Health Service Region IX San Francisco, California

American Samoa Arizona California Commonwealth of the Northern Mariana Islands Federated States of Micronesia Guam Hawaii Nevada Republic of the Marshall Islands Republic of Palau

FROM:

Name

Office/Division

Telephone

From FAX No.

Dept. of Health & Human Service
Public Health Service

ALAN S. HARRIS
Regional AIDS Coordinator

Region IX
50 United Nations Plaza
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FAX (415) 556-2356

To FAX No. 202-632-1096

Attention Kristine Gebbie, R.N.

Organization National AIDS Policy Coordinator

Telephone 202-632-1090

No. of Pages, including this page 2

Message In your meeting this Friday (8/6) with Pediatric AIDS representatives, it is likely that an issue regarding Adolescent AIDS Clinical Research may surface. I wanted you to be aware of the issue and to be prepared to discuss it if necessary. I hope this material is useful and that your meeting is successful.

put in file for

ISSUE **Adolescent AIDS Research Efforts Have Been Adversely Impacted by Site Budget Decisions Following NIAID Recompetition of Pediatric AIDS Clinical Trial Units (PACTUs)**

BACKGROUND

As of 7/27/93, 282 adolescents (age 13-21) and 2,929 children (age 0-12) had enrolled among the 26,953 cumulative entries to the AIDS Clinical Trials Group and 6 adolescents (age 13-18) had enrolled among the 6,938 cumulative entries to the Community Programs for Clinical Research on AIDS. (source: ACTIS) In 1991, NIAID awarded one-time, supplemental funds to 6 PACTUs and 3 Adult ACTUs which had pediatric components (@$200K approx. $1.8M total) to support Adolescent AIDS Clinical Research. In 1992 the 3 adult ACTUs recompeted. University of North Carolina and Tulane (as a new PACTU) were refunded with continuation of their adolescent programs only through part of 1993. University of Minnesota did not propose to continue its adolescent component. Also in '92, two new PACTUs, Children's Hospital of Washington, D.C. and Children's Hospital of Philadelphia, PA were funded to include adolescent components. Among the 6 PACTUs with adolescent components recompeting in 1993, Einstein was not refunded. Of the other five PACTUs which were refunded, UCSF, UCLA, Children's Hospital of Newark, N.J., Johns Hopkins and Mount Sinai Medical Center, N.Y., site based budget decisions have resulted in no adolescent AIDS research component being continued.

Different views exist over the cause of this outcome. The October 1992 NIAID announcement identified Adolescent AIDS research as an "optional activity" and PACTUs were advised that "adolescents accruing to protocol #220 (an observational data base trial w/no medication) would not count toward their (PACTU) enrollment goals". In the face of a basic decision by NIAID to refund 13 of 14 recompeting PACTUs and to invest in necessary, separate laboratory capability for pediatric clinical and vaccine research, some site "core budgets" were funded at lower levels. At a recent meeting, PACTU Principal Investigators (PIs) may have decided collectively to discontinue Adolescent PACTU efforts as a strategy to deal with perceived "core budget" problems. NIAID advises that individual PIs discussed discontinuing adolescent research components and that they were advised it was their decision to choose.

IMPACT & OPTIONS

The national Adolescent AIDS clinical research effort will be severely impaired at a critical time in its evolution - unless either additional funds are provided to restore the 5 Adolescent PACTUs or NIAID reverses its guidance and insists that the five PACTUs retain their adolescent components. While the importance of the adolescent AIDS clinical research program should not be overstated, there exist major needs to understand and resolve motivational questions which will facilitate future adolescent participation in AIDS vaccine trials and to ascertain appropriate dosages of AIDS drugs for adolescents. Experts have advised that restoring the 5 adolescent ACTUs could be achieved for perhaps $500,000 and, if funds are available, this may be a best present option. PHS might also invite AmFAR to join in underwriting some of the costs of the #220 trial which is not dissimilar from their adult observational data trials. In the future, adolescent AIDS research may be better served by a separate institutional sponsorship and funding authority.

Alan Harris: PHS Regional AIDS Coordinator; 8-4-93

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BACKGROUND DISCUSSION PAPER

Improving Access to Care for Families with HIV: Integrating the Ryan White CARE Act and the Pediatric/Family AIDS Demonstration Program

For More Information, Contact:
David C. Harvey
Coordinator of Public Policy
NPHRC Washington Office

A PROJECT OF THE UNIVERSITY OF MEDICINE & DENTISTRY OF NEW JERSEY-NEW JERSEY MEDICAL SCHOOL AND CHILDREN'S HOSPITAL OF NEW JERSEY.

Improving Access to Care for Families with HIV:
Integrating the Ryan White CARE Act and the Pediatric/Family
AIDS Demonstration Program

EXECUTIVE SUMMARY

Unmet Needs

- Although the Ryan White CARE Act has specific provisions for children, adolescents, women and families, there is no evidence to date that these provisions have resulted in significant services provided to these groups. Specifically, Title II of the CARE Act requires that 15% of funds are spent on children, adolescents, women and families. The Title II requirement may be disregarded by many states or primarily fund drug reimbursement. Title I of the CARE Act, which directs funds to cities hardest hit by the epidemic, and Title II do not fund the service infrastructure needed to serve these groups.

- It is estimated that 15,000-20,000 children are currently infected with HIV, and 110,000 women are infected with HIV in the United States. 6,000 HIV infected women will have children each year; 1,500-2,000 children will have confirmed HIV infection. As of 1993, 4,200 children have been diagnosed with full-blown AIDS. The current pediatric AIDS case definition may not be effectively monitoring the impact of morbidity and mortality from HIV in children.

- In 1990, the Pediatric/Family AIDS Demonstration Program served over 12,000 clients that include children, adolescents, women and men. In 1991, this figure rose to over 18,000 clients, which is approximately a 50% increase. Specific data for 1990 show that 5,161 children were served; however, only 2,661 had confirmed HIV infection and may not have had a diagnosis of full-blown pediatric AIDS. The remainder may have been children with HIV or were indeterminate up to two years, or uninfected siblings affected by other family members with AIDS.

- Demonstration projects are located in 19 states, D.C. and Puerto Rico. These locations include major urban areas where incidence levels of children with HIV infection and AIDS are highest. However, demonstration projects report large increases in demand for services each year with little or no increases in funding provided. Some communities with out projects report an urgent need for one.

Recommendations

1. The Administration should consider whether the 15% expenditure of Title II funds under the Ryan White CARE Act is possible to effectively enforce. The federal government should complete a study of locations where demonstration projects are located and assess the level of services provided to children, adolescents and their families through the demonstration program and the Ryan White CARE Act.

2. The Administration should require the Centers for Disease Control to conduct epidemiological studies to project the incidence levels of HIV infection in the United States population and specifically, among children, adolescents, and pregnant women.

3. The Administration should strengthen and expand the non-authorized Pediatric/Family AIDS Demonstration Program to help the 31 established projects cope with increasing case loads and help new projects develop in areas of identified need.

4. The Administration should recognise that comprehensive care systems for children, adolescents, women and their families should also support access to HIV therapeutic trials where such trials may be located.

BACKGROUND DISCUSSION PAPER

IMPROVING ACCESS TO CARE FOR FAMILIES WITH HIV: INTEGRATING THE RYAN WHITE CARE ACT AND THE PEDIATRIC/FAMILY AIDS DEMONSTRATION PROGRAM

Introduction

This discussion paper briefly outlines the status of HIV comprehensive services for children, adolescents, and their families and proposes specific actions for improving access to HIV comprehensive care under the Pediatric/Family AIDS Demonstration Program and the Ryan White AIDS CARE Act.[1] An introduction to the paper is followed by: (1) epidemiology; (2) a description of the Pediatric/Family AIDS Demonstration Program; (3) provisions for children, adolescents, women and families under the Ryan White CARE Act; (4) unmet comprehensive service needs for children, adolescents, and families; and (5) recommendations for the Administration to consider.

Background

Advances in treatment and early HIV diagnosis have made HIV related illnesses a chronic condition that will require long term medical care and social support. Increasingly it is a disease of children, adolescents, women and families. As life expectancy of HIV infected individuals is prolonged and more cases are identified, the need for additional primary care services and specialized HIV care specifically for children, adolescents, women and families through cost-effective, community-based and family-centered comprehensive systems has become critical. Meeting this need for each group will require leadership from both Congress and the Executive branch of government.

There is a pressing and continuing need to develop and maintain comprehensive programs that focus specifically on the needs of children, adolescents and their parents. Existing systems of care are overwhelmed by service demands, resource limitations, and an inadequate supply of medical and social service professionals who are skilled in HIV care for children, adolescents, and their parents. The Ryan White CARE Act, passed by Congress in 1990, does not adequately fund services for children, adolescents, and families because of the magnitude of the crisis among infected adults. Separate from the CARE Act is the Pediatric/Family AIDS Demonstration Program which has been a primary federal response to enhancing the health care infrastructure and its ability to serve this population. It is now urgent to consider incorporating

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[1] For additional information, see Harvey, D. (1993) A Proposal for Legislation to Authorize the Pediatric/Family AIDS Demonstration Program. National Pediatric HIV Resource Center, Washington, D.C. and Pediatric/Family HIV Health Care Demonstration Grant Program: Clients Served, 1988-1990. National Pediatric HIV Resource Center (1992), Newark, NJ.

the demonstration program within the Ryan White AIDS CARE Act to protect the accomplishments of the program and to enhance access to care for this population of HIV affected persons.

