

**REPORT OF THE
VIRGINIA DEPARTMENT OF HEALTH, IN CONJUNCTION WITH
THE JOINT SUBCOMMITTEE STUDYING ACQUIRED
IMMUNODEFICIENCY SYNDROME, ON**

**A Plan for Incorporating HIV/AIDS
Treatment for Infected Children in
the Commonwealth's Children's
Specialty Services Program**

**TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA**



HOUSE DOCUMENT NO. 63

**COMMONWEALTH OF VIRGINIA
RICHMOND
1994**



COMMONWEALTH of VIRGINIA

ROBERT B. STROUBE, M.D., M.P.H.
STATE HEALTH COMMISSIONER

Department of Health

P. O. BOX 2448
RICHMOND, VA 23218

January 11, 1994

TO: The Honorable Lawrence Douglas Wilder
 Governor of the Commonwealth of Virginia

The Members of the General Assembly of Virginia

I am pleased to transmit this report which constitutes the response of the Virginia Department of Health to House Joint Resolution No. 691 of the 1993 Session of the General Assembly of Virginia.

This report offers the results of the Department's plan, developed in coordination with the Joint Subcommittee Studying Acquired Immunodeficiency Syndrome, for incorporating HIV/AIDS treatment for infected children in the Commonwealth's Children's Specialty Services Program.

Respectfully Submitted,

A handwritten signature in cursive script that reads "Robert B. Stroube".

Robert B. Stroube, MD, MPH
State Health Commissioner

Enclosure

**REPORT OF THE VIRGINIA DEPARTMENT OF HEALTH ON
DEVELOPMENT OF A PLAN TO INCORPORATE
HIV/AIDS TREATMENT FOR INFECTED CHILDREN
IN THE
CHILDREN'S SPECIALTY SERVICES PROGRAM
OF THE VIRGINIA DEPARTMENT OF HEALTH**

PURSUANT TO HJR 691

DECEMBER, 1993

PREFACE

HOUSE JOINT RESOLUTION 691

STUDY TEAM MEMBERS

Thomas T. Rubio, M.D.
Division of Infectious Diseases
Eastern Virginia Medical School
Children's Hospital of The King's
Daughters

Bonnie Dattel, M.D.
Department of Obstetrics and Gynecology
Eastern Virginia Medical School

Gilberto E. Rodriguez, M.D.
Division of Pediatric Allergy,
Immunology, and Pulmonology
Medical College of Virginia

Suzanne Lavoie, M.D.
Division of Infectious Diseases
Medical College of Virginia

Mara Dinsmoor, M.D.
Department of Obstetrics and Gynecology
Medical College of Virginia

Melissa Wirt, B.S.W.
Virginia Department of Medical Assistance
Services

Frank T. Saulsbury, M.D.
Department of Pediatrics
School of Medicine
University of Virginia Health
Sciences Center

Three Parents of Children
Infected with HIV/AIDS

Dennis R. Swanson, M.D.
Pittsylvania/Danville Health
District
Virginia Department of Health

Crystal Groth, R.N.
Fairfax County Health
Department
Virginia Department of Health

Kathy A. Hafford, R.N.
Bureau of STD/AIDS
Virginia Department of Health

Nancy R. Bullock, R.N.
Division of Children's
Specialty Services
Virginia Department of Health

Joan Corder-Mabe, R.N.
Perinatal/Maternity Nurse
Consultant
Division of Women's and
Infants' Health
Virginia Department of Health

Donna Sandifer, R.N.
Infection Control
Children's Hospital of The
King's Daughters

Martha Hart, R.N.
Division of Pediatric Allergy,
Immunology, and Pulmonology
Medical College of Virginia

TABLE OF CONTENTS

	<u>Page</u>
EXECUTIVE SUMMARY	i
INTRODUCTION	1
FAMILIES WITH AIDS	2
FAMILY HIV AND AIDS SERVICES PROGRAM	4
COST OF TREATING PATIENTS WITH HIV/AIDS	9
COST PROJECTIONS BY REGION FOR ONE YEAR	12
RECOMMENDATIONS	20
APPENDIX A: HJR 691	22
APPENDIX B: VIRGINIA PEDIATRIC HIV AND AIDS	23
APPENDIX C: VIRGINIA TEEN HIV AND AIDS	24
APPENDIX D: HIV/AIDS REPORTS IN ADULT WOMEN IN VIRGINIA	25
APPENDIX E: HIV AND AIDS TRANSMISSION AMONG WOMEN	26
APPENDIX F: SURVEY OF CHILDBEARING WOMEN, REGIONAL DATA	27
APPENDIX G: SURVEY OF CHILDBEARING WOMEN, HIV SEROPREVALENCE BY REGION	28
APPENDIX H: VIRGINIA'S SURVEY OF CHILDBEARING WOMEN	29
APPENDIX I: COMPREHENSIVE AIDS FAMILY CARE CENTER: A MODEL TREATMENT PROGRAM IN THE BRONX	30
APPENDIX J: CONCEPTUAL FAMILY HIV/AIDS SERVICES PROGRAM	31

Executive Summary

As of June, 1993, a cumulative total of 98 Virginians under the age of 19 had been reported as having AIDS. Forty-four of these young people have died. An additional 166 persons, birth through age 19, had been reported with HIV infection. Thus, 220 young people are currently infected with HIV or have AIDS. The Eastern, Central and Northern Regions of Virginia had the highest prevalence of these conditions.

Since perinatal transmission now accounts for most of the cases of pediatric HIV/AIDS, many HIV-infected children have a mother who is also infected. Often, her illness affects her ability to care for the child. The combination of medical problems presented by this situation is best managed at a Family Services Clinic where both mother and child can be seen in the same area and at the same time by infectious disease specialists. Beyond the physical impact of AIDS this combined family disease leads to unique psychosocial disorders demanding a case management program and a multidisciplinary team.

The Children's Specialty Services (CSS) Program of the Virginia Department of Health provides specialized medical and surgical care for handicapping conditions. In order for the treatment of HIV/AIDS to be added to the CSS network of clinics, additional funding is required.

The study team recommended to and received support from the Joint Subcommittee Studying Acquired Immunodeficiency Syndrome the following:

- A. Fund additional staff costs (\$170,885) for the provision of case management, patient education, social work and nutrition services at the Family HIV/AIDS Services Clinics at the Children's Hospital of The King's Daughters (CHKD) and the Medical College of Virginia (MCV). These two medical centers already have Family HIV/AIDS Services Clinics in place, but need additional staff in order to make the services more comprehensive. Both medical centers serve geographic regions of Virginia with high prevalence of HIV and AIDS. This will be a pilot project for family support services to 190 children and mothers who have their treatment costs covered by Medicaid;
- B. Phase-in funding for Family HIV/AIDS Services Clinics, as they are established, in the Northern and Southwest Regions, and the University of Virginia (UVA) Health Sciences Center.

INTRODUCTION

The 1993 General Assembly in House Joint Resolution (HJR) 691 (Appendix A) charged the Virginia Department of Health with developing a phased-in plan for incorporating HIV/AIDS treatment for infected children in the Commonwealth's Children's Specialty Services Program. This report to the Governor and the 1994 General Assembly includes budget estimates for the phasing-in of services for HIV/AIDS-infected children and their parents and describes the method and sites for gradually introducing such services.

This study was staffed by the Division of Children's Specialty Services of the Virginia Department of Health, with participation by representatives of the following:

Eastern Virginia Medical School
Children's Hospital of The King's Daughters
Medical College of Virginia
University of Virginia Health Sciences Center
Virginia Department of Medical Assistance Services
Parents of Children Infected with HIV/AIDS
District Health Departments, Bureau of STD/AIDS, and Division of
Women's and Infants' Health of the Virginia Department of
Health.

These persons also represented the five geographic regions of Virginia. The study team held three meetings between June and August, 1993 in order to incorporate their various perspectives of HIV/AIDS treatment for infected children. In addition, firsthand information on Virginia's current system of pediatric HIV/AIDS treatment was obtained via needs assessment questionnaires completed by the work group for all areas of the state. Input was also obtained from the following Virginia groups:

HIV Care Consortia
HIV Care Consortia Subcontractors
Regional AIDS Resource and Consultation Centers
AIDS Service Organizations
AIDS Task Force on Development of Comprehensive HIV/AIDS
Plan Pursuant to HJR 436, 1991 General Assembly
District Health Departments
Virginia Nurses Association
Virginia Chapter, American Academy of Pediatrics

FAMILIES WITH AIDS

PEDIATRIC AIDS AND HIV IN VIRGINIA

As of June 22, 1993, Virginia Department of Health had received reports of 78 cumulative pediatric AIDS cases ages birth through 12 years. Thirty-seven of these children have died. Of the 78 cases, 61 (78%) had the underlying risk factor of HIV infection in the mother. The Eastern Region of Virginia had 25 cases which is 32% of the total cases. The Northern Region had 21 cases (27%) and the Central Region had 18 cases (23%). The Northwest and Southwest Regions had a lower number of cases, 6 (8%) and 8 (10%) respectively.

