



## DC Family Policy Seminar

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# “HIV/AIDS: Helping Families Cope”



## *BACKGROUND BRIEFING REPORT*

*The DC Family Policy Seminar aims to provide accurate, relevant, non-partisan, timely information and policy options concerning issues affecting children and families to District policymakers.*

*The DC Family Policy Seminar is part of the National Network of State Family Policy Seminars, a project of the Family Impact Seminar, American Association for Marriage and Family Therapy Research and Education Foundation.*



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# **“HIV/AIDS: Helping Families Cope”**

## *BACKGROUND BRIEFING REPORT*

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# “HIV/AIDS: Helping Families Cope”

This seminar is the sixth in a series designed to bring a family focus to policymaking. The panel features four speakers:

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This seminar focuses on the compelling needs of families with children in which one or more persons are infected with the human immunodeficiency virus (HIV). This background report summarizes the essentials on several topics. First, it provides an introduction to the impact of HIV/AIDS on the family. Next, it briefly describes key issues involved in family-centered comprehensive care for families with HIV/AIDS infection. An annotated list of medical and social service programs for families with HIV/AIDS is included in the report as well as a list of important telephone numbers.

## Introduction

“A person with AIDS is not the sole victim of the disease. AIDS has a rippling effect that touches and alters the lives of family, friends, and neighbors.” (Katherine Foos, “Caring for a Child with Aids”)

AIDS is a great tragedy of our time. Since the first cases were reported in June 1981, 440,000 individuals have been diagnosed with AIDS in the United States. As of June 1994, 243,423 people have died from the disease. According to the Centers for Disease Control and Prevention (CDC), as many as 1 million other people have been infected with the human immunodeficiency virus (HIV)—the virus that causes AIDS. Eventually, almost all these people will die from AIDS.

The District of Columbia has been hit hard by this disease. (Detailed statistics of AIDS for the District are contained in Appendix One.) Over 7,000 AIDS cases have been reported in the District; 50 percent were diagnosed in the past three years (Agency for HIV/AIDS, 1). The actual number of persons with AIDS—and persons who will eventually get AIDS—in the District is much higher. An unknown number of District residents have contracted HIV but do not yet show symptoms of AIDS, while other AIDS cases have not yet been reported (Agency for HIV/AIDS, 1).

AIDS does not discriminate by race, gender, or age. Yet minority groups have been especially afflicted. African-Americans represent 12 percent of the nation's population but 32 percent of its AIDS

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cases; Hispanics represent 9 percent of the population but 17 percent of AIDS cases (as of June 1994; GAO, 1). More than half of the newly reported AIDS cases between July 1993 and June 1994 were African-Americans and Hispanics. The proportion of AIDS cases in women also continues to rise: almost 20 percent of the newly reported AIDS cases are female. Children constitute a relatively small, but especially tragic, portion of the population with AIDS. Since 1981, the U.S. has had 5,734 reported cases of AIDS in children under age 13.

In the District, more than two-thirds of the persons with AIDS are African-American, 28 percent are white, and 3 percent are Hispanic; women account for about 12 percent. More than 100 children under 12 years of age (or 1 percent of the total) have been diagnosed with AIDS.

In developing public policy for families and AIDS, two facts are most important:

- \* AIDS cannot be cured and it almost invariably kills.
- \* AIDS can be prevented.

## The Impact of AIDS on Families

“HIV infection in children is a family affair.”  
(Child Welfare League of America)

Every person who contracts HIV has been someone’s child; most are brothers, sisters, lovers, or spouses; many are or will become parents. No case of AIDS leaves a family untouched.

In this report we will focus on families with children in which father, mother, child, or all three have AIDS. We focus on these families not because they are more special than others, but because they have unique challenges and complexities.

AIDS often spreads through families. While HIV cannot be passed through casual contact, men and women can infect each other through unprotected sexual intercourse; infants can be infected through their mother’s womb (perinatal transmission). Family members can also infect each other

by sharing needles to inject drugs. In the District, as well as nationally, about 65 percent of AIDS cases contracted HIV through sexual contact, 30 percent through sharing needles, and 1 percent through exposure in the womb.

In some families one or both parents have AIDS but the children are not infected. These parents face all the “normal” (that is to say, extraordinary) difficulties of any person with AIDS. They must obtain health care; secure income, housing, and food; and prepare emotionally and financially for their lives and deaths. Parents with AIDS face an additional burden: While they are alive, they must provide for the physical and emotional security of their children realizing that they are unlikely to raise their children to maturity—certainly one of the most difficult realizations for any parent (Pinott, 75).

The surviving children have their own hardships. Children whose parents die of AIDS are often affected by the stigma, secrecy, and denial associated with AIDS in addition to the already enormous grief typical from the loss of a parent (Levine, xiii). They must also often learn to adapt to a new home environment as they begin living with other family members, in foster homes, or in orphanages.

The number of children whose parents have AIDS is large and growing. The CDC predicts that, unless the epidemic changes dramatically, by the year 2000 more than 80,000 children and adolescents in the U.S. will be motherless (Levine, 9). In addition, the CDC predicts that between 1992 and 2000, another 93,000–112,000 uninfected children will be born to HIV-infected mothers.

AIDS will leave many District youth orphaned. Already an estimated 500–800 children and adolescents in the District have lost their mothers to AIDS. By the year 2000, these numbers will more than double (Levine and Stein, 22).

In some families, parents and children are both infected with HIV. The infant who contracts HIV

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in the mother's womb faces extraordinarily difficult circumstances. The fact that the child is infected usually indicates that the parents have their own major problems; the mother must also be infected.

During the 1990s, an estimated 32,000–38,000 infants will be born infected with HIV (Michaels and Levine, 10). Nationally, in almost half the cases of perinatal transmission the mother injects drugs; in a quarter of the cases, the mother was infected through sexual contact with an IV drug user; in most of the remaining cases the mother was infected through sexual contact with a person also infected through sexual behavior.

Few mothers would knowingly pass HIV to their children. Often, however, the mother does not realize that she has been infected. In too many cases, "the first indication of HIV infection for the mother may be an infant who fails to thrive and has frequent infections" (CWLA, "Task Force," 2).

Most young children (80 percent) infected with HIV were exposed to the virus in the womb. Most other HIV-positive children were infected when they received transfusions of tainted blood. (Fortunately, there should be few cases of this in the future due to careful screening.) A small number of young children become infected through incest or sexual abuse by an infected male. "Sexual abuse, substance abuse, and HIV infection can coexist in a familial setting" and increase the risk of transmission to other family members (CWLA, "Residential Group Care," 8).

Although most infected infants contract HIV in the womb, it is important to note that about 75 percent of babies born to HIV-infected women are not infected. If infected women receive proper medical treatment (e.g., AZT therapy), the risk of perinatal HIV transmission falls from 25 percent to 10 percent.