Epidemiology

The HIV epidemic has spread rapidly among women, children and adolescents in United States. Through December of 1992, 4,200 children, 10,528 young people ages 13-24, and 27,210 adult women have been diagnosed with full-blown AIDS.[2] On April 29, 1993, the Centers for Disease Control and Prevention announced that an additional total of 35,000 cases of AIDS had been reported for the first three months of 1993, a 45% increase from 1992. This reflects the changed case definition of AIDS implemented by the CDC in January 1993. These numbers will continue to rapidly rise as asymptomatic persons currently infected with HIV go on to develop AIDS.

Because the onset of AIDS-defining illnesses generally occurs a decade after infection with HIV, the figures quoted above greatly understate the total number of persons with HIV in the United States. Approximately, 15,000-20,000 children,[3] an unknown number of adolescents, 110,000 women, and over 1 million men are estimated to have HIV infection but are not yet diagnosed with AIDS.[4] Using 1989 national sero-survey data for childbearing women, the CDC estimates that 6,000 HIV infected women will give birth to children each year; approximately 1,500-2,000 of whom will be infected with HIV.[5] According to a recent Congressional report, each year at least 40,000 new HIV infections occur among adolescents and adults. Over 46,400, or 19% of the reported cases of AIDS in the U.S. are among young adults in the 20-29 age range. HIV disproportionately affects low-income Black, Hispanic or Latino persons. Fifty-four percent of the reported children with AIDS are of African-American descent, although only about 14% of all the nation's children are black. In addition, 24% of the children with AIDS have been of Hispanic or Latino origin, although only 11% of U.S. children are Hispanic or Latino.

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2 Centers for Disease Control and Prevention (1993, February) HIV/AIDS Surveillance Report. (Year-End Edition). Atlanta, GA.

3 Report of the Surgeon General's workshop on children with HIV Infection and their Families. Washington, D.C.: U.S. Government Printing Office (November, 1988).

4 Centers for Disease Control and Prevention. (1993, February). Office of Technical Information Activity. Atlanta, GA.

5 Centers for Disease Control and Prevention. (1993, February). Office of Technical Information Activity. Atlanta, GA.

The current pediatric AIDS case definition may not be effectively monitoring the impact of morbidity and mortality from HIV in children. Since 1990, revisions to the pediatric classification system and AIDS case definition have been under discussion and during this time numerous states have implemented HIV reporting in children. In May of 1993, the Centers for Disease Control is expected to release a new pediatric classification for HIV reporting in children which may assist with collecting data that more accurately reflects true infection rates among children in the United States.

Financing

Other studies have estimated the cost of providing medical care for children with AIDS. Limited available data suggests that cost for direct medical care of children with AIDS ranges from $40,000 to $50,000, and is significantly higher than other childhood diseases. [6] [7] These studies include costs of direct medical care and do not address costs of other necessary HIV-related services. Other studies have estimated the lifetime costs of treating children with AIDS at over $90,000.[8] Costs are rapidly increasing for treating AIDS as people live longer and treatment improves. A recent study presented at the Amsterdam International AIDS conference estimated lifetime costs of medical care for an adult with AIDS at over $100,000.[9] The cost of treating all people with HIV in 1991 was estimated to be $5.8 billion of which $1.4 billion was spent on treating just persons with asymptomatic HIV infection. It is estimated that the cost of treating all people with HIV will increase 21% each year through 1994.[10]

The United States Health Care Financing Administration has estimated that nationally 40% of all persons with AIDS and up to 90% of children with AIDS are enrolled in Medicaid, the major federal-state health care reimbursement system for low-income persons. Among individuals receiving services at agencies funded by the Pediatric/Family AIDS Demonstration

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6 Boland, M., Conviser, R., Kelley, M., Connor, E., Ratkin, R., Oleske, J. Care needs of HIV-infected children at new jersey children's hospital, AIDS & Public Policy, 7:1, p. 7-17.

7 U.S. Department of Health and Human Services (1991), Family centered comprehensive care for children with HIV infection, p. 40.

8 Hegarty, JD, Abrams EJ, Hutchinson, VE. The medical care costs of human immunodeficiency virus-infected children in Harlem. JAMA 1988: 260: 1901-9.

9 Hellinger FJ, Agency for Health Care Policy and Research, U.S. Department of Health and Human Services. Oral presentation at VIII International Conference on AIDS Amsterdam, July, 1992.

10 Hellinger, FJ, Agency for Health Care Policy & Planning (1991). Forecasting the medical care costs of the HIV epidemic: 1991-1994. Inquiry, Vol. 28:3, p. 213-225: Blue Cross Blue Shield Association.

Program in 1990, 16% had no form of health coverage, and 68% were covered by Medicaid.[11] Medicaid enrollment, however, does not guarantee access to services and drug therapies. The Medicaid Sourcebook reports that early studies have indicated that between 20%-30% of all HIV service charges are reimbursed through Medicaid, although reimbursement rates differ significantly among states.[12] It is expected that Medicaid's role in financing HIV services will expand in the future and that this will be due to the changing demographics of the epidemic and other forms of insurance being less available for persons with HIV. In general, limitations in Medicaid reimbursement include fees lower than customary charges for services provided by medical personnel, restricted coverage for pharmaceutical and ancillary tests, little or no reimbursement for case management services that can prevent unnecessary hospitalization, and most importantly, financial eligibility criteria that rule-out enrollment of many uninsured low-income and unemployed persons.

Pediatric/Family AIDS Demonstration Program.

In 1988, Congress created the Pediatric/Family AIDS Demonstration Program. The program is administered by the Maternal & Child Health Bureau of the Health Resources Services Administration, U.S. Department of Health & Human Services. The demonstration program is currently separate from the Ryan White AIDS CARE Act and is a non-authorized program which has received funds at the initiation of the appropriations committees of Congress. Last year, the program received an appropriation of $20.9 million and has had essentially no increases in funding for the past three years. This is despite a case load increases between 1990-1991 of up to 50% by some projects. In 1992, Congress passed appropriations committee report language that stated the "projects constitute the single largest Federal program providing comprehensive HIV services to children, adolescents, women and families, which now comprise the fastest growing segment of the HIV/AIDS population (Senate Report 102-978, 1992).

The goals of the demonstration program are to: (1) foster the development of comprehensive care systems that provide culturally sensitive, family-centered, community-based care that is integrated into existing systems of care; (2) emphasize prevention within the comprehensive care system to reduce perinatal transmission of HIV and the spread of infection to vulnerable populations, especially minorities and adolescents; (3) increase the access of HIV-infected children, youth, and their families to comprehensive care services; (4) ensure delivery of high-quality care as the appropriate level of care, with an emphasis on ambulatory care

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11 Harvey, D., et.al., Pediatric/Family HIV Health Care Demonstration Grant Program: Clients Served 1988-1990, National Pediatric HIV Resource Center: 1992.

12 Committee on Energy and Commerce, U.S. House of Representatives (November 1988, Committee Print 100-AA). Medicaid source book: background data and analysis. Congressional Research Service, pp. 485-490.

services that may reduce unnecessary hospital stays; and (5) sustain comprehensive care systems for HIV-infected children through appropriate financing mechanism.

Providing access to comprehensive care for families with HIV requires coordinating diverse, multi-disciplinary agencies that provide health care, social services, nutrition, mental health, family support, and educational and vocational assistance. Demonstration project grantees are required to demonstrate that they have identified existing resources serving HIV-affected populations in their communities, and to describe how they will collaborate and coordinate their activities with appropriate programs in the public and private sectors. For example, these projects collaborate with state agencies administering Maternal and Child Health Title V block grant funds for special child health services, with Ryan White Comprehensive AIDS Resources Emergency Act planning councils and consortia, with community health centers, and with child welfare services.

The intent of the program is to work toward the inclusion of HIV services within established systems of care meeting the needs of children, adolescents and families. However, there is a pressing and continuing need to develop and maintain comprehensive programs that focus specifically on the needs of these HIV-affected populations as existing systems of care are overwhelmed by service demands, resource limitations, and an inadequate supply of medical and social service professionals who are skilled in HIV care for women, children and adolescents.

Currently, demonstration programs are located in 19 states, the District of Columbia, and Puerto Rico. Through 1991, the program served over 18,000 clients at 31 direct service sites. The demonstration program is recognized nationally as the principle means toward organizing and providing specific clinical and case management services designed to meet the needs of children, adolescents, and families, including related services for parents and extended family members. With approximately $15 million in direct service allocations in 1990, each project spent an average of between $1,000-$1,500 per client in fiscal year 1990. A study conducted by the Northern Manhattan demonstration project in New York City found a substantial decline in the hospitalization rate and length of stay for HIV antibody positive children. The authors conclude that "...probably the most significant contribution was the resource infusion of the demonstration program which made possible high quality case-managed care thus improving outpatient management of children and reducing reliance on emergency room care."