As of June 22, 1993, a cumulative total of 28 children, birth through age 12, has been reported with HIV infection. Of the 28 cases, 18 (64%) had the underlying risk factor of HIV infection in the mother. The Eastern Region of Virginia had 9 cases, the Northern Region 6 cases, the Northwest Region 5 cases, and the Central and Southwest Regions each had 4. (Appendix B.)

AIDS AND HIV IN TEENS IN VIRGINIA

As of June, 1993, Virginia had received reports of 20 cumulative cases of AIDS in teens ages 13 to 19 years. Seven of these teens have died. Of the 20 cases, 3 (25%) had the underlying risk factor of heterosexual transmission. Half of the 20 cases had hemophilia. The Northern Region had 6 cases, the Southwest Region 5 cases, and the Northwest, Central and Eastern Regions each had 3 cases.

As of June, 1993, 138 HIV infected teen cases had been reported in Virginia. Of the 138 cases, 37 (27%) had the underlying risk factor of heterosexual transmission. Sixteen (12%) of the 138 cases had hemophilia as the underlying risk factor. The Eastern Region had 64, the Central Region 33, the Northern Region 20, the Southwest Region 14, and the Northwest Region 7. (Appendix C.)

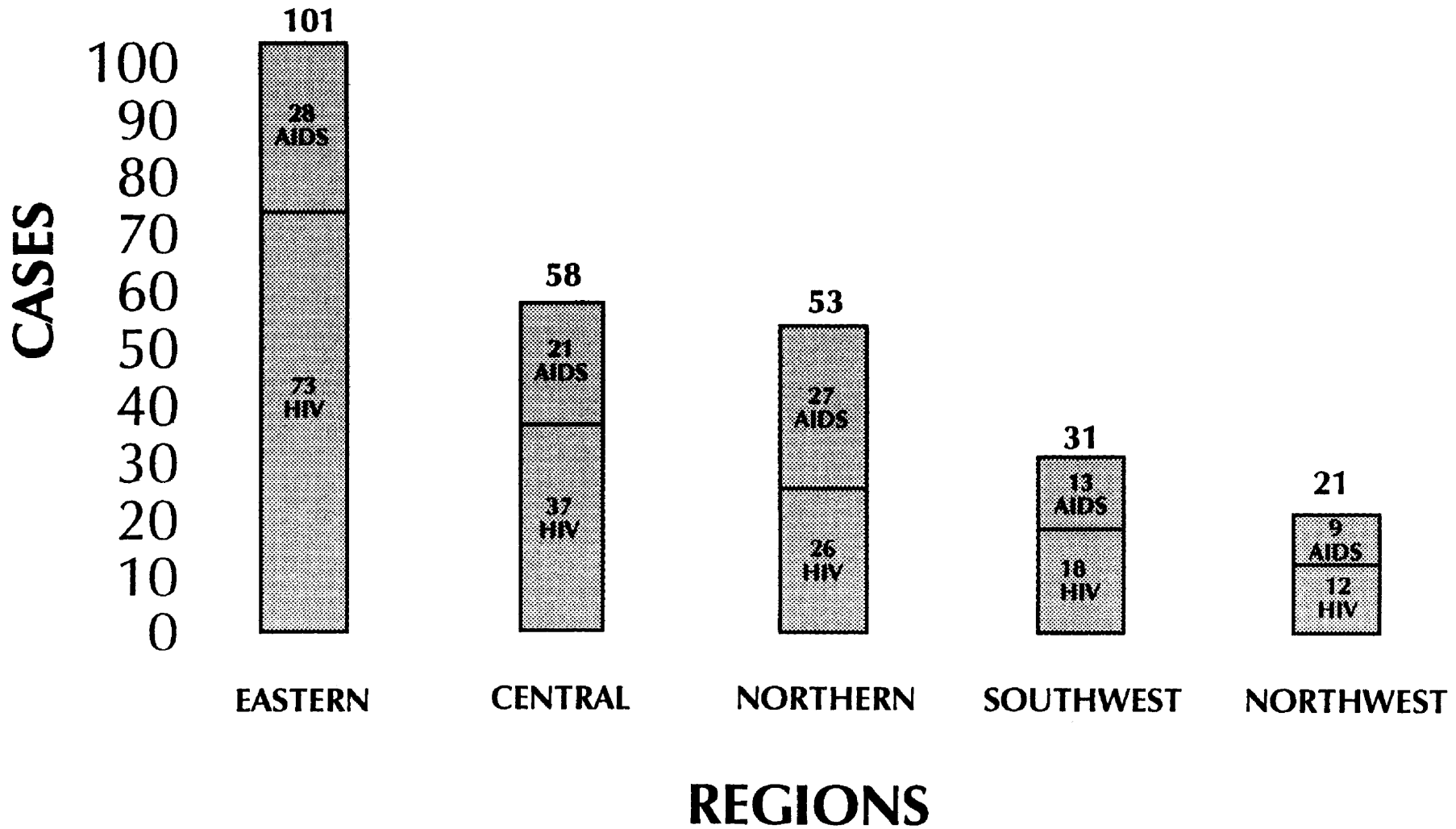
AIDS AND HIV IN ADULT WOMEN IN VIRGINIA

In Virginia, women represent 11% (470) of the 4,311 cumulative adult AIDS cases reported through June, 1993. The mode of transmission of AIDS for women in Virginia is heterosexual in 42% of cases.

Women represent 23% (1,141) of the 4,870 cumulative adult HIV cases reported in Virginia through June, 1993. Heterosexual contact has become an increasingly prevalent mode of HIV transmission in women, accounting for 18% of cases in 1989 and 39% of all cases by 1993. (Appendices D and E.)

Seroprevalence studies have been conducted among women giving birth in Virginia. Of the women testing positive, 45% resided in the Eastern Region, 19% in the Northern Region, 17% in the Central Region, 10% in the Southwest Region, 4% in the Northwest Region and 5% did not live in Virginia or their residence was unknown. (Appendices F, G, and H.)

VIRGINIA HIV/AIDS BIRTH TO AGE 19 CUMULATIVE TOTAL JUNE, 1993



FAMILY HIV AND AIDS SERVICES PROGRAM

HIV infection and AIDS in children cannot be separated from the disease problems in the mothers, as the pediatric AIDS epidemic in the United States is one that is rooted in the problems of HIV infection in women, intravenous drug use, and male and female attitudes about sexual responsibility. A family-centered, comprehensive, coordinated approach to service delivery is required. Such an approach is spelled out in an August, 1991 report from the Surgeon General's office (Novello et al., A Guide: Family-Centered Comprehensive Care for Children with HIV Infection, U.S. Department of Health and Human Services).

This approach is also described in Appendix I, Comprehensive AIDS Family Care Center: A Model Treatment Program in the Bronx. Using these approaches as models, the study team outlined the Conceptual Family HIV/AIDS Services Program (Appendix J).

The Family HIV/AIDS Services Program deals with both the medical and psychosocial issues associated with HIV/AIDS. It offers children and their parents coordinated care in one treatment location, provided by a consistent group of professionals with whom they may be able to build a level of trust. The continuity of treatment providers is crucial. This program provides a coordinated team effort among the pediatric and adult infectious disease specialty physicians, the obstetricians, nurses, social workers, mental health counselors, educational consultants, nutritionists, respiratory therapists, and clerks. The family has an assigned case manager to provide continuous assessment, coordination and monitoring of services and needs; to assist the family in problem-solving; to make referrals to local resources; and to provide education to the family regarding HIV/AIDS, treatment, etc.

Teaching these patients takes a lot of time and is expansive. The focus is everything about well-child care and sick-care to transmission of HIV and need for birth control. Every teaching must be very explicit and given orally and in writing. The parents are often sick themselves further limiting their ability to listen and follow instructions. Without case management, families are lost to follow-up, and children die early. These families are dysfunctional with very complicated needs and limited skills to problem-solve. The Family Services Program includes support services for the family, i.e., transportation to/from medical care, respite care and personal care in the home.

HIV infected patients are considered at risk for nutrition problems including weight loss, lymphadenopathy, diarrhea and/or fever. Patients diagnosed with AIDS are typically malnourished due to poor oral intake; malabsorption; high metabolic rates from infection, fever and/or pneumonia; developmental or neurological impairment; and/or, side effects from medications.

During the symptomatic period of HIV infection, a balanced diet for weight maintenance and prevention of vitamin and mineral deficiencies is important. Once a patient has developed AIDS, recommendation for enteral or parenteral nutrition support is an important component of the treatment plan. Many of the AIDS symptoms affect the nutritional status of these patients. Furthermore, malnutrition may have a major affect on the disability of the patient and his/her ability to function independently.

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

Access to care for adults is limited due to no health insurance coverage and few specialists caring for adults with HIV/AIDS. The medical outcome for the child is much enhanced when the parents are also receiving treatment.

One of the goals of the Family Services Program is to build a relationship with the mother before the baby is born in order to enhance her knowledge of HIV transmission, use of birth control and infectious disease treatment. The number of HIV/AIDS children will continue to grow if we do not help the mothers.

The Conceptual Family HIV/AIDS Services Program (Appendix J) was utilized to develop a needs assessment questionnaire. Firsthand information on Virginia's current statewide system of pediatric HIV/AIDS treatment was obtained by the study team. From this data, service and treatment needs were determined for each region of the state.

