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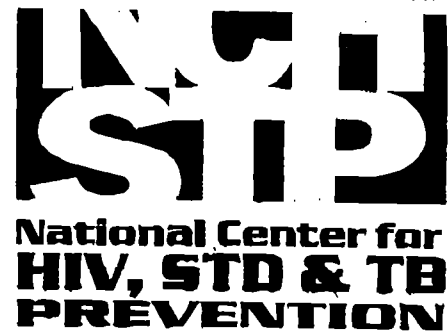
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Office of the Director

Facsimile Transmittal Cover Sheet

To: TODD SUMMERS
Phone: 202-456-2439
Fax: 202-456-2438

From: Office of Communications
Phone: 404/639-8895
Fax: 404/639-8910

Date: 1/27

Number of Pages: 3 (Including cover)

Subject: Pediatric AIDS cases

Comments: Please call if you have any questions or need additional information.

* TODD,

1998 figures are not available, but
here is '87 - '97. It doesn't show
a huge decline (comparing '87 to '97)
since pediatric cases peaked in '92.
Let me know if you need anything
else, Thanks,

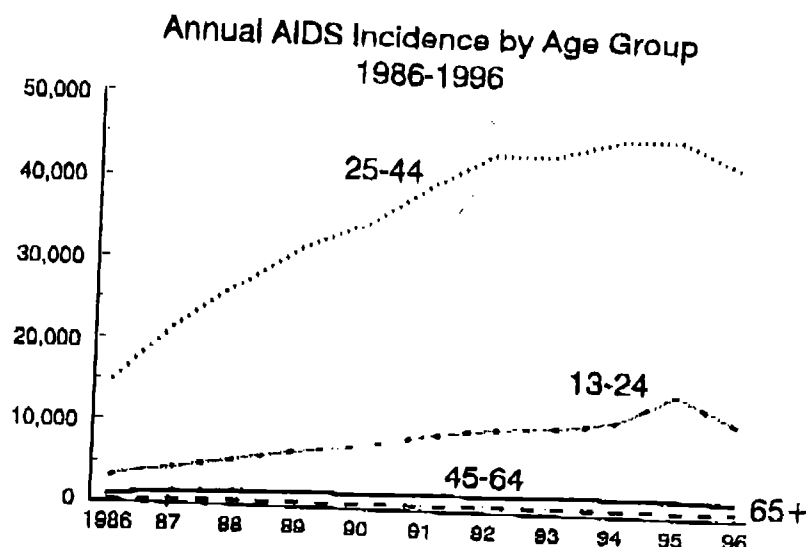
Kitty

KSUES-Groups-
Children

**Estimated Pediatric AIDS Incidence by Year of Diagnosis,
1987 through 1997, United States**

YEAR	CASES
1987	332
1988	595
1989	645
1990	800
1991	800
1992	947
1993	905
1994	806
1995	669
1996	500
1997	299

By age • The greatest proportion of AIDS cases has always been among Americans ages 25-44. In 1996, an estimated 57,260 Americans were diagnosed with AIDS. Of these, almost 75% (42,460) were among people 25-44 years old, 21% were among Americans over the age of 44 (12,260), and less than 4% (2,040) were among people 13-24 years of age. The remainder were pediatric (less than age 13) AIDS cases.



→ **Among children: Perinatal AIDS declines** • Trends in AIDS incidence among children continued to demonstrate the dramatic success of efforts to reduce perinatal (mother-to-child) HIV transmission. In 1994, clinical trials showed that HIV-infected women could reduce the risk of transmitting the virus to their babies by as much as two-thirds through administration of zidovudine (ZDV or AZT) during pregnancy, labor, and delivery, and by giving their babies AZT for the first 6 weeks after birth. In 1994, the Public Health Service (PHS) issued guidelines for using AZT during pregnancy, and in 1995, published guidelines for routinely counseling all pregnant women about HIV and offering them an HIV test. As health care providers across the country incorporated these guidelines into clinical practice, perinatal AIDS incidence dropped dramatically. Between 1992 and 1996, the number of children with perinatally acquired AIDS dropped 43%. But despite declines in all racial/ethnic groups, the majority of perinatally acquired AIDS cases continue to occur among African-American and Hispanic children. This indicates the need for intensified efforts to prevent infection among minority women and to reach women who are infected with early prenatal care and preventive treatment.

Estimated Number of Children With Perinatally Acquired AIDS, 1992 - 1996						
Race/Ethnicity	1992	1993	1994	1995	1996	% Change
White	133	126	92	95	67	-50
African American	566	531	522	415	331	-42
Hispanic	195	195	166	146	111	-43



AIDS Policy Center
For Children, Youth & Families

MEMO

TO: Sandy Thurman, Daniel Montoya, ~~Todd Summers~~

FROM: David Harvey and Clark Moore

RE: World AIDS Day

DATE: November 25, 1998

AIDS Policy Center proposes that the President address the following domestic policy issues in his remarks at the World AIDS Day event:

- The President should call upon states that have not already done so to pass **standby guardianship laws**, to help prevent more children from becoming orphans to AIDS. Standby guardianship laws enable parents with HIV to designate a guardian for their child in the event of the parent's mental incapacitation, physical debilitation, or death. Joint guardianship laws, a variation of standby guardianship laws, permit terminally ill parents to share guardianship with at least one other person. Although the Adoption and Safe Families Act of 1997 established "the sense of Congress that the States should have in effect laws and procedures that permit any parent . . . to designate a standby guardian," many states have not enacted these laws. (To our knowledge, only twelve states have done so, and legislation has been proposed or is being drafted in eight additional states).
- The President should request additional federal funding in FY 2000 for the **Abandoned Infants Assistance Program**, which is administered by the Children's Bureau of the Administration on Children, Youth and Families. This often overlooked program is a critical part of the federal response to AIDS orphans in the United States. Congress passed the Abandoned Infants Assistance Act (P.L. 100-105) in 1988 to address the "boarder baby" phenomenon, wherein infants, particularly those perinatally exposed to drugs or HIV, reside in hospitals indefinitely due to difficulties in locating appropriate living arrangements. This legislation provides funding to support demonstration programs that provide child welfare, permanency planning, and comprehensive health and social services to children and families affected by drugs and/or HIV/AIDS.