The President's supplemental budget request for 1993, which recently failed in the Senate, included $5 million in start-up funding for Title IV of the Ryan White CARE Act and included as a rationale, a link to the demonstration program infrastructure.

> Section 2671 establishes a program of innovative demonstration grants to ensure that clinical research and outpatient health care are accessible and coordinated for the target population of HIV infected children, pregnant women, and their families. The legislation call for demonstration grants to develop innovative models that foster collaboration between clinical research institutions and primary/community based medical and social service providers. These were intended to complement, rather than to supplant, the grants funded under HRSA's Pediatric HIV Demonstration program. HRSA initiated interagency collaboration with NIH in 1991 to plan for Title IV implementation.

The Senate appropriations committee statement of managers (March 23, 1993 Congressional Record, page S3465) clarified Congressional intent related to Title IV as follows:

> ...and $5 million is provided for Title IV, to foster collaboration between comprehensive pediatric and family service projects and clinical research programs. The Committee expects the majority of Title IV funds will supplement ongoing pediatric/family AIDS demonstration projects to increase their capacity to support clinical trials for children, women, and families. In addition, the Committee understands funds will be used to provide planning grants and technical assistance to the 32 states that currently have no organized capacity for referrals and where the benefits of such demonstration projects can be identified.

Ryan White CARE Act.

Statutory Requirements. The Ryan White CARE Act has several specific provisions related to services for children, adolescents, women and families. Currently funded at $185 million for 1993, Title I planning councils are required to develop service priorities and plans and assess administrative efficiency for expenditures of these funds in those cities hardest hit by the epidemic. Membership of councils are required to include as representatives individuals from "affected communities" and service providers from these communities, as well as the "lead agency of any HRSA...pediatric HIV-related care demonstration project operating in the area to be served". In addition, supplemental grants awarded under Title I must demonstrate "that resources will be allocated in accordance with the local demographic incidence of AIDS including appropriate allocations for services for infants, children, women, and families with HIV disease."

Currently funded at $115 million for 1993, Title II state care grants provide funds for care consortia, home and community-based services, insurance coverage, or treatments, and must use "not less than 15 percent of funds...to provide health support services to infants, children, women, and families with HIV disease." Title IIIb was funded at $48 million in 1993 for early intervention services that includes counseling and testing, referrals, outreach services, and case management. There is no specific mention of early intervention services for children, adolescents, women and families.

Title IV, section 2671, which has not been funded prior to the President's FY 1993 stimulus package request and the 1994 budget request, will provide funds for demonstration grants for "conducting, at the health facilities of such entities, clinical research on therapies for pediatric patients with HIV disease as well as pregnant women with HIV disease... and...providing health care on an outpatient basis to such patients and the families of such patients." Requirements include cooperation with biomedical research institutions, and the provision of case management services, referrals, and incidental services.

Funding History. Currently, the federal government is unable to give complete specific data on children, adolescents, women and families served through the Ryan White CARE Act.

Despite a request by the Senate appropriations committee for this data in 1991 and 1992, the Health Resources Services Administration is still compiling this data. However, the Pediatric AIDS Coalition conducted a phone survey in 1991 of all lead state and city contacts for Title I and Title II of the CARE Act. All states and 15 of 16 cities receiving funds under the Act responded to the survey. This survey sought preliminary data on expenditures of funds for children, women and families under both Titles, recognizing that states under the Act must spend 15% of state allocations for this population. Eleven states reported that no funds were spent on this population and sixteen states were unable to give information on expenditures for this population. Of those state and cities that did allocate funds for children, adolescents, women and families, the most common services funded include case management, drug reimbursement, and transportation. Many participants in the study reported intense competition within the community for funding.[13]

Needs assessments and data collection surveys of the National Pediatric HIV Resource Center of Pediatric/Family AIDS Demonstration projects have indicated that no projects receive Ryan White funds for comprehensive service infrastructure development. Some projects receive small amounts of funds for ancillary support services, but all projects rely on demonstration project grants to provide the comprehensive service system infrastructure and provision of direct comprehensive services.[14]

Unmet Needs

1. Although the Ryan White CARE Act has specific provisions for children, adolescents, women and families, there is no evidence to date that these provisions have resulted in significant services provided to these groups. The Health Resources Services Administration currently has no data to document services provided to children, adolescents, women and families, and the Pediatric AIDS Coalition survey found many states out of compliance with Ryan White CARE Act provisions. Specifically, Title II may be ignored by many states or primarily fund drug reimbursement. Title I and Title II do not fund the service infrastructure needed to serve these groups.

2. It is estimated that 15,000-20,000 children are currently infected with HIV, and 110,000 women are infected with HIV in the United States. 6,000 HIV infected women may have children each year; 1,500-2,000 children will have confirmed HIV infection. As of 1993, 4,200 children have been diagnosed with full-blown AIDS. The current pediatric

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13 Harvey, D., Rathburn, J., Leif, E. Ryan White [AIDS] CARE Act Survey: Services Funded for Children and Adolescents. Pediatric AIDS Coalition: Washington, D.C.

14 National Pediatric HIV Resource Center (1991-1992). National Pediatric/Family AIDS Demonstration Program Needs Assessment Survey: Newark, NJ.

AIDS case definition may not be effectively monitoring the impact of morbidity and mortality from HIV in children. Since 1990, revisions to the pediatric classification system and AIDS case definition have been under discussion and during this time numerous states have implemented HIV reporting in children. In May of 1993, the Centers for Disease Control is expected to release a new pediatric classification for HIV reporting in children which may assist with collecting data that more accurately reflects true infection rates among children in the United States.

3. In 1990, the Pediatric/Family AIDS Demonstration Program served over 12,000 clients that include children, adolescents, women and men. In 1991, this figure rose to over 18,000 clients, which is approximately a 50% increase. Specific data for 1990 show that 5,161 children were served; however, only 2,661 had confirmed HIV infection and may not have had a diagnosis of full-blown pediatric AIDS. The remainder may have been children with HIV or were indeterminate up to two years, or uninfected siblings affected by other family members with AIDS. Also in 1990, the program served approximately 1000 adolescents, 5,700 women, and 500 men. Of these groups, 3,633 were not infected with HIV but were part of families providing care to sick members.

4. Demonstration projects are located in 19 states, D.C. and Puerto Rico. These locations include major urban areas where incidence levels of children, adolescents, and pregnant women with HIV infection and AIDS are highest. However, demonstration projects report large increases in demand for services each year with few additional resources to support expanding projects.

   A. Since the Ft. Lauderdale, FL comprehensive pediatric AIDS project was established in Broward Country, Florida in July of 1991, client case loads have increased 600% in less than 24 months. 70 children were initially identified in 1991 and currently, 540 HIV positive children are being served. To date, 203 have confirmed HIV infection and are symptomatic. The project has received minimal increases in funding from the demonstration program since it started.

   B. In Philadelphia, PA, client demand has increased dramatically. In 1992, 178 HIV positive children and 16 HIV positive adolescents were served in addition to 22 children with full-blown AIDS and 2 adolescents with full-blown AIDS. In the first six months of 1993, the project is serving 207 children with HIV, 19 adolescents with HIV; 29 children with AIDS and 2 adolescents with AIDS. In addition, the project provides "one-stop" primary and comprehensive care for women, men and children and is currently serving over 150 women and 50 men over age 21 at the same site that their children receive services.

   C. In Milwaukee, Wisconsin, which does not have a demonstration project, the number of children with HIV infection will equal the number in Boston by 1995

and New Jersey by the year 2000.[15] Milwaukee and surrounding counties does not have a community-based, comprehensive care system in place for children and families. Most children with HIV are currently being seen at a tertiary care facility and lack the benefit of a coordinated, comprehensive care infrastructure that provides services in their community with expert providers.

Recommendations

The Administration's 1994 budget request proposes a $310 million increase in funding for the Ryan White CARE Act. In addition, the Administration has requested a continuation of the Pediatric/Family AIDS Demonstration Program with level funding at $20.9 million. In the context of health care reform and in order to improve access to comprehensive care for a growing population of children, adolescents, women and families affected by HIV and AIDS, the following should be considered:

1. The Administration should consider whether the 15% expenditure of Title II funds under the Ryan White CARE Act is possible to effectively enforce. The federal government should complete a study of locations where demonstration projects are located and assess the level of services provided to children, adolescents and their families through the demonstration program and the Ryan White CARE Act.

2. The Administration should instruct the Centers for Disease Control to conduct epidemiological studies to project the incidence levels of HIV infection in the United States population and specifically, among children, adolescents, and pregnant women.

3. The Administration should strengthen and expand the non-authorized Pediatric/Family AIDS Demonstration Program to help the 31 established projects cope with increasing case loads and help new projects develop in areas of identified need.

4. The Administration should recognise that comprehensive care systems for children, adolescents, women and their families should also support access to HIV therapeutic trials where such trials may be located.

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15 Havens P., Roy, B., Burr, C. (1993) Providing for the Care of HIV Infected Children, Adolescents and their Families in the Mid-Western U.S.