Children's Hospital of The King's Daughters (CHKD), serving the Eastern Region, and Medical College of Virginia (MCV), serving the Central Region, already have a Family HIV/AIDS Services Program in place serving mothers and children. They both need more staff and equipment to make the services more comprehensive as described in the Conceptual Family HIV/AIDS Services Program. The majority of the patients are covered by Medicaid for treatment costs. However, Medicaid does not add additional staff to the clinic. The clinic's caseload is increasing daily. Many community care providers are not providing HIV/AIDS care, but are referring patients to the tertiary center for the specialty care.

The Northern, Northwest, and Southwest Regions do not have a Family HIV/AIDS Services Program in place. University of Virginia Health Sciences Center (UVA), serving the Northwest Region, has a limited caseload and no plans or interest in developing a Family HIV/AIDS Services Program at this time. Both the Northern and Southwest Regions were very interested in developing this type of program. The needs assessment results and service and treatment needs of these three regions are described in the section entitled "Cost Projections By Region For One Year."

ADMINISTRATIVE AND ORGANIZATIONAL STRUCTURE

The Family HIV/AIDS Services Program will be an integral part of Children's Specialty Services Program (CSS). It will provide management and treatment services to children and their parents living in Virginia with HIV infection or AIDS with family incomes below 200% of poverty as determined by federal guidelines. The sliding charge schedule approved by the State Board of Health will apply. Children under age 21 years will be eligible. It is anticipated that the majority of families will have low incomes and be eligible for Medicaid coverage.

To protect the families from the stigma associated with HIV/AIDS diagnosis, each clinic will be designated a "Family Services Clinic." Regularly scheduled clinics will meet to treat and manage the child and parents as a family unit.

The program will be coordinated with the public and private maternity clinics in the geographic catchment areas of the Family Services Clinic. Free maternal testing for HIV infection is offered on a voluntary basis to all women attending maternity clinics in local health departments. The CSS program will not pay for maternity care or delivery, but it will pay for infectious disease treatment of the HIV positive pregnant women.

As the whole thrust of this program is early identification and intervention, the HIV positive pregnant women will serve as the index case. She will be counseled, monitored, and followed. If her immune system deteriorates, she will be treated; otherwise prevention of transmission of infectious disease will be stressed. If a live birth occurs, the infant will be tested and monitored regularly in the Family Services Clinic to determine if a true HIV infection results. The infant will be treated as indicated. The mother and infant will be monitored and treated together in the same Family Services Clinic by the same multispecialty team. If the child dies or becomes HIV negative, the mother will be referred to another source of infectious disease treatment, and CSS will not be a payor of these services. As total support is needed, patients will be instructed to notify the case manager for problems occurring during the day and facility emergency rooms at night. The case manager will have a direct conduit to the physicians.

The Children's Specialty Services Program has a number of highly specialized clinics located throughout the state. Children identified as HIV positive and entered into the Family Services Program will automatically be eligible for consultation and treatment by all CSS specialty clinics as indicated.

For some time, the CSS Hemophilia Clinics have been counseling, testing, monitoring, and treating hemophiliacs who are HIV positive. These clinics have health professionals with AIDS training who are an integral part of the hemophilia team. Services include HIV-related medications. When AIDS develops, the hemophilia patient will be referred to the Family Services Clinic for treatment.

Children demonstrating developmental deficits will be referred directly to the state's network of 12 regional Child Development Clinics operated under the Division of Children's Specialty Services. Children demonstrating neurological complications can be referred for consultation or treatment in the Neurology Program. Other CSS programs available, if needed, include: Neurosurgery, Surgery, Hearing Impairment, Eye Surgery, Plastic Surgery, Cardiology, Endocrinology, Facial Deformities, Urology, Rheumatology and Orthopedics.

EXISTING RESOURCES

The Family Services Program will work closely with the following existing resources:

1. Regional HIV/AIDS Resource and Consultation Centers

Resource and Consultation Centers provide regional and local training, consultation and support for local physicians, health departments, schools, dentists, and public and private agencies providing HIV-related care.

2. AIDS Service Organizations

The AIDS Service Organizations, which are community-based groups, provide AIDS educational outreach and patient support services, i.e., psychosocial counseling, legal assistance, and medical referral.

3. Regional HIV Care Consortia and Their Subcontractors

The HIV Care Consortia and their community-based subcontractors are located in every region of Virginia. These are funded by the Virginia Department of Health with federal funding under the Ryan White Comprehensive CARE Act. The many services provided by the consortia include case management, primary medical care, case finding, dental care, nutrition services, mental health services, group and individual counseling, outpatient hospice care, respite

care, transportation, child care, medical equipment and supplies, lab services, outreach workers, medications, emergency funds, and home health nursing services. These services vary from region to region.

4. Bureau of STD/AIDS, Virginia Department of Health

The Bureau of STD/AIDS provides HIV prevention and health care services throughout Virginia. With state and federal funding, the bureau works collaboratively with public and private community agencies to deliver prevention and education to the general public, health care providers, and those at increased risk; to make available free HIV-related medications; and to provide a range of outpatient health care services.

5. Private Practitioners

The Family Services Program will include children who are HIV positive and have private pediatricians or family practitioners in communities distant from the medical centers. The program will rely on their local medical management under the supervision and follow-up resources of the Family Services Program. After each clinic visit, a typewritten clinic report listing findings, treatment plans, and instructions will be sent to the private physician involved, the local health department and the CSS Central Office.

6. Local Health Departments

All patients referred to the Family Services Program will be admitted through their indicated local health department so that all patients will have local public health nurse follow-up as required. The nurse will contact the family to explain the treatment plan, advise, and counsel. All drugs will be ordered by the clinic from the Department of Health pharmacy and sent to the local health department for distribution and instruction. The local health department will notify the Family Services Program in each of the treatment centers if problems develop in the field.

7. Medicaid

HIV/AIDS patients become Medicaid eligible when they become disabled and have low enough income and resources to qualify for the federal Supplemental Security Income (SSI) program. Patients who are not financially or medically eligible for SSI benefits may qualify for Medicaid as "Medically Needy." In addition, Medicaid recipients may

become eligible for community-based services covered under the Medicaid AIDS waiver. These services include case management, personal care by aides in the patient's home, private duty nursing in the patient's home, respite care for the caregiver and nutritional supplements. "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."¹

COST OF TREATING PATIENTS WITH HIV/AIDS

Treatment modalities for persons with HIV/AIDS change rapidly. The number of new drugs approved in recent years to treat persons with HIV has increased (seven new drugs in 1991 and five new drugs in 1992). "Over the past decade, HIV has transformed from an acute illness involving frequent hospitalizations to an illness with long periods of low-intensity care interspersed among a few periods of hospitalization...cost estimates of treatment should be updated at regular intervals to reflect these changes."² For this report, the average cost of treatment was derived from an analysis done by Fred J. Hellinger in 1992 in 10 cities in multiple sites (hospitals, clinics, and physicians' offices). Estimates of the mean occupancy time in each of the four HIV/AIDS disease stages were obtained during his study. The services included in Hellinger's treatment cost include inpatient, outpatient visits, home health, drug costs and long-term care. The average annual cost of treatment of HIV was \$6,808. The average annual cost of treatment of AIDS was \$33,168. The average annual cost of follow-up services for an HIV-negative child of a woman with HIV/AIDS was \$1,812.²

These annual cost calculations were applied to Virginia HIV/AIDS prevalence data to determine cost of care estimates for one year. The national percentage of HIV/AIDS patients covered by Medicaid also was applied to Virginia HIV/AIDS prevalence data (40% of the adults and 90% of the children). Details of the costs are described later in this report in the section entitled, "Cost Projections By Region For One Year".

HIV/AIDS patients who will need financial assistance from CSS are those who are not covered by Medicaid (60% of adults and 10% of the children) and those who are uninsured or have limited health insurance. CSS will not encumber costs for Medicaid patients since the health care providers will be billing Medicaid directly for the costs. Patients with hemophilia will be eligible to apply for health insurance coverage through Hemophilia of Virginia Inc., a nonprofit organization that procures health insurance and provides legal and financial assistance. CSS will be a payor for their services during the twelve month waiting period of no coverage due to a pre-existing condition stipulation. CSS

will obtain revenue from the CSS annual patient charge. This is a sliding scale charge based on family income. The current annual charge for a full-pay patient is \$120, except for Northern Virginia where it is \$136. It is anticipated that the majority of families will have low incomes and that the revenue will be minimal.

Thus, the cost presented in this report is for 79 patients who do not have Medicaid coverage and would benefit from CSS coverage for these services. This is total cost and does not reveal those costs that would be covered by private health insurance which some patients may have. Historically, 16% of CSS patients have had private health insurance. Also, CSS will be paying for services at the Virginia Medicaid rate which will be lower than these national average treatment costs. In addition, the cost and prevalence of HIV/AIDS have not been projected for future years.

In summary, the cost of the treatment of HIV/AIDS is very dynamic. Research is occurring in New York and New Jersey to analyze the current cost of the treatment of children infected with HIV and those with AIDS. Further refinement will be needed to make the costs in this study more timely to a specific budget period and to the current standards of antiretroviral therapy and medical management of the AIDS/HIV-infected child and adult.