The mandate of AIA programs are to (1) prevent abandonment of AIDS orphans; (2) identify and address needs of abandoned infants, especially those with AIDS; (3) assist AIDS orphans to reside with their natural families if possible, or in foster care; (4) recruit, train and retain foster parents; (5) carry out residential care programs for abandoned children and children with AIDS;

(6) establish programs of respite care for families and foster families; (7) recruit and train health and social services personnel to work with families, foster families and residential care staff.

The AIA program currently funds 27 service sites in 18 states, and has served an estimated 35,000 children, parents and caregivers since the late 1980s. **Federal funding for the AIA program has actually been cut in recent years, from a high of \$14.4 million in FY 95 to \$12.2 million in FY 99.** In FY 1998, Congress directed that the program closely collaborate with CARE Act programs to enhance permanency planning services for children and families living with HIV/AIDS, but gave no additional funds for this purpose. Additional federal funds are needed to 1) enhance permanency planning and child welfare services for children and families living with HIV/AIDS at CARE Act sites; 2) provide for a basic program expansion at existing AIA service sites; and 3) provide for increased training and technical assistance activities to the child welfare and AIDS service systems. APC and NORA recommend a funding increase of \$9.75 million, for a total of \$22 million in FY 2000.

- The President should acknowledge the critical role played by the **Ryan White Title IV** program in addressing the impact of HIV on children and youth. Title IV provides comprehensive health services to children who are orphaned by HIV/AIDS and their families. Title IV projects are also playing a major role in reducing the number of infants who are born with HIV in the U.S. In addition, by improving the health of parents with HIV, Title IV is helping to reduce the number of new orphans in the future.

If you would like additional information on these or other topics, please contact Clark or David at (202) 785-3564.



THE SOURCE

FALL 1995 • VOLUME 5, NUMBER 2

NATIONAL ABANDONED INFANTS ASSISTANCE RESOURCE CENTER

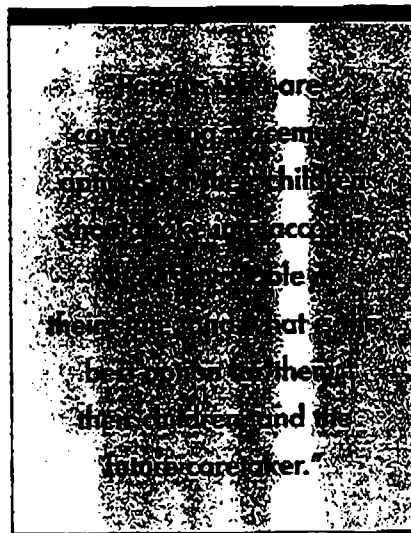
Who Will Care for the Children? Unwinding The Legal Maze

As we enter another year of the AIDS epidemic, women of child-bearing age have become the fastest growing segment of persons with AIDS. Government statistics published in 1993, report that HIV infection in women has increased dramatically and is considered the fourth leading cause of death among women ages 25 to 44 years (Centers for Disease Control, 1993). In 1993, HIV infection among women increased 9.8% compared to 2.5% in men (Selik & Buchler, 1993).

As the number of women who are infected with HIV rises, we see a corresponding increase in the number of children who are directly affected by this disease. Because studies of family structure demonstrate that women are the sole and primary caregivers for the vast majority of children and youth, these figures become especially alarming (Michael & Levine, 1992). When these women die, they leave behind children who require shelter, food, medical care, and emotional support. By the year 2000, it is estimated that 125,000 children will be left motherless by this epidemic (Giballe, Grucndel & Andiman, 1995). AIDS will leave more children motherless than motor vehicle accidents or cancer (Michael & Levine, 1992). As more and more women are diagnosed, the question arises, who will care for the children?

Those who are living with HIV are constantly faced with uncertain thoughts of the future and, especially, the future of

their children. Many fear the myriad of legal mazes they must traverse to find a safe and secure home for their children. A large number of women who die of AIDS fail to name a caretaker, and 53% of parents living with AIDS have no viable plan



for their adolescents (Levine & Stein, 1994). Lack of planning results from several factors, including lack of formal legal advice or knowledge (Nicholas & Abrams, 1992). For example, many believe that informal kinship care is a reasonable option. Placing a child with a relative may be the easiest approach and, with appropriate legal arrangements, most beneficial to the child. Without proper legal arrangements, however, the relative

may not be eligible to receive public benefits or assistance, and will not be able to enroll the child in school or consent for medical care. Because of a child's many needs, legal arrangements are imperative. It is important, therefore, to educate and empower parents regarding permanency planning options (e.g., wills, adoption, and different forms of guardianship) to alter the silent legacy of these children. Following is a brief description of legal options that may be available to families.

Wills

A will is a legal document used to record a parent's wishes upon her death. A will may include a nomination of a caretaker who will serve as a child's future guardian (primary legal caretaker). The drafting of a will is a relatively simple process that can be done with some haste, and allows a parent to retain full legal custody of her children until her death.

A will memorializes a parent's desire for the care of her children. It does not, however, guarantee placement with the parent's chosen guardian. Following a parent's death, the guardian named in the will must petition the court on his or her own behalf. The court then determines what it believes to be the best placement for the child. If there is a surviving biological parent, he or she will have to consent to the nominated guardian. The surviving parent will usually be successful if he or

... Continued from page 1

she wishes to seek full custody following the custodial parent's death.

A will, therefore, is not binding for final determination of arrangements for a child; it only indicates a preference. There may be a significant lapse in time from the parent's death until the guardianship can be completed. During this time the children will have no legal caretaker.

Adoption

Adoption is the placement option that is considered the most permanent. In an adoption, parental rights are terminated and transferred to the adoptive parents. Giving up one's rights as a parent is emotionally traumatic and may not be a viable choice for many.

Adoption may also be a financial hardship for foster parents who plan to adopt because, following the finalized procedure, foster care payments are terminated. Most families will be eligible for some adoption assistance payments, but these will generally be lower than the foster care payments they had been receiving. Children who have "special needs" that their adoptive families cannot meet will qualify for Federal adoption assistance, additional benefits (e.g., Medicaid under Title IV-E or SSI), or state adoption subsidy programs.