15 South Ninth Street
Newark, New Jersey 07107
201-268-8251
800-362-0071
201-485-2752 FAX

NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

900 Second Street, NE
Suite 211
Washington, DC 20002
202-289-5970
202-408-9520 FAX

June 30, 1993

Kristine Gebbe, R.N., M.S.N.
Federal AIDS Policy Coordinator
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear Ms. Gebbe:

I was pleased to meet you last Friday at the White House when the President announced your appointment as Federal AIDS Policy Coordinator. Your appointment represents an historic moment in the fight against HIV and AIDS and I was proud to be a part of the White House ceremony in your honor. On behalf of Mary Boland, R.N., M.S.N. and Carolyn Burr, R.N., M.S., directors of the National Pediatric HIV Resource Center in Newark, New Jersey, we welcome the opportunity to work with you and your office as you begin to reshape the national response to the HIV epidemic.

During the past few months, it has also been an honor for me to be a part of health care reform meetings on HIV and AIDS issues at the White House. These meetings have resulted in several immediate developments related to the care of children, adolescents and families with HIV in the United States, and I wanted to take this opportunity to update you on these developments and to ask for your assistance.

Following meetings with Carol Rasco, Secretary Donna E. Shalala, Ph.D., Mark Smith, M.D., and Patsy Flemming, the Administration approved a proposal to consolidate funding for the Pediatric/Family AIDS Demonstration Program -- funded under general authority of the Public Health Service Act -- to a permanent statutory authority under Title IV of the Ryan White CARE Act. Our position was that by facilitating this consolidation, services and access to HIV clinical trials for children, adolescents and families with HIV would be greatly enhanced. In addition, by consolidating funding for the program in Title IV, the demonstration projects would be well positioned to now receive funding increases since the program have been level funded by the Administration and Congress for the past three years. Finally, we felt the consolidation was important at this point in time before the Administration's health care reform bill is introduced in Congress.

Three weeks ago, the House Appropriations Committee approved this consolidation and Title IV received $22 million in funding, $5 million short of the President's request. In

addition, the Committee adopted report language that holds harmless current grant recipients as they are transferred to Title IV statutory authority. While consolidation of the program within Title IV maximizes the limited resources available, it does not diminish the significant need for new funding to support a rapidly growing group of children, adolescents, women and families affected by HIV and AIDS. We are hopeful that the Administration would support in the Senate, a modest increase of $20 million for Title IV. This would bring the total appropriation for Title IV to $42 million. In addition, we are hopeful that the Administration would support Senate Appropriations Committee report language that further clarifies and strengthens the House report language to hold harmless current grant recipients.

While issues related to the Ryan White CARE Act have been an important focus of our work to date, we look forward to working with your office on other matters of concern related to prevention, research, care and surveillance. For your information, I enclose materials on the Pediatric/Family AIDS Demonstration Program and the National Pediatric HIV Resource Center.

We look forward to receiving your response to this letter and in scheduling a meeting with you with representatives from the field. Please call upon the Resource Center if we can be of assistance to your office.

Once again, congratulations on your appointment.

Sincerely,

David C. Harvey, M.S.W.
Coordinator for Public Policy
Washington Office

cc: Mary Boland, R.N., M.S.N.
Carolyn Burr, R.N., M.S.

Pediatric demonstrations

The bill does not include funding for pediatric AIDS demonstrations, which is $20,897,000 below both the 1993 level and the Administration request. The Committee has chosen instead to allocate these funds to the pediatric AIDS demonstrations supported under Title IV of the Ryan White AIDS C.A.R.E. Act because those demonstrations will have enhanced access to clinical research. The currently-funded projects develop community-based, family-centered, coordinated services for infected infants, children, adolescents, and women at risk, and demonstrate ways to prevent the spread of HIV infection. In 1993, the program will support 33 demonstration projects, 2 consortia projects, 2 resource centers, and 6 hemophilia treatment projects. The Committee understands that the current projects are highly successful and expects that they will be the type of projects that will compete well for funding under the Ryan White Title IV authority.

Ryan White AIDS programs: Title IV pediatric demonstrations

The bill includes $22,000,000 for the pediatric AIDS demonstrations authorized under Title IV of the Ryan White C.A.R.E. Act. This is $16,000,000 above the Administration request and $22,000,000 above the 1993 level. The program will support demonstration grants to develop innovative models that foster collaboration between clinical research institutions and community-based medical and social service providers for the target population of HIV-infected children, pregnant women and their families.

THE RYAN WHITE CARE ACT AND THE PEDIATRIC/FAMILY AIDS DEMONSTRATION PROGRAM

FACT SHEET AND RECOMMENDATIONS

Background

- In 1988 Congress established the Pediatric/Family AIDS Demonstration Program to provide specialized HIV comprehensive health services for children, adolescents, women and families. The program is administered by the Maternal & Child Health Bureau of the Health Resources Services Administration.

- Through 1992, 33 direct service sites have been funded in 19 states, the District of Columbia, and Puerto Rico.

- Congress appropriated $4.43 million in FY 1988 and increased funding to $19.0 million in FY 1990. In FY 1993, Congress appropriated $20.9 million and passed the following report language: "The projects constitute the single largest Federal program providing comprehensive HIV services to children, adolescents, women, and families, which now comprise the fastest growing segment of the HIV/AIDS population."

- The President has requested in the FY 1994 budget, $6 million in start-up funding for Title IV of the Ryan White CARE Act. The Administration's budget rationale and Senate Appropriations Committee report language that was approved as part of the failed FY 1993 stimulus bill, stated that the $6 million should supplement and not supplant the Pediatric/Family AIDS Demonstration Program and that these funds should be used to continue existing comprehensive care projects and enhance the client's ability to access HIV therapeutic trials.

Clients Served

- In 1990, the Pediatric/Family AIDS Demonstration Program served over 12,000 clients that include children, adolescents, women and men. In 1991, this figure rose to over 18,000 clients, which is approximately a 50% increase.

- Specific data for 1990 show that 5,161 children were served; however, only 2,661 had confirmed HIV infection and may not have had a diagnosis of full-blown pediatric AIDS. The remainder may have been children with an indeterminate HIV infection (up to two years), children with HIV, or uninfected but affected. Also in 1990, 946 adolescents, 5,572 women, and 434 men were served by projects. Approximately 50% of adolescents, women, and men served were HIV infected themselves. All clients served were part of families where multiple members were infected or diagnosed with AIDS and needed social and/or medical services.

- Although the Ryan White CARE Act has specific provisions for children, adolescents, women and families, there is no evidence to date that these provisions have resulted in significant services provided to these groups. Specifically, Title II of the CARE Act requires that 15% of funds will be spent on children, adolescents, women and families. The Title II requirement may be disregarded by many states or primarily fund drug reimbursement. Title I of the CARE Act, which directs funds to cities hardest hit by the epidemic, and Title II do not fund the service infrastructure needed to serve these groups.

Unmet Needs

- It is estimated that 15,000-20,000 children are currently infected with HIV, and 110,000 women are infected with HIV in the United States. 6,000 HIV infected women will have children each year; of these, 1,500-2,000 children will have confirmed HIV infection. As of January 1993, 4,200 children have been diagnosed with full-blown AIDS. The current pediatric AIDS case definition may not be effectively monitoring the impact of morbidity and mortality from HIV in children.

- 33 demonstration projects are located in 19 states, D.C. and Puerto Rico. These locations include major urban areas where incidence levels of children with HIV infection and AIDS are highest. However, demonstration projects report large increases in demand for services each year with little or no increases in funding provided. Some communities without projects report an urgent need for one.

Recommendations

1. Congress should strengthen and expand the non-authorized Pediatric/Family AIDS Demonstration Program to help the 33 established projects cope with increasing case loads and help new projects develop in areas of identified need.

2. Congress should direct that current funding for the program be included within Title IV of the Ryan White CARE Act to:

   (A) provide comprehensive services for children, adolescents and their families with HIV and AIDS through existing projects
   (B) as part of comprehensive services, provide funds to help clients access HIV therapeutic trials through existing projects
   (C) provide planning grants for states that have no care infrastructure for children, adolescents and their parents and where there is an identified need

National Pediatric HIV Resource Center

15 South Ninth Street
Newark, NJ 07107

201-268-8251
1-800-362-0071
201-485-2752 Fax

PEDIATRIC/FAMILY AIDS HEALTH CARE DEMONSTRATION PROGRAM

DIRECTORY 1993

Comprehensive Direct Service Projects
Lead & Affiliate Organizations

National Training & Technical Assistance Projects

Hemophilia Special Initiatives

Supported by the U.S. Department of Health & Human Services
Health Resources Administration, Maternal & Child Health Bureau

About the Pediatric/Family AIDS Health Care Demonstration Program

The Pediatric/Family AIDS Health Care Demonstration Program was created by Congress in 1988, under general authority of the Public Health Service Act. Administered by the Maternal & Child Health Bureau of Health Resources Services Administration, U.S. Department of Health & Human Services, the program has the following goals: 1) to foster the development of comprehensive care systems that provide culturally sensitive, family-centered, community-based care that is integrated into existing systems of care; 2) to emphasize prevention within the comprehensive care system to reduce perinatal transmission of HIV and the spread of infection to vulnerable populations, especially minorities and adolescents; 3) to increase the access of HIV-infected children, youth, and their families to comprehensive care services; 4) to ensure delivery of high-quality care with an emphasis on ambulatory care services that may reduce unnecessary hospital stays; 5) and to sustain comprehensive care systems for HIV-infected children through appropriate financing mechanisms.