Among adolescents (youths 13–19), HIV is predominantly spread through drug use and sexual behavior (Wells, 237). Although adolescents

account for fewer than 1% of AIDS cases, most of those who develop AIDS between 20 and 29 years acquired the disease in their teens. AIDS among adolescents is growing because this age group participates in a number of risk-taking behaviors such as drug use and sexual experimentation. "During the period of biologically heightened sexual awareness, initiation into a variety of sexual practices may include heterosexual, bisexual, and/or homosexual experimentation. Inexperience in the use of condoms, faulty sex education, and lack of appreciation of sexual responsibility may enhance the risk of exposure to HIV-infected persons" (CWLA, "Residential Group Care," 8). It is especially difficult to reach the individuals at greatest risk of contracting HIV: out-of-school youth, homeless youth, runaway youth, and "throw-away" youth (Wells, 236).

What happens to children with HIV? According to Novello and Allen, "most pediatric cases occur in a setting of profound social disruption. In addition to poverty and lack of familial or community support, the child's health care needs may be compromised by overriding concerns regarding adequate food, housing, and transportation" (19). In addition, children develop AIDS symptoms sooner after infection and the disease progresses more rapidly than in adults. In adults, AIDS symptoms may not appear for as long as 11 years after infection, while children usually show symptoms by their second birthday (CWLA, "Family Day Care," 7). However, some children live a number of years without showing infection, and the true incubation period of AIDS in children is not yet known (CWLA, "Foster Care," 11). The majority of these children do not live with their own parents; some 60 percent of children with AIDS are cared for by extended families, foster parents, or adoptive parents; about 40 percent are cared for by their mothers (Foos, 31).

What happens to children whose parents have AIDS? It is hard to imagine anything that places more strain on families than AIDS does. It brings together the worst possible combination of poor

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health, emotional tension, and economic stress. Because families are so challenged by this disease, public policy is challenged to address HIV/AIDS through the family.

## Public Policy Towards AIDS in Families

“Families with HIV-infected children frequently are poor and members of a minority community, with limited access to services, transportation, and housing; most have a history of drug dependence or exposure to drug users; and there is generally more than one family member who is infected or ill, often a mother too ill to care for her children.” (Former U.S. Surgeon General Antonio Novello and Director of National AIDS Program Office James Allen.)

The two most important questions about AIDS for policymakers are:

- \* How can AIDS be prevented?
- \* How can the suffering caused by AIDS be reduced?

In the best of circumstances, answering these questions would be difficult. The circumstances of the District are by no means ideal. In the District, families with children affected by AIDS tend to be more troubled and have fewer resources than most other families. The District has a budget crisis: The demands for its funds far outstrip the supply. The District thus faces hard choices about how best to help families where AIDS is already present while it attempts to stop the further spread of AIDS. Both are expensive and difficult. In this section, we briefly examine efforts to include families in the answers.

### ***Preventing AIDS***

There is no cure for AIDS, nor is there likely to be one in the near future. Currently, no medical means (such as vaccinations) can prevent the spread of AIDS. The only way that mature family

members can avoid contracting HIV is to refrain from behaviors that might expose them to the virus. The only ways that infants can be protected is for their mothers to avoid the virus or take early steps to try to prevent perinatal transmission.

This means that family members must neither have unprotected sexual intercourse with those who have been exposed to HIV nor share unsterilized needles. Because it is so difficult for an individual to know who has been exposed to HIV, family members must be made aware that sharing needles or unprotected sexual contact (outside of a monogamous relationship with an uninfected partner) puts them at risk of contracting HIV. “Since HIV infection is contracted generally through high-risk behaviors [e.g., sharing needles or sexual intercourse without condoms], education and intervention aimed at changing those behaviors must be the first line of offense” (CWLA, “Family Day Care,” 34).

Primary and secondary prevention programs are both necessary. Primary prevention programs must convince uninfected family members not to share needles or have unprotected sex except with an uninfected partner. The principle task of secondary prevention programs is to deter those who are HIV-infected from spreading the virus to other family members.

Each adult family member must bear responsibility if infection is to be escaped. Both the man and woman must take care to avoid being exposed to the virus and, if exposed, to not put the uninfected partner at risk. Females must take extra care that they do not pass the virus to their children.

The issue of IV drug use bears special attention. As noted above, perhaps 75 percent of the time that an infant contracts HIV either the mother or her sexual partner uses IV drugs. In many cases, the mother first becomes aware that she is infected when her baby develops symptoms. This is especially unfortunate because, if a woman knows she has HIV, she is in a better position to make an informed decision about whether to bear a child

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and to obtain the prenatal care that can reduce the risk that the child will be infected.

To reduce the spread of AIDS within families (and, in particular to limit the number of infants who contract HIV), three actions merit particular attention:

1. Those that reduce the chance that a person will contract HIV through IV drug use. This can be done by helping drug users either to stop injecting drugs or to use clean needles when they do;
2. Those that encourage IV drug users, especially women of childbearing age, to take blood tests determine if they have been infected with HIV;
3. Those that help infected pregnant women to obtain prenatal care that reduces the risk of passing the virus to their babies.

No single prevention program works for everyone. To be successful, prevention programs need to speak to individuals and families in understandable and persuasive ways. Sensitive subjects such as drug use, family violence, and safer sexual activity, cannot be avoided. According to Novello and Allen, “the link between HIV infection and poverty—the disproportionate infection rates in inner city communities—also necessitates prevention approaches that deal directly with issues of minorities, their culture, and their economic conditions” (23).

Testing and counseling services, especially for women and children, are an important way to augment prevention efforts and may ensure early medical care. Early diagnosis can prevent the spread to others, possibly delay disease progression, and prevent other infections (Novello and Allen, 22). Testing and counseling might be most helpful if linked with other services so that HIV-positive children and families have access to high quality services.

Confidentiality regarding the woman’s and child’s HIV status is essential to any testing

program. According to Novello and Allen, “disclosure of test results may cause infected individuals to lose their homes, their jobs, their insurance, and their social contacts. Children may encounter increased difficulty in finding school placement” (25).

### ***Reducing the Suffering from AIDS***

No matter how successful AIDS prevention programs are, the number of families affected by AIDS will continue to grow during the coming years. In the District, many of these families will have a long list of medical, social, educational, and legal needs. To reduce the suffering of these families, we must consider how a range of medical and social services might best be provided to them.

**Health Care.** Any person with HIV or AIDS faces challenges in obtaining affordable, quality health care. When two or more persons in a family have AIDS—and especially if family members also have drug problems or are poor—the challenges are enormously greater. Our nation’s medical system is not designed as a family-centered institution. Care systems that focus on an individual patient are neither comprehensive nor fluid enough to meet the myriad needs of families undergoing multiple traumas. The specific needs of individual family members do not always mesh easily with those of others in the family.