To initiate an adoption, an application or petition must be completed and filed with the appropriate court. The petition requires a signed document from *both* parents giving up their rights over the child. A hearing will then be scheduled, at which time a judge makes a final determination. This process can take up to a year or more. Because of its time and permanence, adoption is impractical and emotionally unfeasible for many parents living with AIDS.

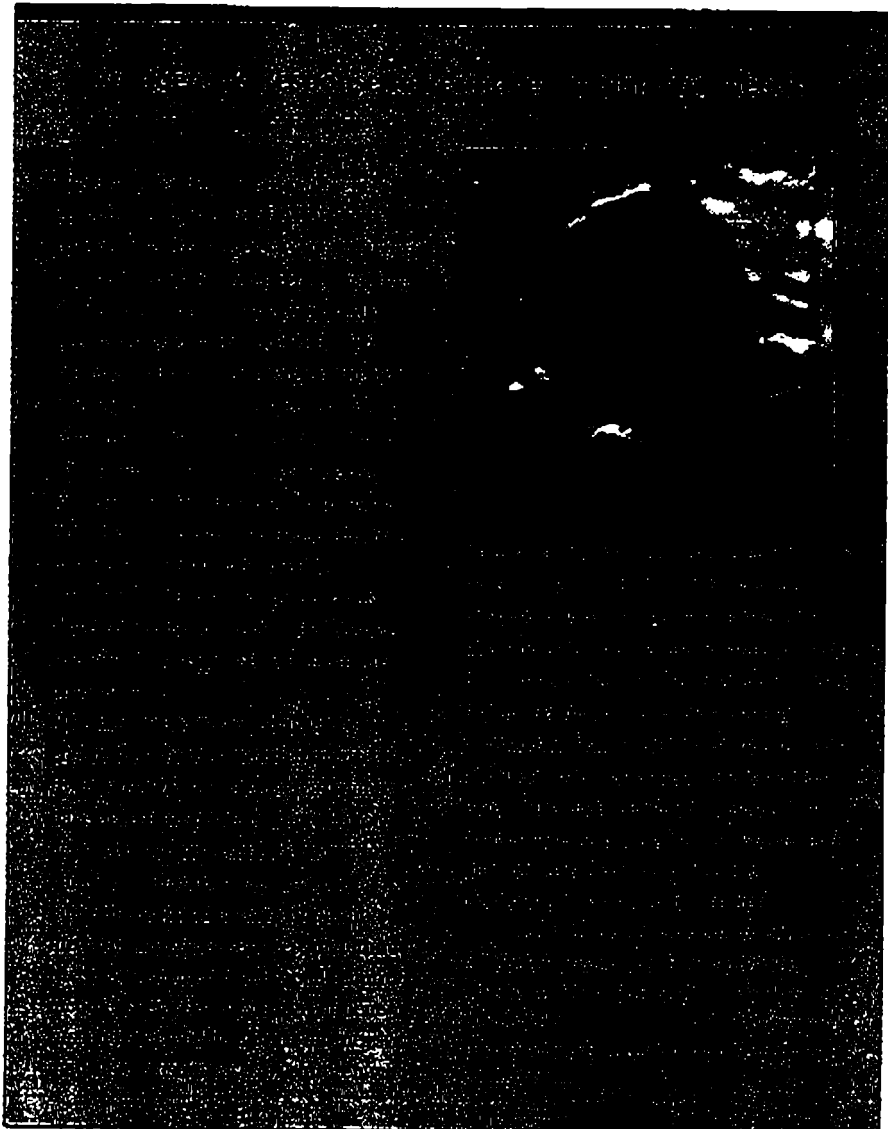
Guardianship

Guardianship is a less permanent placement than adoption and usually a more plausible choice for parents. It involves a process in which a parent's rights are suspended, thereby allowing the legal guardian to serve as the primary caretaker.

A petition must be filed, and a judge makes a final ruling after a hearing several weeks later. In the interim, a court-mandated social worker will visit the prospective guardian's home for a complete home assessment. If there is a surviving parent, he or she must either consent to the placement, abandon the child or waive his or her rights, in order for the placement to proceed. Surviving parents who challenge the appointment of a nominated guardian may succeed, unless demonstrated to be unfit. At the time the guardianship order is signed, all parental rights are suspended. From that point on, the guardian has legal authority and will not have to take any steps following the parent's death.

Although this fairly simple procedure allows a parent to complete the process of finding a home for her children before her

death or disability, she must relinquish her decision-making authority of her children and, sometimes, physical custody, as well. Also, if a child moves in with a formal guardian, the child will generally be removed from the parent's entitlement benefit, leaving the parent with a diminished income. At the same time, legal guardians are typically ineligible to receive foster care benefits. Guardianship, for these reasons, may still not be a preferred arrangement. Many women, therefore, attempt to wait until the last minute to make these guardianship arrangements, but they risk becoming too ill to complete the process. Once again if this process is not completed the child will have no legal caretaker and may end up in the foster system or in legal limbo.



Joint Guardianship and Stand-By Guardianship

Because guardianship, once completed, automatically suspends a parent's rights, this generally is not an appropriate arrangement for parents with HIV/AIDS. HIV is an episodic illness. Women who are infected with HIV may have periods where they feel great, intermixed with periods of severe illness. Many of these women would like to initiate permanency planning options but do not want to lose their rights over their children. Several states have lobbied for more sensitive, flexible, and appropriate legal options for parents with a terminal illness. Joint guardianship and stand-by guardianship have been states' responses to this problem.

Joint guardianship is a permanency planning option available in only a few states, such as California. The primary purpose of joint guardianship is to allow a parent to complete the guardianship process while still healthy, without relinquishing or suspending all of her parental rights. This option enables a parent to choose the legal guardian; allows the child to become familiar with the chosen guardian; and eliminates the uncertainty of the child's future. (See Lewis and Kent article on p. 11 of this issue.) However, because joint guardianship requires a parent to give up some control of her children by sharing decision making responsibility with the joint guardian, this may not be the perfect solution for many parents. A few states, such as New York, Florida and Illinois, have developed an alternative statute, stand-by guardianship.