This Directory lists the lead and affiliate organizations of the Pediatric/Family AIDS Demonstration Projects throughout the U.S. The affiliate organizations are official subcontractors of the lead organizations. The Directory also lists the programs funded as Hemophilia Special Initiatives and those which conduct special issue projects or provide technical assistance on pediatric/family AIDS issues.

About the National Pediatric HIV Resource Center

The National Pediatric HIV Resource Center (NPHRC) offers a range of services to professionals caring for children, adolescents, and families affected by HIV infection. The Resource Center provides consultation, technical assistance, and training, as well as serving as a forum for exploring public policy issues related to the care of children with HIV infection. NPHRC is a project of the Department of Pediatrics, University of Medicine & Dentistry - New Jersey Medical School and Children's Hospital of New Jersey. For more information, please contact NPHRC, Children's Hospital of New Jersey, 15 South 9th Street, Newark, NJ 07107, (201) 268-8251 or (800) 362-0071. The Washington, D.C. office of the Resource Center is located at 900 Second Street, NE, Suite 211, Washington, D.C. 20002, (202) 289-5970.

For Additional Information on Pediatric/Family AIDS Demonstration Projects contact:

Hemophilia and Pediatric AIDS Branch
Maternal & Child Health Bureau
HRSA
Parklawn Building, Room 18-A-27
5600 Fishers Lane
Rockville, MD 20857
1-301-443-9052
1-301-443-1917 (Fax)

Table of Contents

Maternal & Child Health Bureau
Division of Services for Children with Special Health Care Needs
Hemophilia and Pediatric AIDS Branch
5600 Fishers Lane, Room 18-A-27
Rockville, MD 20857
301-443-9051
301-443-1719 (fax)

Contacts:

Merle McPherson, MD, Director
Beth Roy, MBA, Chief
Lauren Deigh, Deputy Chief
Sharon Barrett, MS, Director, Hemophilia Program
Irene Forsman, RN, MS, Nurse Consultant
Joe Leach, Public Health Analyst
Pat McGuckin, Public Health Analyst

Section I

Comprehensive Direct Service Projects

Section I: Comprehensive Direct Service Projects

ALABAMA

Lead Organization:
Pediatric HIV/AIDS Health Care Demonstration Program
University of Alabama @ Birmingham
Department of Pediatrics
751 Children's Hospital Tower
Suite 751
Birmingham, AL 35222
Contact: Marilyn Crain, MD, MPH, Director — 205-934-7883
205-934-8658 (fax)

Pediatric HIV/AIDS Health Care Demonstration Program
University of Alabama @ Birmingham
Department of Pediatrics
Children's Hospital Tower
Suite 654
Birmingham, AL 35294-0011
Contact: Tara Dortch, ASN, BA, Program Coordinator I — 205-934-4731
205-934-8658 (fax)

Affiliates:
AIDS Task Force of Alabama
P.O. Box 55703
Birmingham, AL 35255
Contact: Brain Sturvidant — 205-592-2437
205-592-4998 (fax)

Birmingham AIDS Outreach
P.O. Box 550070
Birmingham, AL 35255
Contact: Sharon Lambert — 205-322-4197
205-322-2131 (fax)

Jefferson Clinic, P.C.
Cooper Green Hospital
P.O. Box 55845
Birmingham, AL 35255
Contact: Jane E. Mobley, MD — 205-934-7900 X 3292
205-933-2905 (fax)

ALABAMA cont...

Jefferson County Health Department
1400 6th Avenue South
Birmingham, AL 35233
Contact: Mary Ann Pass, MD
205-930-1500
205-930-0243 (fax)

The Children's Hospital of Alabama
1600 Seventh Avenue, South
Birmingham, AL 35233
Contact: James C. Dearth, MD
205-939-9621
205-939-9189 (fax)

U.A.B AIDS Center
1918 University Blvd. UAB Station,
Basic Health Science, Room 344A
Birmingham, AL 35294
Contact: Melanie Pollard
205-934-2437
205-934-1640 (fax)

U.A.B. School of Public Health
Health Care Organizations/Policy
PWPT 121
Birmingham, AL 35294-2090
Contact: Steve Mennemeyer, PhD
205-934-3748
205-934-3347 (fax)

U.A.B. School of Public Health
Biostatics, TH 212C
Birmingham, AL 35294-0008
Contact: Laura Perkins, PhD
205-934-5639

U.A.B. School of Public Health
Health Behavior, CBB 502 A
Birmingham, AL 35294-2025
Contact: Kim Reynolds, PhD
205-934-6020
205-934-7539 (fax)

CALIFORNIA

<u>Lead Organization:</u>
Project AHEAD
Special Programs for Youth
San Francisco Department of Public Health
375 Woodside Avenue Building W-1
San Franciso, CA 94127
Contact: Janet Shalwitz, MD, Director
415-753-7780
415-753-7759 (fax)

CALIFORNIA cont...

Project AHEAD
Special Programs for Youth
San Francisco Department of Public Health
375 Woodside Avenue, Building W-1
San Francisco, CA 94127
Contact: Ron Henderson, Coordinator — 415-753-7780
415-753-7759 (fax)

Affiliates:

Bay Area Youth Positives
340 4th Avenue
San Francisco, CA 94118
Contact: Antigone Hodgins, Peer Facilitator — 415-753-7875
415-753-7759 (fax)

Children's Health Center
San Francisco General Hospital
1001 Potrero Avenue
San Francisco, CA 94110
Contact: Dick Brown, MD, Director — 415-206-8376
415-695-6018 (fax)

Larkin Street Youth Center
1044 Larkin Street
San Francisco, CA 94109
Contact: Diane Flannery, Executive Director — 415-673-0911
415-923-1378 (fax)

San Francisco General Hospital
Community and Family Medicine
University of California, San Francisco
1001 Potrero Avenue
San Francisco, CA 94110
Contact: Ron Goldschmidt, MD, Director — 415-206-8651
Family Practice Inpatient Service — 415-206-6135 (fax)

San Francisco General Hospital
Family and Community Medicine
1001 Potrero Ave, Ward 83, Building 80
San Francisco, CA 94110
Contact: Bill Shore, MD, Director — 415-206-8610
Predoctoral Educational Program — 415-476-3454 (fax)

CALIFORNIA cont...

Youth Advocates, Inc.
285 12th Avenue
San Francisco, CA 94118
Contact: Bruce Fisher, Executive Director — 415-668-2622
415-668-0631 (fax)

University of California @ San Francisco
Division of Adolescent Medicine
400 Parnassus Avenue Room AC1
San Francisco, CA 94143
Contact: Charles Irwin, MD, Director — 415-476-2184
Division of Adolescent Medicine — 415-476-6106 (fax)

Lead Organization:
Los Angeles Pediatric AIDS Network (LAPAN)
Children's Hospital of Los Angeles
4650 Sunset Boulevard, Box #30
Los Angeles, CA 90027
Contact: Marcy Kaplan, MSW, Director, Co-Principal Investigator — 213-669-5616
213-664-6814 (fax)

Los Angeles Pediatric AIDS Network (LAPAN)
AIDS Program Office
600 South Commonwealth Avenue, 6th Floor
Los Angeles, CA 90005
Contact: John F. Schunhoff, MD, Co-Principal Investigator — 213-351-8001
213-387-0912 (fax)

Affiliates:
Caring for Babies with AIDS
5920 Comey Avenue
Los Angeles, CA 90034
Contact: Wendy Bass, MA, Case Manager — 213-931-9828
213-931-1440 (fax)

Cedars-Sinai Medical Center
8700 Beverly Boulevard, Room 4520
Los Angeles, CA 90048
Contact: Phillip Brunell, MD — 310-855-4446
Stacey Blum, LCSW — 310-657-1778 (fax)

CALIFORNIA cont...

Children's Hospital of Los Angeles
Allergy/Clinical Immunology
4650 Sunset Boulevard, Box #30
Los Angeles, CA 90027
Contact: Joseph Church, MD 213-669-5616
Marcia Gonzales, MSW 213-664-6814 (fax)

Children's Hospital of Los Angeles
Adolescent Medicine
4650 Sunset Boulevard, Box #2
Los Angeles, CA 90027
Contact: Richard MacKenzie, MD 213-669-2390
Lori Wolfe, MSW 213-913-3614 (fax)

Harbor/UCLA Medical Center
1000 West Carson Street
Torrance, CA 90509
Contact: Margaret Keller, MD 310-212-4175
Caroline Stanton-Martin, LCSW 310-328-6938 (fax)

Huntington Hospital Hemophilia Center
10 Congress Street, #340
Pasadena, CA 91105-3023
Contact: Deneve David, LCSW 818-577-4366
Nadia Ewing, MD 818-796-2875 (fax)

LAC/USC Women's Hospital
1240 North Mission Road, Room 3L6
Los Angeles, CA 90033
Contact: Robert Settlage, MD 213-226-2517
213-226-3306 (fax)

Memorial Miller Children's Hospital
2801 Atlantic Avenue, P.O. Box 1428
Long Beach, CA 90801-1428
Contact: Audra Deveikis, MD 310-595-0812
Claire Towle, MSW 310-988-8694 (fax)

Tuesday's Child
1800 Argyle #507
Los Angeles, CA 90046
Contact: Laura Renteria, BA, Case Manager 213-467-9901
213-467-2326 (fax)

CALIFORNIA cont...