Individuals making provisions for their families need to establish relationships with service providers that are built on trust and a mutual concern for the entire family’s welfare (Perryman, 69-70). Public officials need to establish family-centered, community-based, and coordinated health care for these families (Boland, et al., 3). Standards worth considering in providing such health care include:

1. Health care should include child and family participation, so that all family members can receive treatment as appropriate;
2. Health care should be planned and coordinated;

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3. Health care should be comprehensive, so that family members may obtain health maintenance services and primary care as well as home- and hospital-based services; and
  4. Health care should be accessible and affordable.

Clinical research has shown that the quality and duration of life for children and adults can be improved through specific therapies for HIV-related illnesses. Use of the antiviral agent AZT (azidothymidine or zidovudine) may reduce a variety of symptoms of AIDS (Novello and Allen, 26). HIV-infected infants and children are more susceptible to a number of infections than HIV-infected adults. A child's health status needs to be carefully monitored. Clinical centers that treat HIV-infected children and their families have found that mothers faced with conflicting demands of time and energy often focus their efforts on the medical needs of their infected children at the expense of their own health. Neglect of her own health, ultimately reduces the mother's ability to care for her child. Consequently, "one-stop shopping" is critical for all families so they can receive coordinated care from the same source (Novello and Allen, 27).

**Basic Support Services.** If families affected by HIV/AIDS are to be able to care for their children at home, then they often need "in-home support services." In-home care includes home health services; nutritional support and homemaker services; nursing services to monitor medication and provide direct patient care; respite care; social work support and counseling; and hospice care (Novello and Allen, 30). Family members and friends can be taught in-home support service skills in order to aid in the care of an HIV-infected family member.

Caring for children at home is often more humane and cost-effective than caring for them in hospitals. Unfortunately, in-home services are least available in the inner-city communities. Paying for such services is often difficult and varies from state

to state. Child care is an essential service for the social development of children while their parents address their own health care and service needs to enable them to keep their child at home.

Nutrition is also very important for children and families suffering from HIV/AIDS. For infected children and adults, illness may lead to appetite loss and increased metabolic demands. Parental illness can also make the preparation of nutritious meals difficult. Nutrition support can build upon existing programs such as Women, Infants and Children Nutritional Supplemental Program (WIC) and school meal programs (Novello and Allen, 31).

Housing is another critical need for HIV-infected children and families. Housing can be difficult to find for reasons related to social problems such as poverty, family violence, drug abuse, and community fear and ignorance about HIV. As a person becomes increasingly ill as the AIDS progresses, housing with significant supervision and homemaker services are needed (Novello and Allen, 31).

Transportation is another concern for children and families with HIV infection. Many HIV-infected individuals do not own or have access to cars. HIV-related illnesses or disabilities can also limit the extent to which an individual can use public transportation, and cabs may be prohibitively expensive. Therefore, the provision of transportation is important to enable families to participate in medical and service programs.

**Developmental and Educational Services.** Children with HIV often suffer from a variety of developmental disabilities. Pediatric AIDS has become so widespread that HIV infection will likely become the primary "infectious" cause of developmental disabilities and neurological impairment in children. Most (perhaps 80 to 90 percent) children with AIDS have some kind of central nervous system dysfunction. Poverty and parental drug use also increase the likelihood that infected children will experience developmental problems (Novello and Allen, 27-28).

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Children with HIV infection are candidates for developmental and family support services known as “early intervention” under the Education of the Handicapped Act Amendments of 1986 (although ultimately, it is up to the individual state to decide which children and families are eligible). Head Start is another program for preschool-age children from low-income families that can provide comprehensive developmental services for HIV-infected children and their families. By law, ten percent of Head Start enrollment is reserved for children with special needs, which includes children with HIV infection and their families (Novello and Allen, 28). The Education of the Handicapped Act and Section 504 of the Rehabilitation Act of 1974 establishes the right of all children in the U.S. to a free public education, regardless of disability—an education in the “least restrictive environment.” Therefore, no HIV-infected child can be denied access to public education. This right is vital because school attendance often plays a critical role in a child’s well-being.

**Mental Health Services.** All aspects of child psychosocial development are threatened by HIV/AIDS. All things considered, development is often easier if children have normal contact with members of their family and community and avoid extended hospital stays. A child’s sense of self might be better encouraged if the child has some independence, mobility, and ability to take care of himself or herself. With this in mind, Novello and Allen (30) provide five goals for mental health service programs for families:

1. Monitor developmental delays;
2. Reduce HIV-related distress and associated dysfunctions in the home, school, and interpersonal relationships;
3. Increase adherence to medical treatments;
4. Treat pre-existing or recently developed psychopathology, including depression, anxiety, maladjustment, and mental disorders; and
5. Provide family support.

Families dealing with HIV and death are often reluctant to turn to traditional community mental health sources for counseling. Secrecy, shame, and stigma are powerful in themselves, let alone coupled with financial troubles, housing difficulties, and institutionalized racism (Dane, 67).

**Social and Legal Services.** Families with HIV infection may need a range of legal and advocacy services. Parents who have AIDS may need to prepare wills and medical powers-of-attorney, make legal arrangements for custody, and fight discrimination. State protection and advocacy agencies provide legal services to protect the rights of developmentally disabled persons with HIV infection. In addition, many other state bar associations, legal aid societies, and law schools engage in pro bono work (Novello and Allen, 32).

When children are placed in foster care, the agency is legally responsible to plan the children’s future—whether to return a child to the biological parents, identify appropriate kinship care placements, terminate parental rights, arrange for adoption, and prepare older children to live independently (CWLA, “Foster Care,” 29). It is a federally mandated requirement (from public law 96-272) that the child welfare agency should use “reasonable efforts” to keep families together—even if HIV is involved. The child welfare agency must try to provide services—such as homemaker services, transportation services, and respite care—to enable families to keep the child at home. Yet it is not always possible for children who have HIV to remain with their own families. Some parents are unable or unwilling to care for the child at home (CWLA, “Foster Care,” 30).

Although most children with HIV live at home with their biological families or extended families, 10 to 30 percent live in foster homes. Foster and adoptive parents, like biological parents, need a variety of support services to care for HIV-infected children at home. State health departments work with child welfare agencies to develop policies that facilitate family-centered care for children and families with HIV.

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When both parents are ill, custody proceedings are necessary. Parents making custody decisions have a range of legal options. Parents can transfer child custody to other individuals. “Nothing can take away the pain of planning for another person to raise one’s children. But the law, combined with social services and counseling, can help make the process more compassionate, clear, and effective. When custody planning is in place, parents can go forward, leading their lives loving their children, knowing that their future is assured” (Pinott, 84). Parents transfer their rights to make day-to-day decisions concerning their children and relinquish their right to have their children in their physical care—though parental rights are not terminated (Pinott, 80). Changes in family law allow the appointment of a standby guardian who would only assume guardianship when the parent dies, becomes mentally or physically incapacitated, or chooses to start guardianship for another reason (Pinott, 81). Parents should choose individuals who are responsible and have sufficient emotional and financial resources to care for their children (Pinott, 81).

