

# D.C. Family Policy Seminar

April 18, 1995

## *Seminar Highlights*

# HIV/AIDS: Helping Families Cope

**Mark Rom**

**Director of D.C. Family Policy Seminar**

*Since the first reports in 1981, more than 7,000 AIDS cases have been reported in the District of Columbia-- many within the past three years. Each case of HIV/AIDS has a rippling effect that touches the lives of friends, partners, and family members. This seminar focuses on families in which the father, mother, or children are infected and/or affected by HIV/AIDS. We focus on these families not because they are more special than others, but because they face unique challenges and complexities.*

**Linda Jenstrom**

**Comprehensive HIV Intervention and Prevention Services (CHIPS) for Families Project**  
(Formerly the D.C. Pediatric AIDS Health Care Demonstration Project)

*Families affected by the HIV/AIDS epidemic face a multitude of health and support service needs. As our knowledge of transmission and prevention increases, our policies and protocols will need to respond to their needs and respect their rights.*

### **Main Points:**

- Families affected by HIV/AIDS need the following services:
  - (1) Access to high quality medical services. Primary and many secondary medical care services need to be community-based to increase access.
  - (2) Comprehensive, family-centered case management services. Case management services for individuals often are unable to meet the needs of a family. To help a family cope with HIV/AIDS, case managers need to deliver family-centered care that takes into account the entire family system and draws upon the strengths of different family members.
  - (3) Family support services. The Ryan White Title I Washington Regional HIV Health Services Planning Council and the Title II D.C. Care Consortium both recognize that families need alternative care and support services when they are affected by HIV/AIDS; such as in-home respite care and child care.
- A recent clinical study (ACTG 076) succeeded in reducing the incidence of transmission of the HIV virus from the infected mother to the infant from 25% to 8.3%. HIV-infected pregnant women in the treatment group received AZT to prevent the transmission of HIV to the fetus. The results were so successful among the first 400 cases studied, that they stopped the study and provided AZT to the control group participants. Those results raise several complex policy issues. First, because AZT has only a limited effectiveness of about 18 months, taking AZT during an infected woman's pregnancy may reduce the usefulness of AZT taken later as the

disease progresses. Second, the effects of AZT on the later development of the child or adolescent is unknown. Third, there is a question whether or not pregnant women should be subject to mandatory testing for HIV since AZT seems to significantly reduce the likelihood of transmission to the fetus. Fourth, will women who refuse voluntary testing jeopardize the custody of their own children because of perceived neglect of their child's health and well-being?

- The District's budget problems are going to impact HIV/AIDS services dramatically. Already Medicaid services are denied to women in the first two months of their pregnancy. Emergency housing and financial assistance programs are now defunct. These services have been used heavily by the population affected by the epidemic. In addition, the U.D.C. School of Law may close. The law school has worked on behalf of families on SSI entitlements and on permanent guardianship issues.

**Program:**

- CHIPS for Families is trying to develop a system of quality primary services for asymptomatic and symptomatic patients with HIV infection, with a focus on women and children, to be delivered in community-based clinics. In collaboration with staff of university hospitals and the D.C. Care Consortium, the project developed primary care protocols for asymptomatic and symptomatic women with HIV infection, including pregnant women, and for HIV-positive infants.

- The project is collaborating with the National Pediatric AIDS Resource Center and regional AIDS Education and Training Centers to organize a conference that will be held June 5-7 in College Park, Maryland. This conference—a three day core-curriculum training—has a medical track with an emphasis on pediatrics and services to women, as well as a case management track with an emphasis on family-centered services.

- In response to the results of ACTG 076, the project has been working to develop a policy for the District that is in accordance with federal recommendations. The policy includes offering universal counseling and testing services to all women of childbearing age, complete disclosure of information from the study, provision of information regarding the unknown short or long-term effects of AZT on the unborn children, and support for each women's right to decide whether or not she would like to participate in the treatment regimen.

- Howard University Hospital (HUH), a sub-grantee of the project, also has been working on kinship care issues. Many of the children serviced are primarily cared for by an aunt, a grandmother, or another member of the family. The HUH Kinship Care Coalition has been able to obtain legislation authorizing kinship caregivers to give consent for a child's medical treatment.

**Dottie Wardwimmer  
The Hug Club**

*One of the things that makes policy implementation so difficult with regards to HIV/AIDS and families is that some families do not want their children to know about a parent's or child's HIV status. Individuals who work with HIV-infected families may be caught in ethical dilemmas in which parental wishes confront child advocacy standards.*

**Main points:**

- The issues related to disclosure of HIV infection or AIDS are extremely personal and complex. Disclosure can get in the way of supporting families because many parents do not want their children to know about the disease. Bringing children to an AIDS support group presumes admission that the parent or child is HIV infected and will learn the diagnosis. We believe we must respect the parents' wishes.