Stand-by guardianship allows a parent to complete a process to nominate a secondary individual as a standby to "be empowered to assume the duties of his office immediately on the death or adjudication of incapacity of the last surviving natural parent or adoptive parent of the minor" (Florida Statute, 1991). Stand-by guardianship allows a parent to care for her children when she is able, but upon her death, the legal authority automatically springs over to the stand-by guardian. Under stand-by guardianship, a parent can

make legal arrangements while still in good health; be involved with these arrangements through the court process to insure her wishes will be carried out; and retain parental rights until her death. (See Beatty and Hershfield article on p. 8 of this issue.)

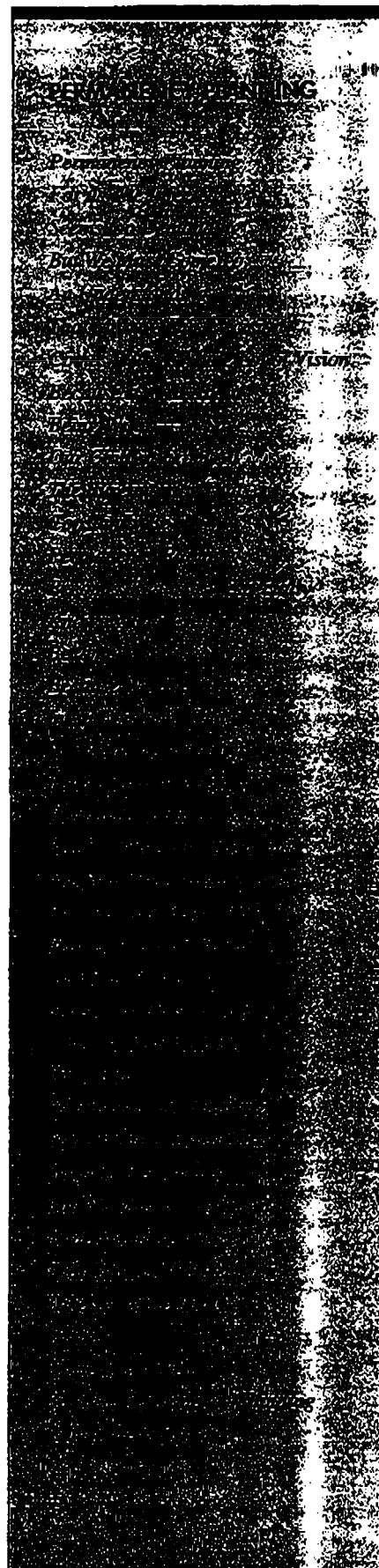
Conclusion

While none of the above alternatives may be a perfect solution, joint and stand-by guardianship appear to be the best means of providing for a secure future for the children without eliminating the rights of a parent. Parents who are considering placement options for their children should take into account what is available in their state, and what is the best option for them, their children, and the future caretaker. Parents who attempt to implement any of the above choices should seek the assistance of a legal advisor or legal service center to make the procedure as smooth and easy as possible. There are several community agencies or attorneys who will work with a parent at no cost. With some consideration and planning, parents can help eliminate the uncertainty of their children's futures and reduce the number of children stranded by this disease.

— **Brenda O'Neal, MSSW**
Project Manager, Los Angeles
Pediatric AIDS Legal Services

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Standby Guardianship

In direct response to the permanency planning needs of HIV-affected families, several states have recently enacted standby guardianship laws that enable terminally ill parents to designate an individual to serve as their child's guardian immediately upon the parent's death or incapacity. Parents are thus able to make a permanent plan for their children without giving up any parental rights until the point that they are unable to provide care. Standby guardianship protects children from uncertain custody determinations while empowering families and giving them a sense of control that is often lost in the face of terminal illness.

Establishing Standby Guardianship

Once a parent decides she* would like to designate an individual to "stand by" as the guardian for her child, most state statutes provide two options for establishing the guardianship. The parent may petition the court for judicial appointment of a standby guardian or may complete a written form designating a standby guardian.

To establish a guardianship by judicial appointment, a parent must file with the court a petition that sets out crucial facts, names the guardian, and designates an event that will trigger the guardianship. Typically, statutes require the triggering event to be either the parent's physical debilitation, mental incapacity, or death. The court considers the petition, investigates the proposed guardian, and determines whether appointment of the standby guardian is in the child's best interest. If the court holds a hearing, the petitioning parent may be excused if she is too ill to attend. Once the court grants the petition, the standby guardianship is established and the standby immediately assumes responsibility for the child when the triggering event occurs. The standby guardian then must file with the court documentation — most often a death certificate or physician's declaration of incapacity or debilitation — of the triggering event. If

the guardian fails to file the documentation within the requisite time period, the court will rescind the guardianship.

A parent may choose to fill out a written designation of standby guardianship rather than filing a petition with the court. Most state statutes include the appropriate form, and the parent need only fill in the blanks. Essentially, the parent fills in the name of the standby guardian and the chosen triggering event. She then signs the designation in the presence of two witnesses, who also must sign the form. Once the triggering event occurs, the standby guardian automatically assumes provisional authority for the child for a statutorily-defined period of time. During that time, the standby guardian must file with the court a petition for appointment as guardian. Most often, the petition must include a copy of the parent's written designation and some evidence that the triggering event has occurred. The court will grant the standby guardian's petition for guardianship if it finds that appointment to be in the best interest of the child.

There are several advantages to both methods of establishing a standby guardianship. The primary benefit of filing a petition for judicial appointment is that the parent can be certain that the guardianship has the court's approval. If the parent anticipates that someone might contest the appointment, she will be present to testify in court and to advocate for her choice of guardian.