Coordination of social and medical services is imperative for family foster care placement of HIV-infected children. It is a complex disease that requires partnerships among child welfare agencies, the health care system, the child, the foster family, and, ideally, the biological family, for support and continuity of care (CWLA, “Foster Care,” 15).

## **The Challenge: Creating a Comprehensive System of Care**

“Because the needs of children, youth and families affected by HIV infection fall within the purview of many agencies, families face the often difficult task of integrating multiple services. Coordinated planning and program development are needed at the community level to facilitate delivery of care. These activities require close collaboration, ongoing consumer and professional involvement.” (Boland et al., 60)

If families with HIV are to be helped, interagency collaboration is essential. Often the state health agency has the first access to children, youth, and families with HIV. The agency’s responsibility is to provide consultation to the range of public and private agencies offering a variety of services (Boland et al., 50). “The need to enlist primary care providers into the delivery of care to families with HIV infection and to ensure integrated care for infected parents and children and affected siblings necessitate creative approaches to systems development” (Boland et al., 40). Public, private, and voluntary organizations must coordinate programs to ensure integration of services (Boland et al., 61). It is very important to ensure a link between the family and community organizations. These links give support to the caregiver (Nehring et al, 217) and lead to better outcomes. Caregivers should be community based. Community agencies should include social service providers, mental health clinics, organizations serving developmentally disabled clients, community-based AIDS organizations, agencies that serve runaway youths, and juvenile justice agencies, religious organizations, and women’s groups (CWLA, “Foster Care,” 16). “The problems associated with poverty, chronically limited access to health care, and drug use make it particularly challenging to provide for the social service and medical needs of HIV-affected families; a family-centered, comprehensive, coordinated approach to service delivery is required” (Harvey et al., 3).

## ***Community Support***

Some communities have developed comprehensive systems of care for children with HIV and their families. Families affected by HIV are increasingly a part of every community. Communities, however, vary in the degree to which they provide services. A key strategy for strengthening community support is to increase public awareness of: 1) the developmental needs of all children, 2) the specific needs of children and youth with chronic illness or disability, including those with HIV

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infection and their families, 3) specific resources needed for children, youth and families affected by current gaps in services, and increases awareness of the need for comprehensive care to support children and families.

### ***Coordinating Care System***

Not only should the system of care be coordinated but the individual services that families receive should be coordinated. Case management is often the vehicle for coordination to ensure that children and families have access to all needed services. Children, youth, and families should receive primary care services from a community-based provider with access to specialty care providers. They should have choices among community-based providers and the services chosen should be coordinated. In addition, home-based care should be available when appropriate (Boland et al., 16).

The health care team is responsible for coordinating care with schools and/or other educational or employment services (Boland et al., 24). The health care team should work within the community to “develop services which meet the medical and social needs of children, youth and families. The continuum of care includes supports such as day care, respite, temporary foster care, and hospice services when needed by the family, youth or child” (Boland et al., 25).

### ***Financing Family-Centered Comprehensive Care for Family with HIV/AIDS***

Preliminary data suggests that the lifetime direct medical care cost for pediatric HIV/AIDS costs about \$50,000 per child. Much of the total cost is due to inpatient services, which are more frequent for children than adults in the final stage of illness. The U.S. Health Care Financing Administration estimates that, “nationally, Medicaid serves at least 40 percent of all AIDS patients and up to 90 percent of all children with AIDS” (Novello and Allen, 40). Costs are likely to

increase as more expensive experimental drug therapies are used and lives are extended. Community-based care continues to contain costs by reducing hospitalization (Novello and Allen, 40). State health departments should work with state insurance commissions and third-party payers to ensure appropriate health coverage for infected individuals. Children with HIV need coverage for “home care, long-term and school-based care, hospice, mental health services, nutritional services and products, rehabilitative and adaptive equipment and services and disposable medical supplies and diapers” (Boland et al., 53).

### ***Locating and Integrating Funding***

Given the scope of services needed to care for HIV-infected children and families, funding for such services comes from a variety of sources. Integrating streams is complicated by the limited flexibility of various federal entitlement programs, block grants, and discretionary grants. Communities need to access funds from federal, state, and local government sources; foundations; businesses; and volunteer efforts (Novello and Allen, 40).

### ***Federal Sources***

Congress has enacted legislation to provide funding for programs and services to children and families affected by HIV/AIDS. In 1988, Congress established the Pediatric/Family AIDS demonstration program to serve children, adolescents, and families under the Public Health Services Act. Between 1988 and 1993, the Pediatric/Family AIDS Demonstration Programs were located in 22 states, Washington, D.C., and Puerto Rico. In 1990 Congress passed the Ryan White Comprehensive AIDS Resource Emergency Act, which provides funds for family-centered care for women, children, and families with HIV infection. In 1993, the Pediatric/Family AIDS demonstration program was consolidated in the demonstration program in section 2671 of Title IV of the Ryan White CARE Act (AIDS Policy Center, 3).

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Medicaid, U.S. Public Health Service Programs, and Federal Human Service, Education, and Nutrition Programs also appropriate a substantial amount of funds to medical and service costs related to family-centered services for HIV/AIDS patients.

### ***State Sources***

States also are involved in helping families with AIDS. The extent often relates to the number of cases in the particular state. States are actively involved in coordination of the delivery of services to children and families with HIV. States also innovatively use federal resources. In addition, states collect information about AIDs and sponsor AIDS clearinghouses.

### ***Private Support***

The private sector also contributes to the provision of services for children and families with HIV/AIDS. According to Novello and Allen, "collaboration among the public sector, private foundations, and community-based organizations may be the only way to build a comprehensive, integrated system of care for children and families with HIV/AIDS" (55). According to the Foundation Center, over 150 foundations have made AIDS-related grants. Robert Wood Johnson Foundation has awarded more than 127 grants totaling more than \$50 million to health care facilities to improve AIDS care and HIV prevention. Other active organizations include the Pediatric AIDS Coalition, the Pediatric AIDS Foundation, the Foundation for Children, the Child Welfare League, the National Foster Parent Association, the Association for Care of Children's Health, the American Cancer Society, the National Community AIDS Partnership, countless church organizations, and many others (Novello and Allen, 56-57.)

### **Conclusion**

HIV/AIDS affects our communities and families. With proper medical and social service supports,

families can better cope with the effects of the disease. As symptoms develop, it is important that family-centered, community-based, coordinated early supportive care and treatment is available in order to extend life. Policymakers have the responsibility of ensuring that the quality of life for HIV-infected children, youth, and families reflects the best that health care systems, communities, and society can offer (Boland et al., 2).