- There are some ethical questions that policy makers need to consider. Is it ethical to collude in keeping a secret from a child? Or, are we simply respecting the parent's right to make important decisions? Is it ethical to tell a child the truth about AIDS when it can also be a burden? Are we, by daring to respect parents' wishes, relinquishing some of the ground which has been gained by mental health professionals and child advocates who have long struggled to bring truth into medical care and child advocacy? Is it ethical to leave children without support while we argue about what is ethically correct? Must a parent, in order to get a service, do something he or she does not want to do? The answers are not simple or clear.

- We need to develop public policies based on a real sense of respect for the reality-based needs and issues of families affected by AIDS. Whenever possible, we need to invite and nurture input on all levels from families and children themselves.

- We must be complete in our commitment to these youngsters. Support services must be planned. Programs should be evaluated according to their outcomes and not merely according to the number served.

- One day the world will welcome children living with HIV with the same loving arms it uses to welcome children with other diseases. Until then, we all must continue to support each other as we look for ways to care for and about these wonderful children and their incredibly brave and burdened families.

**Program:**

- The Hug Club was created for children who are affected by AIDS but do not necessarily know it. It is a place for children to get together. We hold bimonthly meetings during which topics like friendship, being sick, and death are addressed. We never tell the children that they are there because they or a parent has AIDS. The Hug club is based on four premises:

- (1) All children deserve emotional support when confronting difficult situations.

- (2) Each family has the right to determine its own way and time frame for confronting issues.

- (3) Our role is to honor each family's style and simply walk with them as they come to terms with HIV and all that it brings with it.

- (4) If we are patient, respectful, and creative it is possible to negotiate a comfortable and comforting path between the needs and questions of the child and the family's decision about how and when to respond to those needs and questions.

- The primary goal for the club is to provide a supportive place and time to explore feelings, have fun, and be reminded that each person is precious. Secondary, but equally important goals are: (1) to familiarize the children with health care procedures in order to make them less frightening (2) to learn and/or practice coping skills for dealing with difficult situations and (3) to plant seeds for being an informed health care consumer.

- We negotiate with parents. We tell them we will not lie to the child. If and when a child asks--"Do I have AIDS?" or "Does my mom have AIDS?"--the child has an opportunity to explore these possibilities and the parent is notified that the child is asking these questions.

**Joan McCarley**  
**Executive Director of Grandma's House**

*Families affected by HIV/AIDS need and deserve an uninterrupted continuum of care that responds to their medical, physical, economic, educational, and social needs.*

**Main Points:**

- Families affected by AIDS, like all families, need a loving and nurturing environment and a place to live. However due to the stigma, social costs of the disease, and behaviors, such as substance abuse, that often accompany the HIV transmission, these families may be less likely to have access to adequate housing and love.
  
- Policies addressing HIV/AIDS need to encompass education, prevention, and intervention. This is equally true for policies within the legal systems, health care systems, and public school systems.
  
- Funding streams need to be both categorical to target HIV-affected individuals and families, and integrated within existing systems to ensure a continuum of care.

**Program:**

- Grandma's House was founded in 1987 under a larger organization called TERRIFIC, Inc. Grandma's Houses are special homes for infants and children--many of whom have been exposed to HIV. Grandma's House is directed and operated by professionals who have experience in helping people exposed to HIV, drug abusers, young parents, low-income families, and the homeless. Grandma's House provides a nurturing, comprehensive care environment for these children.
  
- The children that come to Grandma's House come through child protective services. The majority of them have been abused, abandoned, and/or neglected. Our goal is to promote a stable, and loving environment and a smooth transition to a permanent family life.
  
- The House staff conduct workshops on death acceptance and grief management, provide drug and other HIV/AIDS-prevention training, and parent effectiveness training. Our program--Potter's Vessel--provides individual, family, and group counseling case management and seeks to reunite broken families.
  
- In May 1995, we are opening a country retreat located in Maryland on a farm where staff and volunteers who care for HIV infected individuals can enjoy retreats, go to training seminars, and obtain needed emotional support.
  
- In Summer 1995, through a joint venture with an historical women's organization, we will open an apartment building for the reunification of mothers and their children.