UCLA Medical Center
Department of Pediatrics
10833 Le Conte Avenue, Room 22-442, MDCC
Los Angeles, CA 90024

Contact:	*Yvonne Bryson, MD*	310-206-6369
	Richard Stiehm, MD	310-206-4764 (fax)
	Mary Whalen, MSW	

CONNECTICUT

Lead Organization:
Connecticut Pediatric AIDS Health Care Demonstration Project
Connecticut Primary Care Association Inc.
30 Arbor Street North
Hartford, CT 06106

Contact:	*Richard Jacobsen, PhD, Co-Principal Investigator*	203-232-3319
		203-236-0618 (fax)
	Kathryn Salisbury, EdD, Co-Principal Investigator	203-772-0680
		203-387-9524 (fax)
	Rose Swift, BA, Coordinator	203-232-3319
		203-236-0618 (fax)

Affiliates:
Bridgeport Community Health Center
471 Barnum Avenue
Bridgeport, CT 06608

Contact:	*Jose Olmo, MSW*	203-333-6864
		203-332-0376 (fax)

Bridgeport Hospital
Department of Pediatrics
267 Grant Street P.O. Box 5000
Bridgeport, CT 06610

Contact:	*Thomas Kennedy, MD*	203-384-3712
	Keith Hovan, RN	203-384-3084
	Sandy Shipkowitz, APRN	203-384-3000 X 2892
	Clinical Coordinator-Nurse Practitioner	
	Joyce Szekeres, RN	203-384-3084
		203-384-3318 (fax)

CONNECTICUT cont...

Fair Haven Community Health Clinic
374 Grand Street
New Haven, CT 06513
Contact: Sarah Forman, RN — 203-777-7411
203-777-8506 (fax)

Hill Health Center
400-428 Columbus Avenue
New Haven, CT 06519
Contact: Robert Windom, MD — 203-776-9594
Lois Saunders, RN — 203-787-5510 (fax)

Southwest Community Health Center
361 Bird Street
Bridgeport, CT 06605
Contact: Nancy Wiltse, MA — 203-576-8368
203-576-8444 (fax)

Yale University School of Medicine
Department of Pediatrics
47 College Street, Suite 218
New Haven, CT 06510
Contact: Brian Forsyth, MD, Physician Educator — 203-785-2475
203-785-7194 (fax)

DISTRICT OF COLUMBIA

Lead Organization:
D.C. Pediatric AIDS Health Care Demonstration Project
Office of Maternal and Child Health
Commission of Public Health
Department of Human Services
1600 L Street, N.W., Suite 907
Washington, DC 20036
Contact: Patricia A. Tompkins, RN, MSN, Chief — 202-673-4551
Linda Jenstrom, Project Director — 202-673-6724
Fozia Abrar, MD, MPH, Health Care Coordinator — 202-727-9021 (fax)
Terry Hawkins, MSW, Case Manager

DISTRICT OF COLUMBIA cont...

Affiliates:

Birth to Three Project
DC General Hospital
Department of Pediatrics
Infant Programs
1900 Massachusetts Avenue, SE, 4th Floor, West Wing
Washington, DC 20003
Contact: Elaine Vowels, PhD, Director — 202-727-3866
202-544-5945 (fax)

Children's Home Health Care
D.C. Pediatric AIDS Health Care Demonstration Project
216 Michigan Avenue, N.E.
Washington, DC 20017
Contact: Judith Schwartz, Supervisor, Social Work — 202-939-4663
202-939-6197 (fax)

P.R.I.D.E. Services
D.C. Pediatric AIDS Health Care Demonstration Project
Howard University Hospital
Department of Pediatrics
2041 Georgia Avenue, N.W., 3N-17
Washington, DC 20059
Contact: Brenda Hicks, LCSW, Case Management Supervisor — 202-865-4564
202-865-4558 (fax)

P.R.I.D.E. Services
D.C. Pediatric AIDS Health Care Demonstration Project
Children's National Medical Center
Special Immunology Services, Floor 1.5
111 Michigan Avenue, NW
Washington, DC 20010
Contact: Tina Adler, MSW, Case Manager — 202-745-3453
202-745-3076 (fax)

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D.C. Pediatric AIDS Health Care Demonstration Project
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DISTRICT OF COLUMBIA cont...

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D.C. Pediatric AIDS Health Care Demonstration Project
Child and Family Services Administration
Commission on Social Services
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FLORIDA

Lead Organization:
Pediatric AIDS Health Care Demonstration Project
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Division of Pediatrics Immunology & Infectious Disease
University of Miami School of Medicine
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FLORIDA cont...

Lead Organization:
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Children's Diagnostic & Treatment Center
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Lead Organization:
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University of South Florida
College of Public Health
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St. Petersburg, FL 33731

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CMS Referral Center
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Tampa, FL 3606

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FLORIDA cont...

Johnie Ruth Clarke Health Center, Inc.
1301 22nd Avenue, South
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Gulf Coast Jewish Family and Mental
Health Services, Inc.
14041 Icot Boulevard
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GEORGIA

Lead Organization:
Pediatric AIDS Health Care Demonstration Project
GA Department of Human Resources
Maternal & Child Health Branch
Division of Public Health
878 Peachtree Street, NE, Suite 214
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Children's Medical Services
GA Department of Human Resources
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Maternal & Child Health Branch
GA Department of Human Resources
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GEORGIA cont...

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LOUISIANA

Lead Organization:
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Children's Hospital - New Orleans
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Affiliates:
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Department of Hospitals
HIV Program Office
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LSU Medical School
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Office of Public Health HIV/AIDS
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MARYLAND

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MD Pediatric AIDS Health Care Demonstration Project
AIDS Administration
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Office on AIDS
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MASSACHUSETTS

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Lead Organization:
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Boston City Hospital Pediatric AIDS Program
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MASSACHUSETTS cont...

Boston Pediatric AIDS Project
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435 Warren Street
Roxbury, MA 02119
Contact: Amy Offenberg, MSW, MPH — 617-442-7400 X 229, 617-442-1409 (fax)

BPAP - Whittier Street Health Center
20 Whittier Street
Roxbury, MA 02120
Contact: Jimena Loveluck, MSW — 617-427-1000, 617-427-0949 (fax)

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55 Dimock Street
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420 Washington Street
Dorchester, MA 02124
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Harvard Street Neighborhood Health Center
632 Blue Hill Avenue
Dorchester, MA 02121
Contact: Geneva Murchison, HIV Educator — 617-825-3400 X 222, 617-825-7217 (fax)

JRI
132 Boylston Street
Boston, MA 02116
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Martha Eliot Community Health Center
38 Bickford Street
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MASSACHUSETTS cont...

Visting Nurses Association of Boston
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MICHIGAN

Lead Organization:
Michigan Department of Public Health
Bureau of Child & Family Services
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MINNESOTA

Lead Organization:
Youth & AIDS Projects
University of Minnesota
Adolescent Health Program
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NEW JERSEY

Lead Organization:
Development of a Statewide Health Services Network
for Children w/HIV Infection & their Families
New Jersey Department of Health
Special Child Health Services
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Children's Hospital AIDS Program
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NEW JERSEY cont...

Newark Beth Israel Medical Center
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O'Neill Center
Pediatric Comprehensive Center
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NEW YORK

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Harlem Hospital Center
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Lead Organization:
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Family AIDS Health Link Project
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Lead Organization:
Model Comprehensive Health Care Program for Adolescents
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Lead Organization:
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NY City Pediatrics HIV/AIDS Comprehensive Center
NY State Department of Health
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Affiliates:
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NYU Medical Center
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Queens Women & Children HIV Project
Queens Hospital Center
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Lead Organization:
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Brooklyn Pediatric AIDS Network
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Kings County Hospital Center
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Lead Organization:
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OHIO

Lead Organization:
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PENNSYLVANIA

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St. Christopher's Hospital for Children
Erie Avenue & Front Street
Philadelphia, PA 19134-1095
Contact: Carole Treston, RN — 215-427-5284
Clinical & Research Coordinator — 215-427-5555 (fax)

PUERTO RICO

Lead Organization:
Puerto Rico Pediatrics AIDS Project
Puerto Rico Department of Health
Office of AIDS Affairs & Communicable Diseases
P.O. Box 71423
G.P.O. San Juan, PR 00936
Contact: Rolando Jimenez Mercado, MPHE, Director — 809-721-2000 X 208
809-723-3565 (fax)

RHODE ISLAND

Lead Organization:
FACTS Family AIDS Center for Treatment & Support
18 Parkis Avenue
Providence, RI 02907
Contact: Paul Fitzgerald, MSW, Director — 401-521-3603
401-861-2981 (fax)

Affiliates:
Rhode Island Department of Health
Three Capital Hill
Providence, RI 02908
Contact: Peter Simon, MD, Assistant Director — 401-277-2312
Division of Family Health — 401-277-1442 (fax)

Rhode Island Hospital
Department of Pediatrics
593 Eddy Street
Providence, RI 02903
Contact: Peter Smith, MD — 401-444-5171
401-444-8845 (fax)

TEXAS

Lead Organization:
Tarrant County Pediatric AIDS Demonstration Project
Catholic Charities
Diocese of Fort Worth, Inc.
2701 Burchill Road
Ft. Worth, TX 76105
Contact: Dolores Berkovsky, CSW-ACP, RN — 817-534-0814
Director of Children's Services — 817-535-8779 (fax)

TEXAS cont...