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*For additional information about the D.C. Family Policy Seminar, or to order copies of the following briefing reports, please contact Kerry Whitacre or Tobi Printz at (703) 524-7802.*

*"Substance Abuse Prevention and Treatment Programs: A Family Approach," February 1995*  
*"Family Friendly Welfare Reform," November 1994*  
*"Preventing Family Violence," September 1994*  
*"Preventing Adolescent Violence," May 1994*  
*"Preventing Teen Pregnancies," December 1993*

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# Resources

## HIV/AIDS and the District of Columbia

HIV/AIDS is a serious problem in the District of Columbia. According to a report by the Agency for HIV/AIDS, as of December 31, 1994, 7,094 cumulative AIDS cases were reported among District of Columbia residents. More than 50% of those cases were reported in the last three years. The greatest relative increases in number of cases per year, from 1988 to 1993, were among females, blacks, heterosexuals with no identified risk factors, and heterosexuals who report injection drug use (Agency for HIV/AIDS, 1-2). The number of cases of HIV infection is unknown but epidemiologists in the District believe the number is increasing.

Despite the growing prevalence of the disease, HIV/AIDS programs and services in the District are in peril. The need for prevention and the demands for family-centered, community-based, coordinated treatment are enormous. Yet the District's fiscal crisis guarantees that the D.C. government will be under pressure to further cut its HIV/AIDS programs and funding. Payments to many HIV/AIDS clinics are overdue, forcing many clinics (such as the Inner-City AIDS Network) to close. It will be difficult to coordinate any budget cuts so that the most needed and effective programs are protected.

Still, there are many reasons for optimism. A variety of public, private, and nonprofit organizations—and many talented and dedicated individuals—in the District offer comprehensive medical and social services for families dealing with the complexities of HIV/AIDS. Currently, the Consortium of Child Welfare meets with HIV/AIDS

care providers throughout the District in an attempt to coordinate services to better meet the needs of families—collaboration that is especially important during the District's severe budget crisis.

The D.C. government offers medical care to all residents in need of medical care, regardless of their abilities to pay, through the District of Columbia General Hospital (DCGH). DCGH provides inpatient, outpatient, emergency, diagnostic, preventative, and rehabilitative services. DCGH provides acute care services for District government-supported, long-term care facilities, such as Saint Elizabeth's Hospital, D.C. Village. The D.C. AIDS Drug Assistance Program (DC-ADAP) finances drug therapies and nutritional supplements to assist District residents living with HIV/AIDS. So far, this program has been unaffected by budget cuts. For more information contact Pat Ferrell at (202) 724-5206. In 1987 the Agency for HIV/AIDS was created in the Commission of Public Health, Department of Human Services, to coordinate policies and funding for programs and projects providing service to HIV/AIDS infected residents (District of Columbia Government, 235-237). The D.C. government also compiles statistical information about all AIDS cases reported in the District. For more information or to get a copy of the report for the D.C. Metropolitan Statistical Area, contact Tanya Williams at (202) 727-2502 of the HIV/AIDS Epidemiology Program of the Agency for HIV/AIDS.

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# D.C. Family Policy Seminar

## HIV/AIDS Organizations and Programs

### April 18, 1995

The following section presents a brief description of resources and programs available within the District of Columbia dealing with HIV/AIDS affected individuals and families. This list is based on information obtained through numerous informal surveys with local organizations and advocates. It does not represent a comprehensive analysis of local resources. Descriptions are included for reference, rather than recommendation purposes. Family-oriented programs are described in italics beneath the sponsoring organization.

#### **Advocates for Youth**

1025 Vermont Avenue N.W., Suite 200  
Washington, DC 20005  
(202) 347-5700

Contact Person: Jennifer Hincks Reynolds

Advocates for Youth (formerly known as The Center for Population Options) focuses on the prevention of teenage childbearing and high-risk sexual behavior. The center's national and international programs seek to aide adolescent decision-making (through life planning and other educational programs), improve access to reproductive health care, promote the development of school-based clinics, and prevent the spread of HIV and other sexually transmitted diseases among adolescents. The organization publishes newsletters, fact sheets and provider- and consumer-oriented publications on adolescent reproductive health. A publications catalog is available.

#### **Agency for HIV/AIDS**

D.C. Department of Human Services  
Commission of Public Health  
Coordination Division  
717 14th Street N.W.  
Suite 600  
Washington, D.C. 20005  
(202) 727-2500

Contact Persons: Jean C. Tapscott, Steve Kilkelly

The Agency for HIV/AIDS in D.C. is operated within the Commission of Public Health, Department of Human Services. The Agency is responsible for the compilation of HIV/AIDS epidemiological data for the District and runs various programs for HIV/AIDS D.C. residents, including programs to aide in accessing HIV/AIDS therapies and nutritional supplements. An HIV/AIDS Epidemiology report for the District of Columbia and the Washington, D.C. Metropolitan Statistical Area is available annually. The newsletter HIV Insider is also available upon request.

#### ***HIV/AIDS Services East of the River Project***

*The Agency for HIV/AIDS, Commission of Public Health, Department of Human Services has begun an AIDS Services Needs Assessment project for neighborhoods located east of the Anacostia River. The HIV/AIDS Services East of the River Project is envisioned to provide a "one stop" center for those individuals and their families affected by HIV/AIDS.*

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**AIDS Action Council**

1875 Connecticut Avenue N.W.  
Suite 700  
Washington, D.C. 20009  
(202) 986-1300

The AIDS Action Council is a national advocacy organization dedicated to shaping AIDS policy. AIDS Action supports and promotes: implementation of a nationally coordinated plan to fight AIDS, the speedy development of urgently needed AIDS treatment, increased federal funding for AIDS programs; nationwide and targeted AIDS prevention counseling, widely available confidential HIV testing and counseling, anti-discrimination protections for people with HIV, and health care reform that meets the needs of people living with HIV/AIDS.

**AIDS Policy Center for Children, Youth and Families**

910 17th Street N.W.  
Suite 422  
Washington, D.C. 20006  
(202) 785-3564  
Contact Person:Jeannie Wong

The Center offers its members the following services: 1) information exchange on clinical, service system design, policy and regulatory information; 2) policy analysis and research related to cost of care, service system design, access to experimental drug research programs, health care reform, and other topics; 3) newsletters and other publications which contain current information on funding notices, advances in HIV therapies and service system design; and 4) a yearly public policy conference where members can come together to exchange information and ideas, receive training on legal and policy issues in the delivery of HIV health and social services, and hear from government officials on policy related topics. The Center also conducts advocacy by monitoring Congressional and federal policy issues and responding to requests from Congress and the Administration for policy recommendations

related to pediatric, adolescent and family HIV services, prevention and research.