Standby guardianship by written designation might be more attractive, though, to parents who are intimidated by the court system or deterred by a petition filing fee. This method is more immediate, less complicated, and does not require the parent to explain her choice of guardian. She can think about her options privately and fill in the form when she reaches a decision. The disadvantage, though, to using a written designation is that the parent will not be able to advocate for her choice should the guardianship be opposed. In addition, the standby guardian will be burdened with filing a court peti-

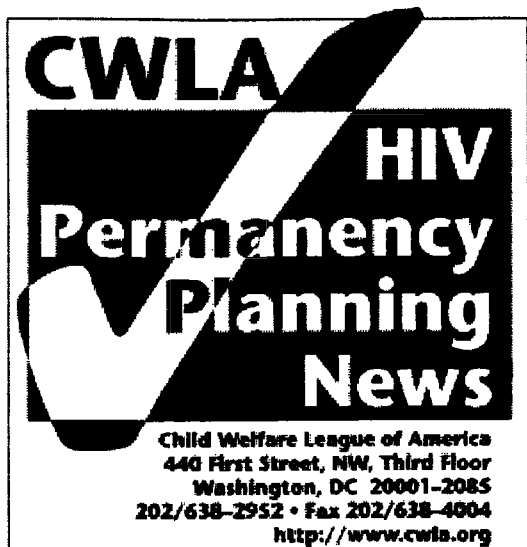
tion during the often stressful time following a parent's death or incapacity.

It is important to note that standby guardianship is not an appropriate option for every parent. Because both parents have an equal right to custody of a child, a standby guardianship can never be established if a child's other parent desires custody and is able to care for the child. Even if this other parent is absent from the child's life or has abandoned the child, the custodial parent must always attempt to notify the noncustodial parent of her intent to designate a standby guardian. The custodial parent must then show that the other parent does not desire custody of the child and consents to the guardianship — or that the other parent did not respond to notification. Most states will allow the appointment of a standby guardian once the custodial parent shows that she has made reasonable efforts to notify an absent parent. Some states will also allow the petitioning parent to present evidence that the non-consenting parent is not a suitable custodian for the child.

Advantages of Standby Guardianship

Standby guardianship provides several advantages for HIV-affected families engaged in permanency planning. Most importantly, standby guardianship provides stability for children facing the loss of a parent and lessens the need for foster care. Also, in situations where adoption is the ultimate goal, standby guardianship can provide a gradual, yet safe, transition for children.

The primary legal advantage of standby guardianship is that it allows a parent to make a permanent plan for her child without being forced to relinquish custody or other parental rights. In a traditional guardianship, parents must transfer some of their rights to the guardian at the time the appointment is made. Even if the parent is not yet sick, the guardian becomes the legal caretaker of the child and has the responsibility for making daily decisions



Volume II May 1998

Alternative Permanency Planning: Legal Options for HIV-Infected Parents

While it may be one of the most difficult decisions HIV-positive parents will make, developing a legal plan for their child's future can be empowering for the parents and ultimately beneficial for the child. For a host of reasons, however, it is often the case that relatives or friends care for children affected by the AIDS epidemic without a legally sanctioned relationship. In the absence of a legal plan, the new caregiver has no legal relationship to the child and no legal authority to make decisions in the child's behalf. For example, the caregiver may have difficulty enrolling the child in school; making medical decisions in the child's behalf; or securing financial support, health insurance coverage, or voluntary social services.

Because of the importance of developing a legal plan, this newsletter focuses on several legal options for per-manency planning for HIV-infected parents. We featured the legal permanency planning option of standby guardianship in our last issue (*Permanency Planning News*, CWLA, May 1997). This issue focuses on other legal permanency planning options that states have implemented or are attempting to advocate in their state legislatures, including the advantages and disadvantages of these options. In addition, it describes particular laws of some states and efforts of other states to improve upon existing legal alternatives. This newsletter also focuses on programs around the country that assist parents in preparing and planning for their children's future care.

It is our hope that this newsletter will provide timely and valuable information, networking opportunities, creative ideas, and a vision for those involved with families affected by HIV/AIDS. Please share this information with friends and colleagues. If you would like to be placed on our national contact list, which will be shared with other organizations that work with families affected by HIV/AIDS, please submit your name, address, telephone number, fax number, e-mail address, program information, resource materials, and advocacy efforts. Your input is greatly appreciated. Send us any ideas you may have or information you would like to see published.

To contact CWLA, write to 440 First Street, NW, Third Floor, Washington, DC 20001-2085; e-mail: bherish@cwla.org; fax: 202/638-4004.

Private Guardianship

The number of overall AIDS-related deaths has decreased significantly over the past several years. In light of recent developments regarding new drug "treatments" for persons with AIDS, the public perception of AIDS as a life-threatening, terminal illness has diminished.¹ Consequently, the issue of permanency planning for HIV-infected parents may not seem as crucial today. However, women remain the fastest growing group among people diagnosed with AIDS. The infection rate of women of childbearing age continues to increase.² AIDS is the third leading cause of death among women ages 25 to 44 and the leading cause of death in African American women of this age group in the United States.³ These statistics translate into an increased number of children who are or will be affected by HIV. Consequently, it is more important than ever that we provide appropriate permanency planning services for HIV-infected parents and their children. HIV-infected parents need psychosocial services, access to legal options, financial assistance, and basic social support services.

Private guardianship is often the most attractive permanency planning option for relatives and/or other guardians because a guardian can care for children without requiring that the children's parent relinquish parental rights. In addition, private guardianship involves no state supervision. State laws vary as to what decisions a guardian can make regarding the child. In New York, for example, a guardian assumes responsibility for making decisions about the child's health, education, and maintenance.⁴

Private guardians also face serious financial disadvantages, however. For example, private guardians do not receive foster and/or relative care subsidies; they do not receive housing benefits, nor do any benefits that the disabled parent received transfer to the children after the parent dies; they are not eligible for Temporary Assistance to Needy Families (TANF); and private guardians frequently have difficulty obtaining insurance for children.⁵

Families' and Children's AIDS Network (FCAN) in Illinois implemented two programs that provide some assistance for private guardians. FCAN reports, however, that these two programs are rarely used for children in the care of the Department of Children and Family Services (DCFS). This may be attributable to the fact that the available benefits are not great enough, in comparison with other programs, to make participation worthwhile. Successor Guardianship, for example, offers benefits to foster parents who are willing to assume guardianship responsibility for children age 14 and over who are DCFS wards. Successor guardians in Illinois receive \$1 less per month than do foster parents.⁶

Children placed with relatives in Illinois may also have the permanency option of Delegated Relative Authority (DRA).⁷ For children for whom goals of adoption, private guardianship and successorship are not currently appropriate, DRA "allows relatives to assume additional responsibilities for children as delegated to them by the Department [of Children and Family Services], and in return reduces Departmental intervention."⁸ Children in the DRA program live with relatives but continue to be under DCFS guardianship; they are "consequently entitled to receive board payments and remain eligible for medical services."⁹