The costs reflected in this study are for the first year of services. The Department intends to conduct an additional study to further develop resource requirements for services in the phased-in plan for future years.

METHODOLOGY FOR PHASING-IN SERVICES

The first phase of the plan will include locations where a Family HIV/AIDS Services Clinic is in place (Children's Hospital of The King's Daughters and Medical College of Virginia). Other areas will be phased in as a Family HIV/AIDS Services Clinic is established (Northern Region, University of Virginia Health Sciences Center, Southwest Region). The last phase will include satellite clinics based on the growing number of patients and reimbursement to community primary care physicians who are willing to treat HIV/AIDS patients with consultation from physicians located at the tertiary medical centers.

HEALTH CARE REFORM

Health care reform will significantly improve access to health care by assuring comprehensive health coverage for all HIV/AIDS patients. Regional alliances and health plans as proposed by President Clinton will make a full range of services available in the standard benefit package. The Ryan White CARE Act, which furnishes federal funds for medical care and family support services for HIV/AIDS patients, is retained in the President's proposal. Since the costs of medical care will be covered by the standard benefit package, Ryan White funds will continue to fund family support services, i.e., case management, transportation, respite care, counseling.

However, universal coverage and reforms will not eliminate all barriers to adequate, appropriate, and quality family-centered care for HIV-AIDS patients. Some concerns are the limited coverage for home care and long-term care, no subsidy for co-payments on HIV drugs and treatment, no coverage for experimental drugs, no coverage for undocumented immigrants except for emergency-room care, and the possibility that Congress may weaken financial support for HIV/AIDS programs in order to balance budgets.

Current predictions indicate that the earliest date that a health reform plan will be implemented is 1997. The role of CSS will likely shift from providing direct service to improving the service system for all children with special health care needs. A mission of CSS is to build and promote a system of care that is comprehensive, family-centered, community-based, coordinated and culturally competent. The access barriers that will not be eliminated by health care reform will be addressed. Methods to monitor quality assurance and outcomes of children's health care will be developed and deployed.

COST PROJECTIONS BY REGION FOR ONE YEAR

CHILDREN'S HOSPITAL OF THE KING'S DAUGHTERS (CHKD)

CHKD has a Family HIV/AIDS Services Program in place serving mothers and children. The hospital works closely with Children's AIDS Network for Interfaith Involvement which provides services such as respite care, transportation, financial help and support groups. CHKD currently has clinic and office space, physicians, nurse, patient care assistant, and social worker assigned to the Family HIV/AIDS Services Program. In order to make the services more comprehensive as described in the Conceptual Family HIV/AIDS Services Program (Appendix J), CHKD needs the following:

<u>Personnel</u>	<u>% Time</u>	<u>Average Annual Salary</u>	<u>Fringe Benefits</u>
Social Worker	100%	\$ 32,829 (Gr. 10 Step 16)	\$ 9,849 (30%)
*Nutritionist	100%	\$ 32,829 (Gr. 10 Step 16)	\$ 9,849 (30%)
*To be assigned to Family Services Clinic and other types of CSS Specialty Clinics at CHKD			
Case Manager (Registered Nurse)	100%	\$ 39,232 (Gr. 12, Step 16)	\$ 11,770 (30%)
Clerk Typist	100%	\$ 18,397 (Gr. 05, Step 10)	\$ 5,519 (30%)
Data Entry Clerk	50%	\$ 7,450 (\$7.45/hr.)	\$ 570 (7.65%)
Total 4.5 Full-time Equivalents (FTE)		\$ 130,737	\$ 37,557
Equipment - Colposcope and camera for pelvic examination of mothers			\$ 10,000
Supplies - condoms parent use			\$ 600
Education-in services and conferences			\$ 1,500
Travel-mileage for professionals			\$ 880
		Total	\$ 12,980

CHKD CURRENT CASELOAD

<u>Children</u>	<u>% Medicaid</u>	<u>Number Medicaid</u>	<u>Number CSS</u>	<u>Treatment Cost Per Patient</u>	<u>Total CSS Cost</u>
Pediatric HIV = 49	90%	44	5	\$ 6,808	\$ 34,040
Pediatric AIDS = 26	90%	23	3	\$ 33,168	\$ 99,504
Follow-up = 34	90%	31	3	\$ 1,812	\$ 5,436
Adolescent HIV = 1	90%	1	0		
Adolescent AIDS = <u>2</u>	90%	<u>2</u>	<u>0</u>		
Total	112	101	11		\$ 138,980
 <u>Parents</u>					
Mothers HIV = 57	40%	23	34	\$ 6,808	\$ 231,472
Mothers AIDS = 14	40%	6	8	\$ 33,168	\$ 265,344
Fathers = <u>0</u>	40%	<u>0</u>	<u>0</u>		
Total	71	29	42		
 <u>Hemophiliacs</u>					
Hemophiliacs AIDS = 1	actual #	1	0		
Hemophiliacs HIV = <u>4</u>	actual #	<u>1</u>	<u>3</u>	\$ 6,808	\$ <u>20,424</u>
Total	5	2	3		\$ 517,240
Grand Total	188	132	56	CSS Total Cost =	\$ 656,220

CHKD TOTAL COST

Personnel, Equipment, etc.	\$ 181,274
Patient Treatment Services	<u>\$ 656,220</u>
Total =	\$ 837,494

MEDICAL COLLEGE OF VIRGINIA (MCV)

MCV has a Family HIV/AIDS Services Program in place serving mothers and children. The hospital works closely with several local agencies which provide services such as home health care, financial help and support groups. MCV currently has clinic and office space, physicians, nurses, social workers and dietician (inpatient only) assigned to the Family HIV/AIDS Services Program. In order to make the services more comprehensive as described in the Conceptual Family HIV/AIDS Services Program (Appendix J), MCV needs the following:

<u>Personnel</u>	<u>% Time</u>	<u>Average Annual Salary</u>	<u>Fringe Benefits</u>
*Nutritionist	100%	\$ 32,829 (Grade 10, Step 16)	\$ 9,849 (30%)
*To be assigned to Family Services Clinic and other types of CSS Specialty Clinics at MCV			
Social Worker	100%	\$ 32,829 (Grade 10, Step 16)	\$ 9,849 (30%)
Case Manager (Registered Nurse)	100%	\$ 39,232 (Grade 12, Step 16)	\$ 11,770 (30%)
Clerk Typist	100%	\$ 18,397 (Grade 5, Step 10)	\$ 5,519 (30%)
Data Entry Clerk	50%	\$ <u>7,450</u> (\$7.45/hr.)	\$ <u>570</u> (7.65%)
Total 4.5 Full-Time Equivalents (FTE)		\$ 130,737	\$ 37,557
Equipment - Win Computer (\$1,840) and Printer (\$1,215)			\$ 3,055

MCV CURRENT CASELOAD

<u>Children</u>		<u>% Medicaid</u>	<u>Number Medicaid</u>	<u>Number CSS</u>	<u>Treatment Cost Per Patient</u>	<u>Total CSS Cost</u>
Pediatric HIV	= 23	90%	21	2	\$ 6,808	\$ 13,616
Pediatric AIDS	= 12	90%	11	1	\$ 33,168	\$ 33,168
Follow-up	= <u>14</u>	90%	<u>13</u>	<u>1</u>	\$ 1,812	<u>\$ 1,812</u>
Total	49		45	4		\$ 48,596

<u>Parents</u>						
Mothers HIV	= 27	40%	11	16	\$ 6,808	\$ 108,928
Mothers AIDS	= 0	40%				
Fathers	= <u>0</u>	40%	—	—		
Total	27		11	16		

<u>Hemophiliacs</u>						
Hemophiliacs AIDS	= 2	Actual #	1	1	\$ 33,168	\$ 33,168
Hemophiliacs HIV	= <u>3</u>	Actual #	<u>1</u>	<u>2</u>	\$ 6,808	<u>\$ 13,616</u>
Total	5		2	3		\$ 155,712

Grand Total	81		58	23	CSS Total Cost =	\$ 204,308
--------------------	-----------	--	-----------	-----------	-------------------------	-------------------

MCV TOTAL COST

Personnel, Equipment, etc.						\$ 171,349
Patient Treatment Services						<u>\$ 204,308</u>
					Total =	\$ 375,657

NORTHERN VIRGINIA

There have been 21 cumulative cases of pediatric AIDS and 6 cumulative cases of pediatric HIV infection reported in Northern Virginia as of June 30, 1993. In addition, there were 6 cumulative cases of teens (ages 13-19) reported with AIDS and 20 cumulative cases of teens reported with HIV infection. The primary provider of care for these children is the Children's National Medical Center located in Washington D.C. where approximately 30 Northern Virginia children are currently receiving care. The majority of these children have Virginia Medicaid. Children's National Medical Center is receiving \$44,275 from Ryan White CARE Act funds (Washington, D.C., Title I funds) for primary care, infectious disease, outpatient treatment, case management and transportation for these Virginia children. In addition, 15 children are receiving care at Georgetown University Children's Medical Center located in Washington, D.C. and the majority of them have Medicaid. Children are also receiving care from private infectious disease physicians in the Northern Virginia area; this number is unknown.