Tarrant County Pediatric and Family AIDS Demonstration Project
2641 Avenue L
Fort Worth, TX 76105
Contact: Sue Smith, CSW-ACP, Project Coordinator — 817-536-1160, 817-536-4671 (fax)

Affiliates:
AIDS Outreach Center
1125 West Peter Smith
Forth Worth, TX 76104
Contact: Thomas Bruner, MA, LPC, Executive Director — 817-335-1995, 817-335-3617 (fax)

John Peter Smith Hospital
Tarrant County Hospital District
1500 South Main
Forth Worth, TX 76104
Contact: Patti Wetzel, MD — 817-927-3701, 817-927-3537 (fax)

Lead Organization:
Dallas Pediatric HIV Health Care Demonstration Project
University of Texas, Southwestern Medical Center
Dallas Children's Medical Center @ Dallas
1935 Motor Street
Dallas, TX 75235
Contact: Janet Squires, MD, Director — 214-640-2329
Mary Mallory, MSN, PNP, Coordinator — 214-640-2776, 214-640-5702 (fax)

Affiliates:
AIDS Arms Network
2727 Oak Lawn Avenue Suite 222
Dallas, TX 75219
Contact: Debbie Hurst, Executive Director — 214-521-5191, 214-528-5879 (fax)

Bryan's House
2713 Knight Street
Dallas, TX 75219
Contact: Susan Streng, Executive Director — 214-559-3946, 214-559-2827 (fax) or 214-528-5879 (fax)

TEXAS cont...

Dallas Child Guidance Clinic
8915 Harry Hines Boulevard
Dallas, TX 75235
Contact: Diana Cunningham, PhD — 214-351-3490
214-352-3482 (fax)

Oak Lawn Community Services
P.O. Box 191094
Dallas, TX 75219
Contact: Terry Stone — 214-520-8108
214-528-9145 (fax)

Parkland Memorial Hospital
Department of Maternal and Child Health
5201 Harry Hines Boulevard
Dallas, TX 75235
Contact: Janice Blissett, RN, NP — 214-590-8158
OB/GYN Nurse Practitioner — 214-590-2757 (fax)

Visiting Nurse Association
1440 West Mockingbird Lane Suite 500
Dallas, TX 75247
Contact: Vivianne Armstrong, RN — 214-689-0044
214-631-8106 (fax)

Lead Organization:
Pediatric AIDS Health Care Demonstration Project
University of Texas Health Science Center @ San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284-7811
Contact: John Mangos, MD, Director — 210-567-5202
Terence Doran, MD, Medical Director — 210-567-5250
210-567-6921 (fax)

Affiliates:
Coastal Bend AIDS Foundation
1118 Third Street
Corpus Christi, TX 78404
Contact: Judy Hale — 512-814-2001
512-814-6502 (fax)

TEXAS cont...

Hidalo County Health Care Corporation
1203 East Ferguson
Pharr, TX 78577
Contact: Frank Vasquez, Jr. — 210-787-8915
210-787-2021 (fax)

Lower Rio Grande Subspecialty Clinics
1203-A East Ferguson
Pharr, TX 78577-2706
Contact: Rosalind Gonzalez, MSN, Clinic Administrator — 210-702-2311 (fax)

Providence Home
2650 Castroville Road
San Antonio, TX 78237
Contact: Sister Barbara Hyzak, RN — 512-434-2111
512-433-2806 (fax)

Valley AIDS Council
2220 Haine, Suite 45
Harlingen, TX 78550
Contact: Ted Edson — 210-428-9322
210-428-5903 (fax)

Lead Organization:
Greater Houston HIV Alliance
811 Westheimer, Suite 103
Houston, TX 77006
Contact: Michael Springer, Executive Director — 713-526-2323
713-526-2369 (fax)

WASHINGTON

Lead Organization:
Seattle-King County Pediatric AIDS Demonstration Project
Northwest Family Center
Seattle King County Health Department
1001 Broadway, Suite 210
Seattle, WA 98122
Contact: Julie Sarkissian, Manager — 206-720-4319
Gerrie LaQuey, Supervisor — 206-720-4300
206-720-4302 (fax)

WASHINGTON cont...

Affiliates:

Children's Hospital & Medical Center
Social Work Department
4800 SandPoint Way, NE P.O. Box 65371
Seattle, WA 98105
Contact: Jody Carpenter, SW — 206-526-2167
206-527-3858 (fax)

Community Health Services
Yakima County Health District
104 North 1st Street
Yakima, WA 98901
Contact: Terry Jones, Director — 509-575-4270
509-575-7894 (fax)

People of Color Against AIDS Network
1200 South Jackson, Suite 25
Seattle, WA 98144
Contact: Catlin Fullwood, Executive Director — 206-322-7061
206-322-7204 (fax)

Seattle King County Demonstration Project
Youth Care
333 1st Avenue West
Seattle, WA 98119
Contact: Karen Frazier — 206-282-1288
Program Manager of Prevention Services — 206-282-6463 (fax)

Section II

Hemophilia Special Initiatives

Section II: Hemophilia Special Initiatives

CALIFORNIA

Children's Hospital - Oakland
Hemophilia Program
Hematology/Oncology Department
747 Fifty-Second Street
Oakland, CA 94609

Contact: Joseph E. Addiego, Jr., MD, Medical Director	510-428-3372
	510-601-3916 (fax)
Bobbie Steinhart, LCSW, Project Director	510-428-3091
	510-428-3382 (fax)

COLORADO

Mountain States Regional Hemophilia Center
4200 East Ninth Avenue, Box C-220
Denver, CO 80262

Contact: Audrey Costello, MSW, LCSW	303-372-1750
Co-Primary Investigator, Project Director	303-372-1060 (fax)
Marilyn J. Manco-Johnson, MD, Primary Investigator	
Brenda Riske, RN, MSN, MBA, Co-Primary Investigator	

IOWA

University of Iowa Hospitals and Clinics
Department of Pediatrics
200 Hawkins Drive - 2520 JCP
Iowa City, IA 52242-1009

Contact: C. Thomas Kisker, MD, Project Director	319-356-3422
Regional VII Hemophilia Program	319-356-7659 (fax)

MINNESOTA

University of Minnesota
Comprehensive Hemophilia Center
Harvard Street at East River Parkway
Box 713
Minneapolis, MN 55455
Contact: Nigel Key, MD, Project Director — 612-626-6455
Roxana Boelsen, RN, BAN, Project Manager — 612-625-4955 (fax)

MISSOURI

Region VII Hemophilia Treatment Centers
University of Iowa
Truman Medical Center
2301 Holmes Street
Kansas City, MO 64108
Contact: Ann C. Johnson, ACSW, Project Coordinator — 816-556-4165
816-556-3953 (fax)

NEW YORK

Mt. Sinai Hemophilia Treatment Center
19 East 98th Street, Box 1078, Room 9-D
New York, NY 10029-6574
Contact: Suzanne Gaynor, RN, MBA, Dr.P.H. — 212-241-8303
Co-Principal Investigator — 212-722-6079 (fax)

Mt. Sinai School of Medicine
AIDS Center
One Gustave Levy Place, Box 1040
New York, NY 10029
Contact: Debbie Indyk, PHD, Co-Principal Investigator — 212-241-7863
212-722-6079 (fax)

Mt. Sinai School of Medicine
Clinical Trials Unit
One Gustave Levy Place, Box 1023
New York, NY 10029
Contact: Henry Sacks, MD, Co-Principal Investigator — 212-241-8254
212-860-4607 (fax)

NEW YORK cont...