Authority delegated to relatives under the DRA program includes some, but not all, decision making that was formerly the sole responsibility of DCFS, including the ability to:

- obtain regular medical and dental checkups (but not major medical care, which still requires DCFS authorization);
- take children out of state (for up to 30 days);
- release confidential information under certain circumstances; and
- manage any funds provided for services for the child(ren).¹⁰

Subsidized Guardianship

Some states have received child welfare waivers that allow them to use federal funds to support the care of children in private guardianship. Under these waivers, states can create formal, *subsidized guardianship* arrangements and use Title IV-E funds to subsidize the guardians. In the past, Title IV-E funds were reserved for payments to foster care providers. To date, California, Connecticut, Delaware, Illinois, Maryland, and North Carolina have received five years of funding from HHS as part of a demonstration project for subsidized guardianship.¹¹ In addition, the new Adoption and Safe Families Act of 1997 (P.L. 105-89), authorizes HHS to conduct up to ten demonstration projects per

year from fiscal years 1998 through 2002, including projects designed to address kinship care.¹²

Subsidized guardianship has numerous advantages. *Connecticut Voices for Children* advocated for subsidized guardianship in Connecticut last year and stressed the following benefits to such legislation: first, subsidized guardianship provides more continuity and stability for children by placing them in the custody of trusted and loved adults, rather than in the custody of the state; children are more likely to move from home to home when placed in foster care. In addition, becoming a court-appointed guardian does not terminate parental rights. Thus, caregivers, who are often relatives, are not faced with requesting that the court terminate the parental rights of their own family members. Finally, subsidized guardianship conserves state resources by decreasing foster care expenditures and reducing costs associated with judicial oversight of foster care placements.

Generally, to be eligible for the guardianship assistance, a child must be in the legal custody of the state and have been living for a minimum amount of time in a successful out-of-home placement with a prospective guardian. In addition, some states limit the subsidized guardianship option to children for whom both adoption and reunification with parents have been ruled out as appropriate permanency planning options. Further restrictions may apply and vary from state to state. For example, Maryland will not subsidize kinship families "which are deemed by the State to be functioning marginally or where significant ongoing services are needed."¹³

In July of 1997, Connecticut passed Public Act 97-272, establishing a program of subsidized guardianship. Under this law, the guardian receives both a special-needs subsidy and a medical subsidy. The special-needs subsidy is a "lump sum payment for one-time expenses resulting from the assumption of care of the child when no other resource is available to pay for such expense."¹⁴ The program also provides a monthly subsidy payable to the relative caregiver that "shall be equal to the prevailing foster care rate."¹⁵ The subsidy is available to those children living with relative caregivers who have been in foster care no less than 18 months. Advocates plan to introduce legislation this session to amend the current subsidized guardianship law to include subsidies for children who have been in foster care for six months.

Currently, Connecticut is discussing broadening its waiver to allow expansion of subsidized guardianship to other types of guardians, such as standby guardians or guardians to children who are not in the foster care system. Connecticut intends to introduce such legislation this session to extend subsidies to those not in the foster care system so as to avoid placement into foster care at all.

Co-Guardianship

joint guardianship or *co-guardianship* (as opposed to standby guardianship), which provides for equal sharing of custodial rights and responsibilities until the death or resignation of one of the joint guardians, at which point the remaining guardian assumes full custody and responsibility for the child.¹⁶ As in standby guardianship, the goal of co-guardianship is to ensure that a terminally ill parent can secure the guardianship without relinquishing parental rights until the parent is no longer able to care for the child. Once an HIV-infected parent begins this process, the necessary court investigation will be completed and the court order and letters of guardianship will be in place. When the parent is no longer able to care for the child, the guardian chosen by the parent can assume full responsibility.

Practitioners in California cite several advantages to co-guardianship. First, when the HIV-infected parent chooses a co-guardian, that co-guardian assumes some responsibilities for the child from the beginning and helps to ease the parent's burden. Thus, the parent and the co-guardian are involved both emotionally and legally with the child once the parent begins feeling ill. Second, from the child's perspective, having a co-guardian involved gives that child an additional adult on whom to rely when the parent is ill. Finally, the joint guardian is a part of the child's life before and after the parent's

death. In this sense, it provides the child with a sense of continuity and comfort.

Connecticut also passed a co-guardianship statute during the last legislative session. Title 17, section 45a-616(b) allows the parent, through a court process, to appoint one or more persons to serve as co-guardians of the child. The parent may either ask the court to appoint the guardian immediately or upon the occurrence of a specified contingency, "including, but not limited to, the mental incapacity, physical debilitation, or death of that parent."¹⁷

Update on Standby Guardianship

The Adoption and Safe Families Act of 1997 (P.L. 105-89) includes a provision that encourages states to pass a *standby guardianship* law. Section 403 provides: "It is the sense of Congress that the States should have in effect laws and procedures that permit any parent who is chronically ill or near death, without surrendering parental rights, to designate a standby guardian for the parent's minor children." While this provision does not require states to pass such legislation, it can be used as persuasive authority in those states trying to pass a standby guardianship law.

Standby Adoption: A Proposal

By Linda S. Coon, Legal and Policy Director, Family Options Project, Chicago

In recent years, one of the responses to the impact of the HIV epidemic on family systems has included the development of permanency planning initiatives and programs. One of the earliest initiatives in Illinois with respect to permanency planning for HIV-affected families involved the passage of legislation creating standby and short-term guardianships. These two guardianship alternatives, although not limited to families with HIV or any other terminal illness, are being used with increasing frequency by families affected by HIV. In standby guardianship situations, a court appointment may be made designating a person approved by the parent and the court to act as standby guardian, effectively "standing" by until such time as the parent is incapacitated or dies. In short-term guardianship situations, parents can designate another adult to assume guardianship responsibilities on a short-term basis (up to 60 days).