Although all health departments in the Northern Region provide maternity care, and family planning for HIV positive women and well-child follow-up for HIV positive children, none provide medical care and case management for HIV positive children.

The Office of HIV Services, Women and Children Program of the Inova Health System at Fairfax Hospital is convening a task force to develop a Pediatric HIV/AIDS Treatment Program. They are interested in developing a Family Services Program to treat children and parents.

Numbers of Women in Northern Virginia Health Departments' HIV Case Management Programs:

Arlington:	Referral to medical care. Caseload in past year: 18
Alexandria:	Case management and medical care through health department clinics. Caseload in past year: 40 women
Fairfax:	Case management and medical care. Caseload in past year: 22 women
Prince William:	Case management and referral for medical care from private physicians. Caseload in past year: 25 women
Loudoun:	Not available

The Office of HIV Services of the Inova Health System at Fairfax Hospital provides medical care and case management to women as well as men in the Northern Region. Current caseload: 15 women.

Numbers of HIV positive women and children receiving health department services in the past year:

Arlington:	Maternity Care:	5 - 7 HIV positive women
	Well-Child Care:	5 HIV positive children
Alexandria:	Maternity Care:	3 HIV positive women
	Well-Child Care:	3 HIV positive children
Fairfax:	Maternity Care:	3 HIV positive women
	Well-Child Care:	0
Prince William:	Maternity Care:	7 HIV positive women
	Well-Child Care:	7 children (primarily for immunizations)
Loudoun:	Not available	

Children's Specialty Services Hemophilia Clinic in Northern Virginia has two patients with AIDS and three patients who are HIV positive. All five patients have private health insurance.

In summary, collectively the cities and counties in Northern Virginia have a high prevalence of HIV/AIDS. However, the impact on individual cities and counties has been low. Currently, there is not a medical source located in Northern Virginia that provides HIV/AIDS treatment to parents and their children in a Family HIV/AIDS Services Program. Medical care is fragmented among multiple primary care physicians, infectious disease specialists, and obstetricians in the public and private sector. Many children are receiving HIV/AIDS treatment in Washington, D.C. There is not a children's hospital or a public hospital located in Northern Virginia. Locally-based medical services for children need to be established close to where they live. In addition, transportation, child care/respice for HIV positive mothers and housing are needed.

Hiring a Nurse Coordinator to assess, with representatives of the district health departments, the collective needs of the parents and children in Northern Virginia would be beneficial. In addition, the nurse would facilitate activities to meet these needs, assist in the development of Family HIV/AIDS Services Clinics in several locations throughout the region, and facilitate the case management services for the families. This will be the first step in the phased-in plan. The second phase would include funds to pay for HIV/AIDS treatment services for those parents and children with no Medicaid or health insurance coverage. Additional support services, i.e., transportation, baby-sitter, would also be a part of the second phase funding.

The Nurse Coordinator will be supervised by the Division of Children's Specialty Services (DCSS) Northern Virginia Nurse Supervisor and housed in the existing DCSS office in Fairfax. Cost for the first year is as follows:

<u>Personnel</u>	<u>% Time</u>	<u>Average Annual Salary</u>	<u>Fringe Benefits</u>
Public Health Nurse Senior	100%	\$44,841 (Grade 12, Step 16) Northern Virginia Salary	\$13,452 (30%)
Total Cost =			\$58,293

UNIVERSITY OF VIRGINIA HEALTH SCIENCES CENTER (UVA)

UVA currently serves mothers and children in separate clinics. They have no plans or interest in a Family HIV/AIDS Services Program at this time. They have five pediatric HIV patients and 10 pediatric AIDS patients who have either Medicaid or private health insurance. Funds of \$1,000 would assist them in professional education expenses on HIV/AIDS.

Children's Specialty Services Hemophilia Clinic at UVA has one patient with AIDS and two patients who are HIV positive. All three patients have Medicaid.

SOUTHWEST VIRGINIA

The Southwest Region has the lowest incidence of pediatric and teen HIV and AIDS. CSS Hemophilia Clinic has one patient with AIDS in this region. He is covered by Medicaid. A pediatric infectious disease specialist is providing care to 12 to 14 HIV/AIDS patients from the Roanoke area at the Roanoke Memorial Rehabilitation Center. She currently holds two clinics a month. The specialist is very interested in developing a Family HIV/AIDS Services Program. She indicated the hiring of a Nurse Coordinator to develop this program would be beneficial. Cost is as follows:

<u>Personnel</u>	<u>% Time</u>	<u>Average Annual Salary</u>	<u>Fringe Benefits</u>
Public Health Nurse Senior	100%	\$ 39,232 (Grade 12, Step 16)	\$11,770 (30%)
Total Cost =			\$51,002

The second phase of funding would include funds to pay for HIV/AIDS treatment services for those parents and children with no Medicaid or health insurance coverage. Additional support services, i.e., transportation, baby-sitter, would also be a part of the second phase funding.

SUPPORT SERVICES FOR CHKD AND MCV PATIENTS

Transportation

Payment of transportation will follow the Medicaid model. Costs of taxi, bus, and designated driver for travel to medical services will be paid at the Medicaid rate.

Budget:	Buses \$4 x 20 patients x 8 trips =	\$ 640
	Taxi \$15 x 10 patients x 8 trips =	\$ 1,200
	Designated Driver \$15 x 10 patients x 8 trips =	<u>\$ 1,200</u>
	Total =	\$ 3,040

Baby-Sitter

Payment of baby-sitter costs for siblings, while parents and HIV/AIDS child are away from home receiving medical services, will be at \$4.25 an hour.

Budget:	\$4.25 x 4 hours x 14 patients x 8 trips =	\$ 1,904
	Support Services Total Cost =	\$ 4,944

OUTREACH/EDUCATION

Staff Needed: One Health Educator - STD/AIDS Program

Description of Need: Community misunderstanding and lack of support have been identified as major problems for families affected by HIV/AIDS. Families express a feeling of being isolated when they have an HIV positive child. Schools must begin to understand and deal with this infection because children, who a few years ago would have lived only a few years, are now attending school.

Job Responsibilities: This position would have a primary responsibility for statewide coordination of community efforts around pediatric HIV/AIDS. He/she would have a critical role in providing education to school personnel and PTAs as requested. Close coordination would be maintained with other individuals and agencies involved in pediatric HIV, including, but not limited to, the Department of Education, the Bureau of STD/AIDS within the Virginia Department of Health, and community-based organizations. This position will be housed in the Bureau of STD/AIDS.

Budget:	Salary and Fringe:	\$ 35,000
	Travel:	5,000
	Supplies:	<u>2,000</u>
	Total =	\$ 42,000

TOTAL COST PROJECTIONS BY REGION FOR ONE YEAR

Children's Hospital of The King's Daughters	\$ 837,494
Medical College of Virginia	\$ 375,657
Northern Virginia	\$ 58,293
University of Virginia Health Sciences Center	\$ 1,000
Southwest Virginia	\$ 51,002
Support Services	\$ 4,944
Outreach/Education	<u>\$ 42,000</u>

Total = \$ 1,370,390

Projected Revenue from CSS Annual Patient Charges \$ 2,820

General Funds Needed = \$ 1,367,570

RECOMMENDATIONS

The study team report was presented to the Joint Subcommittee Studying Acquired Immunodeficiency Syndrome on November 29, 1993. Three comments were received from the subcommittee.

First, the number of personnel requested in the study demonstrated the ideal. However, within the current economic climate, full funding is unlikely. The study adequately justified the treatment costs, but the subcommittee questioned the personnel costs. Recommendation was made to reduce the number of staff and their costs.

The second comment questioned the ethicality of spending this much money for 15 children and 64 adults. To clarify, \$95,380 covers treatment costs for 21 children (includes 6 pediatric hemophiliacs) and \$605,744 covers the treatment costs of 58 mothers. The remaining costs at CHKD and MCV are for personnel and equipment that will benefit these 79 patients plus the 190 children and mothers that have Medicaid coverage.

The third comment questioned why treatment of parents was included in this program when CSS does not cover costs for parents in other programs. In response, HJR 691 indicated that the Department shall develop this program in a manner which includes the parents of the HIV-infected children in a family-oriented system of care.

During the work session on December 14, 1993, the Joint Subcommittee endorsed the funding of staff costs for the provision of case management, patient education, social work and nutrition services at the Family HIV/AIDS Services Clinics at CHKD and MCV. If funded, this will be a pilot project for family support services to 190 children and mothers who have their treatment costs covered by Medicaid. The cost of the pilot project is \$170,885.

The Joint Subcommittee Studying Acquired Immunodeficiency Syndrome recommends the following:

- A. Fund additional staff costs (\$170,885) for the provision of case management, patient education, social work and nutrition services at the Family HIV/AIDS Services Clinics at the Children's Hospital of The King's Daughters (CHKD) and the Medical College of Virginia (MCV). These two medical centers already have Family HIV/AIDS Services Clinics in place, but need additional staff in order to make the services more comprehensive. Both medical centers serve geographic regions of Virginia with high prevalence of HIV and AIDS. This will be a pilot project for family support services to 190 children and mothers who have their treatment costs covered by Medicaid;
- B. Phase-in funding for Family HIV/AIDS Services Clinics, as they are established, in the Northern and Southwest Regions, and the University of Virginia (UVA) Health Sciences Center.