**Black Women's Agenda**

3501 14th Street, N.W.  
Washington, D.C. 20010  
(202) 387-4166  
Contact Person:Dr. Margaret White

The Black Women's Agenda, a membership- and coalition-based organization, administers an AIDS education projects directed toward black women and their families. Projects in all areas of public policy focus specifically on high-risk areas and on providing information, training and workshops.

**Center for Women's Policy Studies National Resource Center on Women and AIDS**

2000 P Street, N.W.  
Suite 508  
Washington, D.C. 20036  
(202) 872-1770  
Contact Person:Irene Snow

The National Resource Center on Women and AIDS serves as a resource center for researchers, policy-makers, advocates, and caregivers. The center publishes an annual Guide to Resources on Women and AIDS and an accompanying Action Kit. Through its Woman to Woman publications and workshops, the center assists national women's organizations to put women and AIDS on their agendas and to use their organizing and advocacy skills to serve women in AIDS crisis.

**Child Welfare League of America**

440 First Street N.W.  
Suite 310  
Washington, D.C. 20001-2085  
(202) 638-2952  
Contact Person:David Liederman

The Child Welfare League of America (CWLA) brings together more than 700 public and private nonprofit voluntary child welfare agencies. The

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league sets standards for child welfare practice, proposes public policy initiatives, and provides consultation, training, and technical assistance for its member agencies. Areas of concern include: adolescent pregnancy and parenting, adoption, AIDS, chemical dependency, child abuse and neglect, child care, child poverty, cultural competence, developmental disabilities, foster care, family preservation, homelessness, juvenile justice, kinship care, and residential group care. A publications catalog is available.

**Community of Hope, Inc.**

1417 Belmont Street, N.W.

Washington, D.C. 20009

(202) 232-9022

Contact Person:Lois Wagner

Community of Hope (COH), Inc, is a multi-service, neighborhood-based organization. COH offers a variety of programs which concentrate on the housing, educational, and health needs of the local neighborhood, including HIV/AIDS affected families and individuals. These programs respond to the spiritual and temporal needs of people, and are intended to help families and individuals overcome socio-economic constraints and become self-reliant.

**Consortium for Child Welfare**

4406 Georgia Avenue N.W.

Washington, D.C. 20011

(202) 723-3211

Contact Person:Tom Wells

The Consortium is composed of twelve non-profit family serving agencies for the Washington, D.C. area and provides a variety of services through the collaborative efforts of the member agencies. Its main purpose remains “to develop, strengthen and improve services to children and their families in the D.C. child welfare system.” The Consortium is concerned in issues relating to HIV/AIDS orphans, permanency planning, and general child care in the arena of HIV/AIDS policy.

**COSSMHO**

1501 16th Street N.W.

Washington, D.C. 20036

(202) 797-4339

Contact Person:Donald Babb

The National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) is funded by the Centers for Disease Control and Prevention to provide technical assistance and training programs on HIV and STD prevention for Hispanics. COSSMHO’s Community HIV and AIDS Technical Assistance Network (CHATAN) targets agencies serving Hispanics at high risk for HIV/STDs, including community-based organizations (CBOs) and health agencies. CHATAN focuses on providing intense and ongoing technical assistance to local agencies, as well as training for community-based organizations and health care agencies. The long range goal of COSSMHO is to expand and strengthen prevention activities for Hispanics at high risk of HIV infection and STDs.

**D.C. CARE Consortium**

801 Pennsylvania Avenue S.E.

Suite 300

Washington, D.C. 20003

(202) 543-5144

Contact Person:Bruce Weiss

The D.C. Comprehensive AIDS Resources and Education Consortium (D.C. CARE Consortium) consists of more than fifty service organizations for persons infected with HIV and those living with AIDS. The Consortium provides strategic planning and coordination among HIV/AIDS service providers in D.C. and administers programs in enhanced individual and family-centered case management.

**Family-Centered Care for Women and Children**

**D.C. General Hospital HIV Center, 34 South**

1900 Massachusetts Avenue S.E.

Washington, D.C. 20003

(202) 675-7590

Contact Person:Fred Pardo

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The HIV Center Program is an outpatient center at the D.C. General Hospital for the care of HIV positive individuals. The Center provides specialized care within the Washington community without regard to a person's ability to pay. The Center is staffed with a team of professionals experienced in caring for persons with HIV infection. Services for individuals, families, friends and "significant others" include: counseling and testing, HIV education, social work and psycho-social support, medical evaluation and continuing care, specialized treatment services, referrals, and appointment scheduling.

**D.C. Women's Council on AIDS**

715 8th Street, S.E.  
Washington, D.C. 20003  
(202) 544-8255  
Contact Person:Diane Jones

The D.C. Women's Council on AIDS is a private, non-profit organization focused on preventing the spread of HIV among women and creating a network of support for women affected by the virus. The Council promotes health education for all women, provides access to medical care and case management, offers community-based services in social services, and expands outreach and programming to women not traditionally identified with high risk behaviors.

**Department of Human Services  
Commission of Public Health**

1660 L Street, NW  
Washington, DC 20036  
(202) 727-3866  
Contact Person:E. Elaine Vowels, Ph.D.

***Birth to 5 Linkage & Tracking Project***

*The Birth to 5 Linkage & Tracking Project is designed to establish a central registry to identify at-risk and disabled infants from birth to five years of age born in the District. This system, initiated in April 1986, is a project of the Commission of Public Health, Department of Human Services.*

**Episcopal Caring Response to AIDS**

733 15th Street, N.W.  
Suite 315  
Washington, D.C. 20005  
(202) 347-8077  
Contact Person:Rev. Jerry Anderson

The mission of the Episcopal Caring Response to AIDS, Inc. (ECRA) is "to provide support and services to those affected by HIV/AIDS, regardless of religious affiliation or lack thereof." To fulfill this mission the ECRA maintains: an HIV/AIDS chaplaincy, conducts spiritual retreats, sponsors a home for people with AIDS, co-sponsors the Greater Southeast Community HIV/AIDS Project, and financially supports three HIV/AIDS Food Banks. ECRA also provides educational training to clergy and laity, and other interested groups, both religious and secular.

***Greater Southeast Community HIV/AIDS Project***

*The Greater Southeast Community HIV/AIDS project is a joint-ministry partnership in outreach between the Episcopal Caring Response to AIDS and St. Philip the Evangelist Episcopal Church. This project provides HIV/AIDS service delivery and spiritual counseling support in the D.C. metropolitan area for both the individual and the families, friends and caregivers.*

**Family and Medical Counseling Service, Inc.**

2041 Martin Luther King Jr. Avenue S.E.  
Suite 105  
Washington, D.C. 20020  
(202) 889-7900  
Contact Person:Angela Fulwood

Family and Medical Counseling Services, Inc. (FMCS) is a non-profit, community based organization. FMCS provides HIV services including: case management, community outreach, primary medical care, nutrition counseling, support groups, and psychosocial services. The scope of services incorporates families in HIV/AIDS, including counseling/psychotherapy, HIV/AIDS Prevention Education and Parenting Skills Development.