Advantages of standby guardianship include the ability of parents to designate someone of their choosing as standby guardian, and to petition the court for a formal appointment of the standby guardian. Parents have the ability to provide testimony as to their preference concerning future guardianship of their children while they are alive and able to do so. After the standby guardian is appointed, the parents may retain day-to-day care, custody, and control of their children until the parent dies or is no longer able to make and carry out day-to-day child care decisions. *Short-term* guardianship provides the parent with the ability to temporarily delegate guardianship responsibility, and has proven to be especially helpful during periods of time when parents are hospitalized or otherwise incapacitated.

These two alternative guardianships have provided Illinois families with increased flexibility in permanency planning.¹⁸ Few HIV-affected families, however, have chosen adoption as an option for their children when doing permanency planning. Generally, those families that have chosen adoption have been families appropriate for related (or stepparent) adoption, or ones in which the parents have already died. Except in those instances where the parents still retain their parental rights (as in stepparent adoption), adoption is seldom chosen as a permanency goal in instances where the parent is still living. Parents are understandably reluctant to consent to adoption when it means that all their parental rights will end. Yet some have expressed the wish to find future adoptive homes for their children. Family advocates have developed a proposal for standby adoption that could help families

who want the security of a court appointment, but who also want to retain their parental rights as birth parents and preserve the birth family's living situation.

What Standby Adoption Would Mean

Standby adoption is envisioned as an adoptive appointment that does not take effect until the occurrence of a future event--usually the death of the parent. Standby adoption would involve following the procedures required to accomplish a regular adoption in adoption court, except that the appointment would not take effect immediately, but would become effective at the parent's death. Unlike Illinois standby guardianship law, which permits any parent, regardless of health status, to petition for appointment of a standby guardian, standby adoption would not be available to all parents. Rather, because of the finality of adoption decisions and the special circumstances of terminally ill parents, standby adoption would only be available to terminally ill parents.

As conceptualized, standby adoption has the following advantages:

- It would let parents designate a person(s) of their choosing as adoptive parents, and, if approved by the court, ensures that the adoption is completed without requiring parents to give up custody of the child, and without requiring that they relinquish parental rights.
- It would provide finality for birth and adoptive parents and for the child, in that, as with regular adoptions, the adoption becomes legal upon the court's order.
- It would give birth parents the opportunity to provide testimony concerning the adoption to the court while they are still alive. Frequently, because birth parents do not want to give up their parental rights, they are (understandably) unwilling to initiate adoption proceedings, and thus do not have the opportunity to be heard in court.
- Like standby guardianship, the standby adoptive appointment would not take effect until the occurrence of a future event: either the death of the parent, or the parent's consent to termination of his or her parental rights so that the adoption could be immediately legalized.

It is anticipated that parents might consent to termination and legalization when they are no longer able to provide care and custody, and wish for the adoption to be completed. Because of the finality of adoption decisions, standby adoption would, however, provide greater security in terms of permanency than would a standby guardianship appointment.

Making standby adoption a legal alternative for Illinois families would require modifying Illinois adoption law in much the same way that Illinois guardianship law was changed in order to accommodate standby guardianship. Providers of social and legal services for HIV-affected families believe that making standby adoption a legal option could help ensure permanency for children and help provide parents with peace of mind concerning their children's future.

Program Highlights: Permanency Planning for Families Affected by HIV/AIDS

Everyone involved in permanency planning--parents, children, and new caregivers--needs ongoing supportive services. HIV-infected parents need help preparing and planning for their children's future care. The child needs help coping with the parent's illness and preparing for the parent's death. The

new caregiver needs assistance in preparing to take on a new parenting role. Once the parent dies, both the caregiver and the child need ongoing support to cope with grief and loss, as well as to ease the transition into a new family.

Professionals around the country in the permanency planning field note a lack of clinical supports for the new caregiver. Many programs do not address follow-up work and counseling for the new caregiver once the parent dies. Since most funds are tied to the HIV-infected individuals themselves, case managers are rarely able to work with the future caregiver once the HIV-infected parent dies.

Despite this obstacle to funding, programs do exist that specifically address the needs of HIV-infected parents and new caregivers. We chose several programs throughout the country that exemplify a comprehensive approach to permanency planning. A common thread running throughout the following highlighted programs is that they work with the HIV-infected parent, the child(ren) and the future caregiver throughout the parent's illness and continue support services once the parent dies. Another commonality among successful programs appears to be the collaboration of social service providers and attorneys to serve families in a comprehensive manner. By interweaving legal and social services, the programs effectively ensure that the emotional and psychological needs of the family are legally protected and their decisions enforced.¹⁹

1. The AIDS Resource Foundation (Newark, NJ): The AIDS Resource Foundation for Children's Permanency Planning Project provides counseling, legal help, and linkages to services for parents living with HIV/AIDS. Case managers, the agency's consulting psychologist, and lawyers from Legal Services and other legal agencies work cooperatively with families on guardianship planning. Social workers provide counseling to parents and children in their homes, as well as at the agency's offices in Newark. When it is necessary to meet with a lawyer to petition the court for standby guardianship, draft wills, or obtain legal counseling, the social worker arranges a meeting with the lawyer, the parent, and the eventual guardian. Once the guardianship plans have been made, the family continues to receive support from the agency. Case managers link the family with services and help to obtain medical care. Counseling is also available to other family members. In addition, the agency provides a number of after-school programs and a family summer camp. Contact: AIDS Resource Foundation, 182 Roseville Avenue, Newark, NJ 07107.

2. AIDS Legal Council of Chicago (Chicago, IL) As part of its Abandoned Infants Assistance (AIA) funds, AIDS Legal Council of Chicago recently began a pilot program in conjunction with the Department of Family and Children's Services where a social worker and lawyer work together with the client. In addition to casemanagers, a social worker offers a full range of therapy and counseling, in conjunction with the attorney, who presents the legal options. The social worker and attorney meet on a weekly basis to review the case. The project also provides an evaluation component, for which the agency assesses each family six months after the guardianship has been granted. Contact: AIDS Legal Council of Chicago, 220 South State Street, Suite 1330, Chicago, IL 60604.

3. Center for Family Connection (Cambridge, MA) This agency provides clinical counseling on facilitating relationships between the caregiver and the dying parent through education, counseling and negotiation. When the parent is ready to negotiate a standby guardianship with a caregiver, the agency works with attorneys to arrange a legal agreement. Contact: Center for Family Connection, 2326 Massachusetts Avenue, Cambridge, MA 02140.