References

1. David C. Harvey, Improving Access to Care for Families with HIV: Integrating the Ryan White CARE Act and the Pediatric/Family AIDS Demonstration Program, National Pediatric HIV Resource Center, Washington, D.C., 1993, p. 5.
2. Fred J. Hellinger, Ph.D., "The Lifetime Cost of Treating a Person with HIV," Journal of the American Medical Association, July 28, 1993, Vol. 270, No. 4, pp. 474-478.

GENERAL ASSEMBLY OF VIRGINIA--1993 SESSION

HOUSE JOINT RESOLUTION NO. 691

Requesting the Virginia Department of Health to develop, in coordination with the Joint Subcommittee Studying Acquired Immunodeficiency Syndrome, certain plans for incorporating HIV/AIDS treatment for infected children in the Commonwealth's Children's Specialty Program.

Agreed to by the House of Delegates, February 9, 1993

Agreed to by the Senate, February 23, 1993

WHEREAS, in Virginia, the response to the AIDS epidemic has been carefully developed to provide appropriate education, care, and treatment, within appropriated funds, to citizens infected with human immunodeficiency virus; and

WHEREAS, in the early stages of the HIV epidemic, almost all of the individuals infected were adult men; and

WHEREAS, the demographics of the HIV epidemic have changed over the last 10 years and will continue to change; and

WHEREAS, the number of women infected with HIV has increased significantly over the last several years; and

WHEREAS, in 1990 and 1991, the Centers for Disease Control have noted statistics indicating the greatest proportion of increase in the number of reported cases of AIDS was among women, with a fifteen percent increase; and

WHEREAS, this increase in women has been primarily among women of child-bearing age; and

WHEREAS, among children born to HIV-infected women, approximately 30 percent develop the infection through perinatal exposure; and

WHEREAS, a few children also contract HIV through other modes of transmission, such as sexual activity; and

WHEREAS, the number of children who are HIV infected appears to be increasing in the Commonwealth; and

WHEREAS, no state funds have been specifically earmarked for services to HIV-infected children in Virginia; and

WHEREAS, primary care provided in a timely and cost-effective manner can assist such children in remaining stable and increase the quality and length of their lives; and

WHEREAS, although services are being delivered to children in the Commonwealth through the already existing clinics and other resources, the Children's Specialty Program, with its sole focus on children needing intensive services, appears to be an ideal vehicle for delivery of primary care to these children in an efficient and effective manner; and

WHEREAS, every expansion of an existing program or proposal for a new program must be based on sound data and careful planning, especially during this time of fiscal exigency; and

WHEREAS, in order to deliver such services through the Children's Specialty Program, the Department of Health would have to develop a plan to phase in the services and the required budget estimates; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Health be hereby requested to develop, in coordination with the Joint Subcommittee Studying Acquired Immunodeficiency Syndrome, a phased-in plan for incorporating HIV/AIDS treatment for infected children in the Commonwealth's Children's Specialty Program. Insofar as possible, the Department shall develop this program in a manner which includes the parents of the HIV-infected children in a family-oriented system of care.

The Department shall collaborate with the joint subcommittee on development of this plan and shall provide the joint subcommittee with interim reports on its progress as deemed necessary.

By November 1, 1993, the Department shall complete its plan, which shall include budget estimates for the phasing in of services to HIV-infected children, and shall be specific as to the method and sites for gradually introducing such services. The Department shall report its findings and recommendations to the Governor and the 1994 General Assembly in accordance with the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX B

Virginia Pediatric HIV and AIDS
BIRTH THROUGH 12 YEARS OF AGE
THROUGH JUNE 22, 1993

HIV			AIDS		
Year of Diagnosis	Number	Percent	Year of Diagnosis	Number	Percent
Before 1991	11	39.29	Before 1987	12	15.38
1991	8	28.57	1987	11	14.10
1992	9	32.14	1988	6	7.69
			1989	7	8.97
			1990	9	11.54
			1991	13	16.67
			1992	16	20.51
			1993	4	5.13
Year of Report					
Before 1991	3	10.71	Before 1987	6	7.69
1991	13	46.43	1987	4	5.13
1992	8	28.57	1988	10	12.82
1993	4	14.29	1989	5	6.41
			1990	12	15.38
			1991	16	20.51
			1992	19	24.36
			1993	6	7.69
Gender					
Male	16	57.14	Male	44	56.41
Female	12	42.86	Female	34	43.59
Race					
White	13	46.43	White	27	34.62
Black	13	46.43	Black	46	58.97
Other	2	7.14	Other	5	6.41
Risk					
Hemophilia	3	10.71	Hemophilia	4	5.13
Transfusion/Transplant	5	17.86	Transfusion/Transplant	12	15.38
Mother at Risk	18	64.29	Mother at Risk	61	78.21
Undetermined	2	7.14	Undetermined	1	1.28
Region					
Northwest	5	17.86	Northwest	6	7.69
Northern	6	21.43	Northern	21	26.92
Southwest	4	14.29	Southwest	8	10.26
Central	4	14.29	Central	18	23.08
Eastern	9	32.14	Eastern	25	32.05
TOTAL	28		TOTAL	78	

Virginia Teens HIV and AIDS

13 - 19 YEARS OF AGE
THROUGH JUNE 22, 1993

	HIV		AIDS	
Year of Diagnosis				
Before 1991	55	39.9%	Before 1991	9 45.0%
1991	40	29.0%	1991	4 20.0%
1992	34	24.6%	1992	7 35.0%
1993	9	6.5%	1993	0 .0%
Year of Report				
Before 1991	31	22.5%	Before 1992	8 40.0%
1991	42	30.4%	1992	5 25.0%
1992	31	22.5%	1993	7 35.0%
1993	34	24.6%		
Gender				
Male	64	46.4%	Male	15 75.0%
Female	74	53.6%	Female	5 25.0%
Race				
White	42	30.4%	White	12 60.0%
Black	94	68.1%	Black	6 30.0%
Other	2	1.4%	Other	2 10.0%
Risk				
MSM	29	21.0%	Hemophilia	10 50.0%
Hemophilia	16	11.6%	Heterosexual	3 15.0%
Heterosexual	37	26.8%	Other**	5 25.0%
Other*	3	2.2%	Undetermined	2 10.0%
Undetermined	53	38.4%		
Region				
Northwest	7	5.1%	Northwest	3 15.0%
Northern	20	14.5%	Northern	6 30.0%
Southwest	14	10.1%	Southwest	5 25.0%
Central	33	23.9%	Central	3 15.0%
Eastern	64	46.4%	Eastern	3 15.0%
TOTAL	138		TOTAL	20

* Other Risk HIV may include MSM/IVDU, IVDU, and Transfusion Blood/Products.

** Other Risk AIDS may include MSM, MSM/IVDU, IVDU, and Transfusion Blood/Products.

APPENDIX D

HIV Reports in Adult Women in Virginia						
<i>by transmission mode</i>	1989	1990	1991	1992	1993*	TOTAL
IDU	6	69	97	76	37	285
Blood/Blood Products	<3	10	13	7	5	35
Hemophilia	<3	<3	<3	<3	<3	3
Heterosexual Contact	4	85	132	173	52	446
Multi-Heterosexual	7	56	83	35	8	189
Unknown	3	42	48	55	32	180
*reported through June 30, 1993						
AIDS Reports in Adult Women in Virginia						
<i>by transmission mode</i>	1982-89	1990	1991	1992	1993*	TOTAL
IDU	34	18	18	42	49	161
Blood/Blood Products	21	13	8	10	12	64
Hemophilia	<3	<3	<3	<3	<3	<3
Heterosexual Contact	41	22	35	34	64	196
Unknown	5	7	8	10	18	48
*reported through June 30, 1993						

Bureau of STD/AIDS
Virginia Department of Health

*HIV and AIDS Transmission Among Women**U.S. Data*

Nationwide, women represent 11% of the 284,840 adult AIDS cases reported through March 1993. A total of 32,477 adult women have been reported with AIDS. The primary mode of transmission reported for women is injecting drug use, with 49% of the U.S. cases. Heterosexual transmission accounts for 36% of the AIDS cases among women. Receipt of blood or blood products accounts for 6%, less than 1% are associated with hemophilia, and 9% are NIR.

Virginia AIDS Cases

In Virginia, women represent 11% of the 4,311 adult AIDS cases reported through June 1993. A total of 470 adult women have been reported with AIDS in Virginia. The primary mode of transmission for women in Virginia is heterosexual transmission (42%), followed by injecting drug use (34%), receipt of blood or blood products (14%), hemophilia (<1%) and NIR (10%).