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**Family Place**

3309 16th Street, NW  
Washington, DC 20010  
(202) 265-0149

Contact Person:Adriana Ferpozzi

The Family Place is a non-profit, community-based organization focusing on social policy concerns for Hispanic individuals and families in the D.C. area. As a sister-organization with the New Community Family Place, services provided for Hispanic HIV challenged families and individuals include drop in and networking, father and mother support groups, parenting classes, referrals to testing, and specific workshops on nutrition and prenatal care. Services are provided in a bicultural and bilingual setting.

**HIV Community Coalition of Washington, D.C.**

Room 4103  
1255 23rd St., NW  
Washington, DC 20037

Contact Person:Philippa Lawson

The HIV Community Coalition (HCC) is a confederation of people living with HIV and AIDS in the D.C. metropolitan area. HCC provides information about HIV and HIV/AIDS services, awareness and advocacy for policies and programs affecting people living with HIV. Among its services, HCC provides forums where people affected by HIV can voice concerns and opinions. HCC sponsors educational and outreach activities focusing on topics and issues of concern to people with HIV. A newsletter for, about, and by people with HIV entitled HIV/Alive is available.

**La Clinica del Pueblo**

1470 Irving Street, N.W.  
Washington, D.C. 20010  
(202) 462-4788

Contact Person:Vilma Iraeta

La Clinica del Pueblo provides services including: HIV testing and counseling, outpatient HIV primary care, specialty care consultants, a

laboratory, individual and couple therapy, support groups, case management, assisted transportation and accompaniment, alternative medicine, counseling on nutrition and family issues, and HIV/AIDS outreach education.

**Metro TeenAIDS**

P.O. Box 15577  
The Jubilee Center  
651 Pennsylvania Ave. S.E.  
Washington, D.C. 20003-5577  
(202) 543-9355

Contact Person:Joe Symoun

Metro TeenAIDS advocates for Washington area teens and for adolescent HIV/AIDS education, prevention, and treatment services. Metro TeenAIDS promotes, coordinates, supports, and conducts education, prevention, and referral programs geared to reducing the rate of HIV infection in youth, and to serving the needs of those already infected.

***Metro TeenAIDS Parents and Other Heads of Households Workshops***

*Metro TeenAIDS provides workshops each year to over 500 parents to inform them of HIV rates among adolescents. Workshops focus on how the virus is being transmitted among youth, and how parents can help to explain risks and remain better informed. Parent workshops are held in schools, churches, at the work-place, and in other community group setting.*

**National Association of People with AIDS**

1413 K Street, N.W.  
8th Floor  
Washington, DC 20005  
(202) 898-0414

Contact Person:Yasmine Branden

The National Association of People with AIDS (NAPWA) is a nonprofit organization that serves local coalitions of people with AIDS by providing information on self-empowerment, education, and interaction with local AIDS service providers. The

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association works to foster a greater understanding of the realities of AIDS and the need for prevention and care programs. Services include: a speakers' bureau, field training, coalition building, and centralized information and referral services.

**National Center for Social Policy and Practice  
National Association of Social Workers**

750 First Street N.E.  
Suite 700  
Washington, D.C. 20002  
(202) 408-8600  
Contact Person: Jim Brennan

The National Center for Social Policy and Practice (NCSPP) focuses on the direct link between the practice of social work and the making of public policy. Issues of concern include AIDS, homelessness, child welfare and family violence. The Center also manages research grants and projects in social work.

**National Leadership Coalition on AIDS**

1730 M Street, N.W.  
Suite 905  
Washington, D.C. 20036  
(202) 429-0930  
Contact Person: B.J. Stiles

The National Leadership Coalition on AIDS works to improve the business and labor response to HIV/AIDS, to enhance public/private sector collaboration, to stimulate greater private sector involvement in local and national AIDS efforts, and to support work-place education on HIV/AIDS. The coalition disseminates current HIV/AIDS materials and provides technical assistance to the minority and small business sectors.

**National Minority AIDS Council**

300 Eye Street, N.E.  
Suite 400  
Washington, DC 20002  
(202) 544-1076  
Contact Person: Paul Akio Kawata

The National Minority AIDS Council (NMAC) promotes leadership on HIV/AIDS-related issues within communities of color. The council provides information, resources, and technical assistance to organizations offering HIV/AIDS-related services to ethnic minorities, and strives to facilitate a coordinated response within African-American, Latin, Asian/Pacific Islander, and Native American communities. Publications include: Technical Assistance Manual for Volunteer Program Development, Computer Technical Assistance Manual, the NMAC HEALer, and two bimonthly newsletters, NMAC Update and NMACTA.

**National Network of Runaway and Youth Services, Inc.**

1319 F Street N.W.  
Suite 401  
Washington, D.C. 20004  
(202) 783-7949  
Contact Person: Brian Sullivan

***Safe Choices Project***

*The National Network's Safe Choices Project addresses the needs of HIV among youth in high-risk situations by providing HIV prevention materials, training and technical assistance to youth workers. The project seeks to collaborate with community-based organizations, national organizations, state / local education / health agencies, and other youth-service professionals towards the implementation of HIV prevention services.*

**National Women's Law Center**

1616 P Street, NW  
Suite 100  
Washington, DC 20036  
(202) 328-5160  
Contact Person: Linda Cooper

The National Women's Law Center is a non-profit organization focusing on advancing and protecting women's legal rights. The Center addresses policy issues such as child support, employment, education, reproductive rights and health, public assistance and social security. The

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Center provides fact sheets on women and AIDS and the issue of AIDS and incarcerated women.

**New Community Family Place**

1312 8th Street N.W.  
Washington, D.C. 20001  
(202) 265-1942

Contact Person: Mark Robinson

The New Community Family Place is a non-profit organization with primary services for the Shaw area of D.C. The New Community Family Place offers HIV challenged services for families infected and affected by HIV/AIDS. Programs in HIV/AIDS include: free lunch programs, drop in and networking, father and mother support groups, parenting classes, referrals to testing and specific workshops on nutrition and prenatal care. Clients must have a child under the age of four or be expecting a child to qualify for services.