**Tom Wells**  
**Executive Director of the D.C. Child Welfare Consortium**

*The 90's is the re-decade: rebuilding communities and returning to families. How do we return to strengthening families with HIV or other problems? We have to discern how to strengthen, re-arm, and re-invent our public policies for families.*

**Main Points:**

- The Levine study (1993), reported in *A Death in the Family: Orphans of the HIV Epidemic*, predicts that by the year 2000, D.C. will have from 1200 to 2000 children orphaned by AIDS. Nationwide, they estimate the figure will be from 125,000 to 150,000 children orphaned by AIDS. The fastest growing population of AIDS cases is among women of child-bearing age.
- To date, there are some 800 children who have been orphaned by AIDS in the District. Currently, there are 44 children who are HIV positive in the foster care system. We are already changing our systems to accommodate these children in the child welfare system. We have the resources to incorporate these children, to strengthen their families, and to rebuild their communities so that they can nurture families. The numbers are manageable.
- We should not be daunted by the numbers. We have plenty of resources for foster care. The challenge is how to make it work. How do we use the resources in such a way that helps, strengthens, and invests in families and children.
- We have to work smart to deal with HIV/AIDS. We need to allocate money in a way that invests in families. Cost per child per day in group facility is \$150. Cost per child per day in a foster home is \$12-15.
- D.C. has a shortage of foster care families, but the shortage is not nearly as great as in other cities and communities. When we invite families to become foster families, we remove barriers so that people can become substitute families.
- The D.C. Child Welfare Consortium successfully reformed systems and coordinated services to solve the border baby problem in the District. The same lessons can be applied to service the children left orphaned by AIDS.

**Program:**

- With the HIV project of the D.C. Child Welfare Consortium, we have placed ads in the classified section soliciting families to become foster families for a child infected with HIV. We now have 14 families taking care of 24 children with HIV. In addition, we provide extensive education to help foster families provide care for children with HIV.



**Discussion and Community Announcements**

*The D.C. Family Policy Seminar graciously acknowledges the generous space and facilities offered by the Charles Sumner School. The Sumner School is a D.C. public school building, offered for use free of charge for group meetings for non-profit organizations. This facility also features concerts and art exhibits to highlight local talent.*

**ANNOUNCEMENTS**

**(1) Needs Assessment for Children and Families:**

**Bruce Weiss, D.C. Care Consortium:** The D.C. Care Consortium started a needs assessment of children and families affected by HIV/AIDS epidemic in the District. The Care Consortium has a provider survey that is being distributed to every agency dealing with families and HIV. Also, the Consortium welcomes everyone willing to work on the issues surrounding children and families with HIV/AIDS. Part of our work is creating family-centered case management. We are creating a curriculum to train case-managers throughout the city so that they are able to implement family-centered care. Contact Bruce Weiss at (202) 543-5144.

**(2) Mothers Against Drunk Driving - D.C. Chapter:**

**Tobi Printz:** We are looking for volunteers or anyone who would be interested in heading up a D.C. Chapter of Mothers Against Drunk Driving. Please call Tobi Printz at (202) 298-6294.

**(3) Phone number correction:**

**Linda Jenstrom:** The Comprehensive HIV Intervention and Prevention Services (CHIPS) for Families was formerly the D.C. Pediatric AIDS Health Care Demonstration Project (PAHCDP). It remains a project of the Office of Maternal and Child Health, Commission of Public Health, D.C. Department of Human Services. The new address is UDC Van Ness Campus, Building 552; 4340 Connecticut Avenue, NW, Room B-10; Washington, DC 20008. Telephone: (202) 686-0567. Fax: (202) 686-2793

**(4) Study on Boarder Babies and Drug-Infected Women:**

**Dr. Vijaya Melnick: Center for Applied Research and Urban Policy at UDC:** Our organization conducted a study on boarder babies and drug infected women in 1992. We studied all facilities that work with women and children up to the age of 5. We looked at seventeen model programs across the country trying to see what kind of programs are successful and whether or not they can be applied in D.C. These publications are available for a small reproduction and handling fee. Contact Dr. Melnick at (202) 274-5106 or Cherrie Williams at (202) 274-5599.

**DISCUSSION:**

**(1) AIDS and the Latino Population**

**Hilda Crespo, ASPEDA Association:** How much does the Latino population utilize HIV/AIDS services in the District? Are there outreach/services directed to Latinos in the District?

*Responses:*

**Linda Jenstrom:** CHIPS for Families has seen a very small number of Latinas perhaps because of the locations in which the project case managers are delivering services. Recently, the project's case managers are seeing more Latinas in the high risk pregnancy clinic at D.C. General. Through Title I and Title II funds of the Ryan White Act, and appropriated funds administered by the Agency for HIV/AIDS, there are special projects that target the Latino population.