Heterosexual transmission accounts for the highest percentage of AIDS cases among women in Virginia, regardless of race. Thirty-seven percent of white, 44% of black, 42% of Hispanic and 50% of Asian women report heterosexual transmission. Blood transfusion and injecting drug use as transmission modes differ among races, however. Injecting drug use accounts for 22% of white, 39% of black and 42% of Hispanic cases. Blood transfusion accounts for 30% of white, 6% of black, 5% of Hispanic and 25% of Asian cases. The percentage of cases reporting receipt of blood or blood products as a risk has decreased since 1986. Prior to 1986, 50% of all AIDS cases reported in women were associated with receipt of blood or blood products. Since 1986, only 13% have been associated with the receipt of blood or blood products. Both injecting drug use and heterosexual transmission have remained the primary modes of transmission for women in Virginia since 1986; injecting drug use and heterosexual transmission account for 76% of the total AIDS cases reported in women.

Virginia HIV Cases

Women represent 23% of the 4,870 adult HIV cases reported through June 1993. A total of 1141 adult women have been reported with HIV in Virginia. The primary mode of transmission for women in Virginia is heterosexual transmission (39%) followed by injecting drug use (25%), multi-heterosexual contact (17%), receipt of blood or blood products (3%), hemophilia (<1%) and undetermined (16%). The transmission mode does not differ significantly by race.

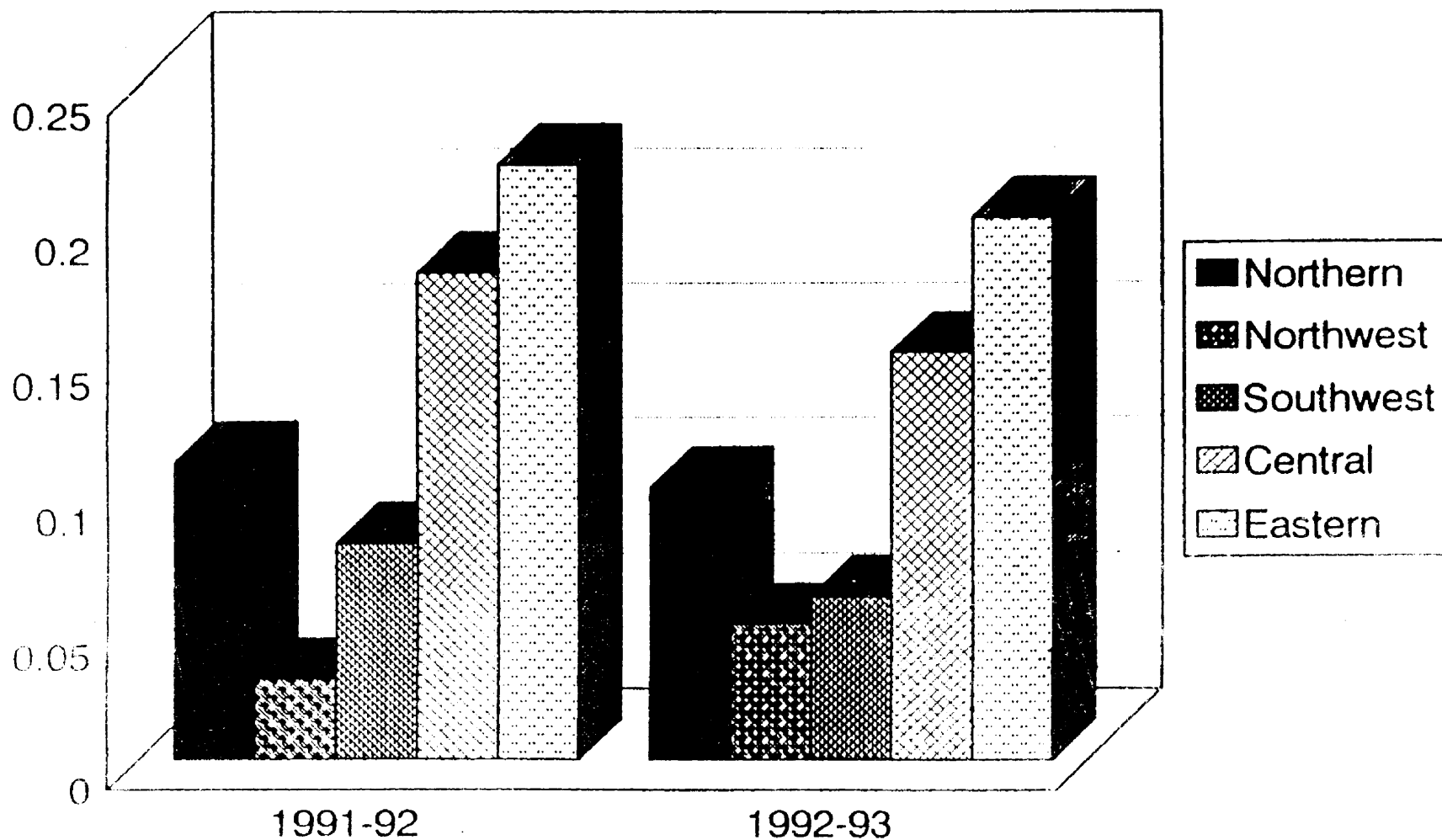
Because HIV reporting did not begin until 1989, the percentage of cases reporting receipt of blood or blood products as a risk is low. The percentage was the highest in 1989, when 9% of the HIV cases reported in women were associated with receipt of blood or blood products. Since 1990, this percentage of HIV cases associated with the receipt of blood or blood products in women has remained between 2% and 4%. Injecting drug use has remained steady at approximately 25% of each year's HIV reports in women. Heterosexual contact has become an increasingly prevalent mode of HIV transmission in women. Eighteen percent of the cases reported in 1989 indicated heterosexual contact, while 50% indicated heterosexual contact in 1992. When those cases indicating multi-heterosexual contacts are included as heterosexual transmission, this category accounts for 56% of the total HIV cases reported in women in Virginia.

APPENDIX F
Survey of Childbearing Women
Regional Data

	Phase 1					Phase 2					Phase 3					Phase 4					
	Tested	%	Pos	%	Sero+	Tested	%	Pos	%	Sero+	Tested	%	Pos	%	Sero+	Tested	%	Pos	%	Sero+	
NW	4,689	11.10	2	4.17	0.04%	11,115	12.91	4	4.30	0.04%	11,273	12.33	3	2.26	0.03%	5,563	12.53	3	5.38	0.05%	
North	9,618	22.77	9	18.76	0.09%	19,121	22.21	21	22.58	0.11%	21,013	22.98	24	18.06	0.11%	10,143	22.85	10	17.86	0.10%	
SW	6,005	14.22	7	14.58	0.12%	13,237	15.37	11	11.83	0.08%	13,597	14.87	11	8.27	0.08%	6,413	14.45	4	7.14	0.06%	
Central	6,591	15.61	3	5.25	0.05%	14,066	16.34	15	16.19	0.11%	15,226	16.66	28	21.05	0.18%	7,438	16.76	11	18.64	0.15%	
East	13,039	30.87	24	50.00	0.18%	24,553	28.52	37	39.78	0.15%	26,550	29.04	59	44.38	0.22%	13,175	29.88	27	48.21	0.20%	
VA-Unk	933	2.21	0	0.00	0.00%	201	0.23	0	0.00	0.00%	144	0.16	0	0.00	0.00%	6	0.01	0	0.00	0.00%	
Not VA	1,077	2.55	1	2.08	0.09%	2,299	2.67	2	2.15	0.09%	2,527	2.76	6	4.51	0.24%	1,312	2.96	0	0.00	0.00%	
Unk	280	0.66	2	4.17	0.71%	1,506	1.75	3	3.23	0.20%	1,104	1.21	2	1.50	0.18%	336	0.75	1	1.79	0.30%	
TOTAL	42,232	100.0	48	100.0	0.11%	86,098	100.0	93	100.0	0.11%	91,434	100.0	133	100.0	0.15%	44,388	100.0	56	100.0	0.13%	
	Aug 1989 - Feb 1990					Jul 1990 - Jun 1991					Oct 1991 - Sep 1992					Oct 1992 - Mar 1993					
	TOTAL																				
	Tested	%	Pos	%	Seropositivity																
NW	32,640	12.36	12	3.64	0.04%																
North	59,895	22.67	64	19.39	0.11%																
SW	39,252	14.86	33	10.00	0.08%																
Central	43,321	16.40	57	17.27	0.13%																
East	77,317	29.27	147	44.55	0.19%																
VA-Unk	1,284	0.49	0	0.00	0.00%																
Not VA	7,215	2.73	9	2.73	0.12%																
Unk	3,226	1.22	8	2.42	0.25%																
TOTAL	264,150	100.0	330	100.0	0.12%																
Virginia Department of Health, Bureau of STD/AIDS																					

Virginia's Survey of Childbearing Women

HIV Seroprevalence by Region



APPENDIX H

Virginia's Survey of Childbearing Women

Virginia's Survey of Childbearing Women is currently in its fourth year of data collection. Survey dates and types of samples included are as follows:

Phase 1: August 1989-February 1990: Full term births normal on all newborn screening.

Phase 2: July 1990-June 1991: Full term and premature births normal on newborn screening.

Phase 3: October 1991-September 1992: All births including those abnormal on newborn screening.

Phase 4: October 1992-September 1993: All births including those abnormal on newborn screening. (Data for this time period is complete from Oct 1992 - Mar 1993.)

Phases 3 and 4 follow the CDC protocol for collecting data on all births in the state and can be compared. Phases 1 and 2 are not directly comparable to phases 3 and 4 without accounting for the differences in sample collection.