**Office of Maternal and Child Health  
Commission of Public Health, Department of  
Human Services**

4340 Connecticut Avenue, NW  
Room B-10  
Washington, DC 20008  
(202) 673-6724

Contact Person: Linda Jenstom

***Pediatric//Family AIDS Health Care  
Demonstration Project (P.R.I.D.E.)***

*The Pediatric AIDS Health Care Demonstration Project is a family-centered, case management project which currently serves approximately 160 families affected by HIV/AIDS annually. The program calls for a family-centered and community-based development of care systems, the emphasis of prevention to reduce perinatal transmission of HIV and the spread of infection among minorities and adolescents, and the sustained financing of HIV-infected children's care. Training and technical assistance is also provided to public health clinics and other community-based health providers in helping infected and affected women and children. The lead organization in the District of Columbia*

*is the Office of Maternal and Children Health Commission of Public Health, Department of Human Services. Other demonstration projects are currently under-way in DC General Hospital, Children's National Medical Center and Howard University Hospital.*

**Pediatric AIDS Coalition**

The Homer Building  
601 13th Street, N.W.  
Suite 400 North  
Washington, DC 20005  
(202) 347-8600, (800) 336-5475  
Contact Person: Damian Thorman

The Pediatric AIDS Coalition brings together 38 national organizations that advocate for children, adolescents, families, and caregivers whose lives are affected by HIV infection and AIDS. The coalition supports federal legislation that addresses the needs of HIV-infected children, adolescents, and their families. It also serves as the Pediatric Task Force within the National Organizations Responding to AIDS.

**Planned Parenthood of Metropolitan  
Washington**

1108 16th N.W.  
Washington, D.C. 20036  
(202) 347-8500

Contact Person: Wayne Pawlowski

Planned Parenthood of Metropolitan Washington attempts to reduce the barriers of poverty, language, cultural differences, lack of accurate information, and fear of the health care system. In partnership with the District of Columbia Health Department, PPMW fields outreach educators to work with low-income individuals, who are then referred to a PPMW clinic for free services. Planned Parenthood offers: diagnosis and treatment of sexually transmitted diseases for men and women, HIV/AIDS testing and counseling, teen information sessions, infant mortality reduction, training to professionals and volunteers, a Latino Outreach Program, and the STARR project

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(Starting Again for the Recently Released) which provides HIV/AIDS and pregnancy prevention information to women recently released from incarceration.

**Safe Haven Outreach Ministries**

817 L Street S.E.  
Washington, D.C. 20003  
(202) 546-7146  
Contact Person:Zorita Hinton

Safe Haven Outreach Ministry, Inc. was incorporated in the District in May of 1992. The 11 apartment buildings, 16 apartments, and 6 homes of "Safe Haven" currently house 105 men, women and children - 38% of whom are HIV positive or have AIDS. Safe Haven relies on volunteer resources to increase outreach and provide support to its residents and clients. Areas of concern for Safe Have Outreach Ministries include property acquisition, management, placement, case management and substance abuse treatment.

**Sexual Minority Youth Assistance League (SMYAL)**

333 1/2 Pennsylvania Avenue S.E.  
Washington, D.C. 20003-1148  
(202) 546-5940  
Contact Person:Carol Gush

The Sexual Minority Youth Assistance League supports gay and lesbian youth in a confidential and non-judgmental location. Free services in HIV/AIDS include support groups, a drop-in program and a helpline. SMYAL increases public awareness and understanding of gay and lesbian youth through training and education.

**St Frances Center**

5135 Mac Arthur Blvd., N.W.  
Washington, D.C. 20011  
(202) 363-8500  
Contact Person:Dottie Wardwimmer

St. Frances Center is a non-profit organization founded in 1975 to serve as a source of guidance,

information and support for people living with illness, loss and bereavement. The philosophy that guides all programs is: respect for individuals and their experiences, awareness and acknowledgment of the pain of loss, and loyalty to people in times of illness and death.

***The Hug Club***

*The Hug Club is a monthly Saturday morning "fun time" for children who have not been told about their HIV infection. The club is meant to provide a supportive setting for children's feelings and a relief period for burdened families. The HUG CLUB holds as its belief that each family has the right to determine its own way and timeframe for confronting issues.*

***HIV/AIDS Training Program***

*The St. Francis Center, in addition to HIV/AIDS counseling and services, offers training programs in death-related topics specific to HIV/AIDS. Such family-centered programs include: Needs of Lovers, Spouses, Significant Others, Needs of Parents, Needs of Children, Stress and Burnout-Needs of the Caregiver and Grief and Bereavement.*

**Terrific Inc.**

1222 T Street S.E.  
Washington, D.C. 20009  
(202) 462-8526  
Contact Person:Joan McCarley

***Grandma's House***

*Grandma's Houses are special homes in Washington, D.C. for infants and children who have been exposed to the HIV virus which causes AIDS. Grandma's House is directed and operated professionals who have experiences in helping people exposed to HIV, drug abusers, young parents, low-income families, the homeless. The House staff conducts workshops on death acceptance and grief management, provides drug and other HIV/AIDS-prevention training, parent effectiveness training.*

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**United States Conference of Mayors AIDS Program**

1620 Eye Street, N.W.  
Washington, D.C. 20006  
(202) 293-7330

Contact Person:Richard C. Johnson

The United States Conference of Mayors (USCM) AIDS Program publishes the Local AIDS-Related Services National Directory, which lists more than 2,000 AIDS groups. Other publications include: AIDS Information Exchange, HIV Capsule Reports, HIV/AIDS Technical Assistance Reports, HIV/AIDS Prevention Case Studies, Local Health News, and U.S. Mayor.

**Whitman-Walker Clinic**

1407 S Street, N.W.  
Washington, DC 20009  
(202) 797-3500

Contact Person:Pat Hawkins

The Whitman-Walker Clinic is the primary provider of community-based HIV/AIDS services in the Washington, DC metropolitan area. Volunteer and professional staff members provide medical, legal, mental health, housing, and education and prevention services in coordination with local government agencies.

**Hotlines and Information Services**

Public Health Service 24 Hour Information and Crises Hotline (800) 342-AIDS  
AIDS Clinical Trials Information (800) TRIALS-A  
CDC AIDS/HIV Hotline (800) 342-2437  
CDC National AIDS Clearinghouse (800) 458-5231  
DC AIDS Information Line (202) 332-2437  
Food and Friends (202) 488-8278  
HIV Community Coalition (202) 884-8857  
Linea de Informacion Del SIDA (800) 322-SIDA  
Pets DC (202) 234-7387  
Project Inform Treatment Info (800) 822-7422  
Whitman Walker Legal (202) 797-3527

Whitman Walker Max Robinson Center of Anacostia (202) 562-1160

Whitman Walker Medical Services (202) 745-6133

**IMPORTANT TELEPHONE NUMBERS**

**Testing Information**

District of Columbia  
202-332-EXAM

Virginia  
800-533-4148

Maryland  
800-638-6252

**General Information**

DC Agency for HIV/AIDS  
202-727-2500

DC AIDS Info Hotline  
202-332-AIDS

Linea de Servicios del SIDA  
800-322-SIDA

**Hotlines**

National AIDS Hotline  
800-342-AIDS

National AIDS TTY Hotline  
800-AIDS-TTY

National AIDS Spanish Hotline  
800-344-SIDA

**HIV/AIDS Drug Assistance Programs**

DC Residents  
202-724-5468

Virginia Residents  
800-533-4148

Maryland Residents  
301-225-6800

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