**Jean Tapscott, Acting Deputy Director of the Agency for HIV/AIDS:** Coming to these events makes me want to do more of what I'm suppose to be doing at the Agency for HIV/AIDS. I encourage everyone to be advocates. We would like to see other programs develop programs to address the needs of children and families. Our agency does fund HIV/AIDS programs, education, and counseling specifically for the Latino community. Funds have been directed to Walker Whitman, Joseph House, Salude, Clinica del Pueblo, and Christ House among others. Unfortunately, we never have enough money. We need organizations to lobby for more money for special populations affected by HIV/AIDS. In addition, we need help in determining the allocation of funds for specifically target groups.

**Dottie Wardwimmer:** About half of the families who participate in the Hug Club are Latino.

**Joan McCarley:** The Affected HIV Children and Families Committee of the D.C. Care Consortium is looking for a co-chair. We need greater representation from the Latino community on this committee. We generally meet the fourth Friday of each month. Speak to Bruce Weiss or myself if you are interested. In addition, one of our programs has been successful in reaching Latino youth. Our PEERS program (Prevention Education and Risk Reduction Strategies Programs for teenagers) empowers teenagers to address HIV/AIDS prevention with their peers. This program works closely with the Latin American Youth Center.

## **(2) Adolescents Whose Parents are Suffering from AIDS**

**Cherrie Williams, Center for Applied Research and Urban Policy, UDC:** Can you address what policy makers can do for adolescents whose parents are suffering from AIDS?

*Response:*

**Dottie Wardwimmer:** When a child loses a parent to AIDS, not only does she or he lose a parent, but she or he often loses the support networks necessary to help the normal grieving process. Many children do not find out their parents have AIDS until the parent dies, or even afterwards. First they lose their parent in a real way and then they lose a parent in a figurative way. One of the initial responses when a teenager learns that her/his parent has died of AIDS is to feel abandoned and betrayed by the parent. The youths have to accept the fact that her/his parent, at some point, engaged in a risk factor--possibly the same risk factor the parent once lectured the child about, such as drug use or unprotected sexual intercourse. Adolescents also have to work through shame. Children can tell their friends when a parent dies of cancer or of a heart attack, but most children are still unable to tell their friends that a parent has died of AIDS. Grief experienced by teenagers is not simple. Very often it is intertwined with many other factors.

### **(3) Business and AIDS**

**Nila Vehar, National Leadership Coalition on AIDS:** How can the business community support the activities of AIDS organizations and service providers other than financial support?

Responses:

**Linda Jenstrom:** Adopt a Community-Based Organization (CBO) and volunteer business skills, technical assistance, and other forms of support.

**Joan McCarley:** TERRIFIC, Inc. is a community--based organization. All of our Grandma's Houses depend upon the business community for support and continued existence.

**Dottie Wardwimmer:** We need day-time volunteers. Businesses could allow some employees to donate some of their time during the weekday.

**Bruce Weiss, D.C. Cares Consortium:** We have found that businesses are often willing to donate insurance policies, benefits, hardware needs, old desks, computers, printers, legal assistance, etc.

### **(4) Families and the Decision to Disclose AIDS**

**Margaret Copeman, Healthy Start:** Why don't families tell their children they are suffering from AIDS? I work in Ward 7, and I find it very difficult to get women infected with HIV to come to my services.

Responses:

**Dottie Wardwimmer:** Women do not disclose information about AIDS for many reasons. For one thing, even admitting to oneself is difficult. In addition, looking in the face of your own child, knowing you have AIDS and you will not be around to watch them grow up is extremely painful--especially if the child is also infected. Getting help often means going public with the disease. Our society does not honor women when they do come forward--we shun and chastise them.

**Joan McCarley:** Many women in the District acquire AIDS through drug use and may not readily disclose information of their HIV status due to their fear of being arrested or of having their children taken away.

**Linda Jenstrom:** Women may also be in an abusive relationship; and it may endanger her life if she discloses her condition.

### **(5) AIDS Prevention and Women**

**Karen Mackey, D.C. Public Schools:** What measures are being employed for AIDS prevention among women?

Response:

**Linda Jenstrom:** The Agency for HIV/AIDS, with funds granted by Centers for Disease Control and Prevention offer many programs that focus on prevention and education for

women. Many of the programs emphasize negotiation skills. The D.C. Women's Council on AIDS is also very active, with programs that emphasize sister-to-sister support.