Race: The racial group at highest risk throughout the survey has been black. A total of 58,540 samples from black women have been tested with 224 samples (0.38%) testing positive for HIV antibodies. This compares to a seropositivity rate of 0.13% for the entire sample and 0.04% (66 positive out of 166,831 tested) for samples from white women. While the rates for whites have been consistent (or declined slightly) over the four survey phases (0.06, 0.04, 0.04, 0.03), the rates among blacks increased significantly during the first three phases and the rates during the fourth phase are currently similar to phase 3 (0.24, 0.35, 0.45, 0.43).

Age: While there have been no significant changes with regard to mother's age during the survey, phase 3 should be noted for two trends that were not evident in the first two phases. First, the total number of HIV positive 15-19 year old women bearing children during phase 3 exceeded the total number of 15-19 year old women reported positive in both phase 1 and phase 2, and the Seroprevalence rate for this age group exceeded the rates for all age groups except the unknown and under 15 age groups. Second, the phase 3 trend towards younger HIV positive females was enhanced by the rate within the "under 15" age group (0.43%).

Region: The HIV seroprevalence rate has consistently been highest among women residing in the Eastern Region, although this difference is directly associated with race.

Birth Type: Since the inclusion of premature births during phase 2 and the inclusion of all births during phases 3 and 4, information on type of birth (full term vs. premature, newborn screening (NBS): normal vs. abnormal) has been collected. The HIV seroprevalence rate has been significantly higher among women giving birth to premature babies during phases 2-4; and the rate among women giving birth to babies testing abnormal on one or more of the newborn screening tests was significantly higher than the rate among women giving birth to babies testing normal on NBS during phase 3. Again, however, this difference was associated with race.

COMPREHENSIVE AIDS FAMILY CARE CENTER: A Model Treatment Program in the Bronx

A diagnosis of AIDS hits all families hard. But it's especially difficult for families who have lived with loss, poverty, and a sense of depression and hopelessness even before the HIV or AIDS diagnosis. Additional problems of single parent families, widespread drug use, and the fact that many of the children may also suffer from cancer or hemophilia (if they acquired HIV from contaminated blood products) present program providers with a complex range of issues that must be addressed, both medically and through supportive efforts on behalf of the families.

In 1981, Dr. Arye Rubinstein, Director of Allergy and Immunology, at Yeshiva University's Albert Einstein College of Medicine in the Bronx, New York, diagnosed the first suspected case of pediatric AIDS in the United States. Three years later, he established the nation's first pediatric AIDS center. And later, the Comprehensive AIDS Family Care Center developed as the complexities of dealing with both the medical and psycho-social issues associated with pediatric AIDS became manifest. A coordinated team effort among pediatric immunologists, social workers, nurses, and health planners, the family-centered program has been recognized as a model for the care of AIDS-affected families.

As of October, 1992, there were 242,146 diagnosed cases of AIDS nationwide, according to the Center for Disease Control; 4,051 of these were among children under the age of 13. The number of people estimated to be HIV-infected is about four times that number — nearly one million.

The number of HIV-positive newborns is the highest in the country in the Bronx, where the AIDS Family Care Center is located. Defining family members as "anyone who has close social contact with an HIV-infected woman or child," the Center treats patients referred by all the surrounding hospitals and community agencies.

To date, the Center has treated more than 3,000 HIV-diagnosed individuals. Currently, there are 350 children in treatment at the Center, as well as 150 pregnant women involved in federally sponsored experimental drug trials (since 1989, the Center has housed the National Institute of Health's AIDS Clinical Trial Group).

A child with AIDS signals an entire family at risk, says Anita Septimus, M.S.W., the Center's Director of Social Services.

Intravenous drug use is associated with over 70% of the families, many of whom are at the poverty level; 80% are from minority backgrounds. When an HIV-positive infant is identified, the mother often simultaneously discovers that she is also infected, and that she has infected her child. Sometimes, the adults are as sick or sicker than their children. The Center offers them all coordinated care under one roof, provided by a consistent group of professionals with whom they may be able to build some level of trust.

"People are reluctant to divulge the fact that they have AIDS, as they might be willing to do if they had cancer," says Septimus. The stigma associated with an AIDS diagnosis breeds isolation among a group that is already isolated and vulnerable. "A family-centered approach helps minimize isolation, and the continuity of treatment providers is crucial — the same doctor, nurse and social worker may serve the entire family. These families don't want to have to repeat their stories over and over again."

The Family Center's multidisciplinary staff consists of an administrator (Septimus); 8 pediatric immunologists; 6 nurses; 4 social workers; a pregnancy study coordinator and three support staff. Because the Center serves a multi-cultural community, Septimus strives for the same diversity in the staff and as many bilingual health professionals as possible. "We are sensitive to cultural issues, and that helps us serve the community better," she says.

The Center's family support component consists of eight major service areas:

- Information and referral services identify the appropriate medical and mental health care treatments for a family.
- Psychosocial assessments evaluate the type and number of mental health care services a family may need.
- Crisis intervention provides immediate services for suicidal patients, help for emergency shelter needs, and grief counseling.
- Weekly support groups provide mothers, primary caregivers, and siblings with support and problem-solving techniques.
- Family therapy is designed to help families improve communication and develop adaptive ways of operating as a unit. It helps families to restructure themselves, while respecting the prevailing kinship system, sibling roles, and generational hierarchy.
- Outreach and advocacy programs help families negotiate public assistance agencies, and provide school advocates, legal interventions, substance abuse outreach, protective and foster care, and necessary social and financial supports.
- Treatment coordination insures that patients will keep their medical appointments and followups.

The Center also organizes summer camp programs; arranges for members of the hospital's Clown Care Unit to visit weekly the inpatient children who are receiving IV Gamma Globulin treatments; takes part in funerals and memorial services; and organizes holiday celebrations. These efforts help both patients and health professionals to see one another as people.

Spending time together also gives the professionals more opportunity to educate parents and caregivers in the complex tasks of helping their children maintain optimal health.

Septimus emphasizes some key issues to consider concerning support for AIDS-affected families. "We need to pay particular attention to non-infected siblings, since they're going to lose a brother or sister and a parent. They're the future orphans of AIDS." She also points to the need to provide emotional (and in-home) support for the grandmothers "who are supporting both a dying daughter and grandchild. That way, they'll be more prepared when the time comes," says Septimus.

The Comprehensive AIDS Family Care Center charges no service fees. Most patients are on Medicaid or receive aid through a variety of social services in the community (the state Human Resource Administration, for example, provides housing entitlements for individuals with AIDS). The Center receives funding from a number of federal, state and city sources, including the New York State Department of Health, the National Institute of Health, and COBRA, a case management refund program. In New York City, AIDS has become the leading cause of death for women aged 25 to 35. Since women are more likely to contract AIDS heterosexually than men, the overall implications for the future of pediatric AIDS are alarming. Septimus urges counseling and AIDS awareness. "An effort must be made to lessen the stigma so people can seek the care they need. We can't afford the luxury of ignoring AIDS."

Christine Vogel is staff writer for the Family Resource Coalition.

APPENDIX J

CONCEPTUAL FAMILY HIV/AIDS SERVICES PROGRAM

HOSPITAL OUTPATIENT AND INPATIENT SERVICES

PHYSICIANS

Pediatrician with Infectious Disease Specialty
Adult Infectious Disease Specialist
Obstetrics and Gynecology

NURSES

Clinic Nurses (1 or more)
- Perform patient treatments, etc.

Inpatient nurses

Clinical Nurse Specialist
- Provide patient education, i.e., transmission
birth control, etc.

SOCIAL WORKER

Medical Social Worker (1 or more) mostly for outpatient services

SUBSTANCE ABUSE COUNSELOR

Counselor during clinic (Utilize counselor from Community Services Board
in geographic area in which the patient lives).

EDUCATIONAL CONSULTANT

Liaison between the multidisciplinary medical team and the school in which
the patient attends. Arranges training of school personnel and students
on HIV transmission, universal precautions, etc.

NUTRITIONIST

Clinic nutritionist
Inpatient (Hospital) nutritionist

RESPIRATORY THERAPIST

Therapist during clinic to teach family

CLINIC AIDE

CHILD CARE

- Volunteers to watch siblings while mother is being examined and while patient getting treatments.
- Play Therapist for inpatient services

CLERKS

- Register clinic patients
- Maintain patient records
- Schedule tests/hospitalization/etc.

NOTE: Clinic space must have enough rooms to house the multidisciplinary team and to have an isolation area.

CASE MANAGEMENT SERVICES

Health Care professional with clinical knowledge of HIV/AIDS

- Provides continuous assessment, coordination and monitoring of services and needs
- Is available to family for problem-solving
- Makes referrals to local resources
- Provides education to family regarding HIV/AIDS, treatment, etc.

SUPPORT SERVICES

Transportation to/from medical care (payment of tolls, taxi/bus/train fares)

Therapist for family coping/emotional/psychological care/group dynamics/support groups.

Respite care

Personal care in the home when at-risk for hospitalization

Private Duty Nursing in the home

Nutritional supplements

Bereavement Counselor

Hospice

Developed July/August, 1993 by HJR 691 Study Team.