Mt. Sinai School of Medicine
Office of the Dean
One Gustave Levy Place, Box 1006
New York, NY 10029
Contact: Louis Aledort, MD, Principal Investigator — 212-241-7971
212-996-9764 (fax)

OHIO

Children's Hospital Medical Center
Hemophilia Treatment Center
Elland & Bethesda Avenues
Cincinnati, OH 45229-2899
Contact: Ralph A. Gruppo, MD, Director — 513-559-4269
513-559-3549 (fax)

Children's Hospital Medical Center
Pediatric/Adolescent HIV Treatment Center
Elland & Bethesda Avenues
Cincinnati, OH 45229-2899
Contact: Raymond Baker, MD, Director — 513-559-4506
513-559-7247 (fax)
Pamela Daniel, RN, Nurse Coordinator — 513-559-4578
513-559-7655 (fax)

WISCONSIN

Great Lakes Hemophilia Foundation
8739 Watertown Plank Road, Box 13127
Wauwatosa, WI 53213-0127
Contact: Janice R. Hand, MBA, Project Director — 414-257-0200
Kathleen Marquardt, RN, MS, Project Coordinator — 414-257-1225 (fax)

Section III

National Training & Technical Assistance Projects

Section III: National Training & Technical Assistance Projects

CALIFORNIA

Legal & Ethical Issues in the Delivery of
HIV/AIDS-Related Services to Adolescents
National Center for Youth Law
114 Sansome Street, Suite 900
San Francisco, CA 94104
Contact: Abigail English, J.D.

415-543-3307
415-956-9024 (fax)

CONNECTICUT

The Yale Program for Uninfected
Children of HIV Affected Families
Yale University School of Medicine
230 South Frontage Road
P.O. Box 3333
New Haven, CT 06510-8009
Contact: Melvin Lewis, M.D., Director

203-785-2513
203-785-6106 (fax)

The Yale Program for Uninfected Children
Yale Child Study Center
47 College Street, Suite 218
New Haven, CT 06510
Contact: Steven Nagler, MSW
Clinical Services Coordinator & Educator
Wendy Ann Wyatt, MSW
Clinical Coordinator-Social Worker

203-785-6862
203-785-6860 (fax)

DISTRIC OF COLUMBIA

Project CHAMP
Children's National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010-2970
Contact: Robert Parrot, MD

202-745-4004/5450
202-939-5989 (fax)

LOUISIANA

Resources for Adolescents Program (RAP)
Children's Hospital - New Orleans
Kingsley House, 2nd Floor
914 Richards Street
New Orleans, LA 70130
Contact: Michael Kaiser, MD, Director 504-524-4611
M. Beth Scalco, BCSW, Program Coordinator 504-523-2084 (fax)

MARYLAND

Social Responses to the Reproductive Choices
of HIV Infected Women
Johns Hopkins University
School of Hygiene & Public Health
Department of Health Policy & Management
624 North Broadway
Baltimore, MD 21205
Contact: Ruth Faden, Ph.D., Professor 410-955-3018
Nancy Kass, SCD., Assistant Professor 410-955-0310
410-955-0876 (fax)

Promoting Family-Centered Care for Children with HIV
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
Contact: Linda Crites, Ph.D., Coordinator 301-654-6549
301-986-4553 (fax)

MASSACHUSETTS

Children with HIV Infection in School
Children's Hospital
Developmental Evaluation Center
300 Longwood Avenue
Boston, MA 02115
Contact: Allen Crocker, MD, Director 617-735-6509
617-735-7429 (fax)

MASSACHUSETTS cont...

The National Center for Drug Exposed
& HIV Infected Children & Their Families
Foundation for Children with AIDS
1800 Columbus Avenue
Roxbury, MA 02119
Contact: Geneva Woodruff, Ph.D., Director — 617-442-7442
617-442-1705 (fax)

NEW JERSEY

National Pediatric HIV Resource Center
University of Medicine & Dentistry
Children's Hospital AIDS Program
15 South 9th Street
Newark, NJ 07107
Contact: Mary Boland, RN, MSN, Director — 201-268-8273
Contact: Carolyn Burr, RN, MSN, Coordinator — 201-268-8251
800-362-0071
201-485-2752 (fax)

National Pediatric HIV Resource Center
Washington Office
900 Second Street, NE, Suite 211
Washington, DC 20002
Contact: David C. Harvey, Policy Analyst — 202-289-5970
202-408-9520 (fax)

NEW YORK

Enhanced Access for High Risk Latino and
African American Women, Children, Infants
and Families
Dominican Sisters Family Health Service, Inc.
279 Alexander Avenue
Bronx, NY 10454
Contact: Margaret Sweeney, Administrator — 718-665-6557
718-292-9113 (fax)

NEW YORK cont...

Ethical and Policy Issues in Pediatric AIDS
Columbia University
600 West 168th Street
New York, NY 10032
Contact: Ronald Bayer, Ph.D., Principal Investigator — 212-305-1957
212-305-6832 (fax)

Pediatric HIV/AIDS Health Care Finance Study
New York State Department of Health and Health Research
Empire State Plaza
Albany, NY 12237
Contact: Herbert Fillmore, MSW, Director — 518-474-6034
518-486-1346 (fax)

TEXAS

Development of an Educational Program to Train Volunteers
and Foster Families to Work with HIV-Positive Children
Baylor College of Medicine
Department of Pediatrics
One Baylor Plaza
Houston, TX 77030
Contact: Mariam R. Chacko, MD, Director — 713-770-3440
713-770-3451 (fax)
Susan Hirtz, RN, MPH, Project Coordinator — 713-770-2045 (fax)

National Pediatric HIV Resource Center
15 South Ninth Street
Newark, NJ 07107
1-201-268-8251
1-485-2752 fax

Directory Listing Change Form

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☐ National Technical Assistance & Research Project - Section II
☐ Hemophilia Special Initiatives - Section III

Contact Person: _____

Project Name: _____

Agency: _____

Address: _____

_____

City: _____

State: _____

Telephone #: _____

Fax #: _____

Affiliate to: _____

Please complete this form and return to: ***Linda Luciano***
Project Manager
National Pediatric HIV Resource Center
15 South Ninth Street
Newark, NJ 07107
201-268-8251
201-485-2752 Fax

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PEDIATRIC/FAMILY HIV HEALTH CARE DEMONSTRATION GRANT PROGRAM

Clients Served, 1988-1990

NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

Newark, New Jersey

May, 1992

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NATIONAL PEDIATRIC HIV RESOURCE CENTER
SUMMARY OF ACTIVITIES

NPHRC 1990-1991

15 South Ninth Street
Newark, New Jersey 07107
201-268-8251
800-362-0071
201-485-2752 FAX

NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

900 Second Street, NE
Suite 211
Washington, DC 20002
202-289-5970
202-408-9520 FAX

August 23, 1993

Kristine Gebbie, R.N., M.N., F.A.A.N.
National AIDS Policy Coordinator
750 17th Street, NW
Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

Thank you for meeting recently with representatives of the Resource Center and our public policy committee. We look forward to working with you in the future on issues related to children, adolescents, pregnant women and families affected by HIV disease.

As you requested, I attach a list of national AIDS organizations and individuals who are specifically concerned with Congressional appropriations and the Ryan White CARE Act. I have included an asterisk by those four organizations that also have a particular interest in various Titles of the CARE Act. Please note that this list may not be inclusive of all national organizations concerned with AIDS appropriations issues.

I am certain that national AIDS organizations would welcome a meeting with you to specifically discuss Congressional appropriations; however, I would suggest that several issues be addressed prior to a meeting in order to facilitate a process and to develop an ongoing working relationship with organizations and your office. First, groups will want to hear specifically about the role of your office on budget and appropriations matters. For example, the National AIDS Policy Coordinator may only be responsible for developing recommendations to forward to DHHS and this could be outlined for organizations during a first meeting. Second, any attempt to facilitate a process to develop recommendations on appropriations should be carefully considered to include the role of national organizations and federal agencies in the process, a request for rationale and justification, and future priorities. I am stating the obvious by warning that this will be a complex task.

Please contact me with any additional questions or if I can assist with helping to prepare for a meeting on appropriations and the CARE Act.

Sincerely,

David C. Harvey
Coordinator of Public Policy

Julie Scofield*
National Alliance of State & Territorial
AIDS Directors
444 North Capitol Street, NW, Suite 617
Washington, DC 20001
202-434-8090

Regina Aragon*
CAEAR Coalition
San Francisco AIDS Foundation
25 Vaness Avenue
Suite 660
San Francisco, CA 94102

David Harvey*
National Pediatric HIV Resource Center
900 Second Street, NE, 211
Washington, DC 20002
202-289-5970

Dave Cavenaugh*
National Association of Community Health Center
1330 New Hampshire Avenue, NW, #122
Washington, DC 20036
202-659-8008

Dan Bross*
AIDS Action Council
1875 Connecticut Avenue, NW, Suite 700
Washington, DC 20009
202-986-1300

Jane Silver
American Foundation for AIDS Research
1828 L Street, NW, Suite 802
Washington, DC 20036
202-331-8600

Paul Kawata
National Minority AIDS Council
300 I Street, NE, Suite 400
Washington, DC 20002-4389
202-544-1076

Cornelius Baker
National Association of People with AIDS
1413 K Street, NW, 10th Floor
Washington, DC 20005
202-898-0414

Terry Beswisk
Human Rights Campaign Fund
1012 14th Street, NW, 6th Floor
Washington, DC 20005
202-628-4160

Bill Bailey
Coalition for AIDS Prevention & Education
American Psychological Association
750 First Street, NE
Washington, DC 20002-4242
202-336-6066

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*Aragon - Title I
*Scofield - Title II
*Cavenaugh - Title IIIb
*Harvey - Title IV
*Bross - All Titles