4. Council on Adoptable Children, AIDS Orphans Adoption Program (New York, NY) COAC's goal is to place as many children who are orphaned by AIDS as possible in permanent, loving, nurturing homes. A key component of the program is to identify HIV-infected parents who have no next of kin and who need assistance in finding adoptive parents. The staff counsels parents in making permanency plans for their children. An attorney is accessible to provide legal assistance and to facilitate the parent's plan. COAC also has a family support component that provides postplacement psychological counseling for children and adults. The program recruits and trains parents who plan on adopting and who wish to be guardians as well. Contact: New York Council on Adoptable

Children, 666 Broadway, Suite 820, New York, NY 10012.

5. Families Connecting for Kids (Denver, CO) Families Connecting for Kids is a program created by the Adoption Exchange, also in Denver. The program provides a range of services to HIV-affected families that are designed to support the family as a unit throughout its struggle with the disease. The program provides information and counseling regarding the legal options families have when planning their children's future. The agency has an extensive network of counselors and lawyers who are willing to provide services to families on a pro bono basis. The staff also helps coordinate medical and social services for the families. Contact: Adoption Exchange, 925 S. Niagra, Suite 100, Denver, CO 80224.

6. Family Pairs (Birmingham, AL) Family Pairs is a program developed by the Children's Aid Society in Birmingham. The program's purpose is to "provide a support network and continuum of care in helping HIV-positive parents make permanent plans for their children." The primary goal of Family Pairs is to keep families together as long as possible. The staff visits the HIV-infected parents' home and works with the parent and family to counsel them regarding available permanency planning options. The staff assists in helping the parents identify and screen a permanent resource family for the child, assists the parents with the available legal options, and provides ongoing counseling for the parents and child to ensure a smooth transition and to ease their grief. A "Family Pair" is a family, individual, or relative who is paired with an HIV-affected family. The program recruits, screens, and trains the Family Pair to provide varying degrees of support to the HIV-affected family. Support can include: friendship services, transportation, respite foster care, or temporary foster care. In some cases, the Family Pair may become an adoptive resource for the child. Contact: Children's Aid Society, 3600 8th Avenue South, Birmingham, AL 35222.

7. Living Legacy Project (Somerville, MA) The Living Legacy Project works collaboratively with the Boston Pediatric AIDS Project and a Legal Aid agency to provide family-centered, home-based counseling to HIV-infected parents to help them to plan and prepare for the future care of their children. Social workers provide home-based counseling to family members on issues related to HIV-education, permanency planning, disclosure, guardian choice, family conflict, grief, and death and dying. The agency works with the clients to mentally and emotionally prepare them to make plans for their child's future. In addition, the agency encourages the parents to put together scrapbooks and videotapes of memories for the child. The agency then collaborates with the program's legal advocate to complete a legally enforceable plan. In the rare instance where no suitable kin can be found, it provides counseling and legal assistance in matching children with families who want to adopt. The agency continues to work with the guardian once the parents die, offering stabilization services and grief counseling to families, guardians, and children. Contact: Living Legacy Program, 270 Washington Street, Somerville, MA 02143.

8. Second Family (Oak Park, IL) A program of Lutheran Social Services of Illinois, Second Family assists parents in finding loving, stable, and supportive families to care for their children after the parents' death. When placement with relatives is not possible, the birth parents choose from a pool of prospective parents (second families) who are recruited and trained by LSSI staff to care for the special mental and physical needs that many children in this situation experience. Second families take increasing responsibility for children as the HIV-infected parent's health deteriorates. In addition to developing permanent placement plans for their children, Second Family helps HIV-infected parents link with AIDS services in their communities and coordinate social and medical services. Second Family grew out of the 1991 task force convened by FCAN in Chicago. This program recently received the Drucker Foundation Award for Nonprofit Innovation in March 1997. Contact: Second Family, 1144 Lake Street, Third Floor, Oak Park, IL 60301

9. Tanya's Children (Los Angeles, CA): Tanya's Children is a center for parents with HIV/AIDS to obtain adoption information, legal referrals, counseling, emotional support and other services. The agency works collaboratively with attorneys by referring HIV-infected parents to Public Counsel, who provides legal service to these families. While the parent works with Public Counsel on legal issues, Tanya's Children reviews potential adoptive parents or legal guardians who have completed a

foster parent training program and provides a narrowed list to the parent, unless the parents and children have pre-selected a friend or family member to assume one of the roles. Tanya's Children fosters a relationship between the parents and potential guardian if the parents choose someone they do not know. Contact: Tanya's Children, 15117 Ventura Blvd. #1, Sherman Oaks, CA 90018.

10. Yale Child Study Center (New Haven, CT): Yale Study Center is beginning a pilot program, funded by the Abandoned Infant Assistance (AIA) Act, that uses the standby guardianship law in cases of substance-abusing parents. Parents currently dealing with drug addiction who cannot adequately parent identify a guardian to care for their child(ren) while they are incapable of doing so. This enables the parents to provide stability for the child without eliminating the parents from the child's life. Contact: Yale Child Study Center, 47 College Street, Suite 218, New Haven, CT 06510.

HIV Permanency Planning News was written and compiled by Hillary Kushins, a 1998 graduate of the University of Maryland School of Social Work and School of Law.

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Endnotes:

¹ Despite advances in medicine for those living with HIV/AIDS, no cure exists to date. A recent study at the Johns Hopkins Medical School, for example, reported that the newest drug therapy "triple drug cocktails," did not eradicate the disease-causing virus, even when standard tests showed that the drugs had diminished the virus to undetectable levels. Reported by Jonathon Bor, "AIDS Cocktail a respite, not a cure," *Baltimore Sun*, Nov. 14, 1997, p. A1.

² In the United States in 1985, 7% of new AIDS cases reported were women. In 1990, the percentage rose to 10%, 13% in 1992, 19% in 1994, and 25% in 1996. Centers for Disease Control and Prevention (CDC), *HIV/AIDS Surveillance Report*, 1996.

³ National Institute of Allergy and Infectious Disease, *Women and HIV Infection*, National Institutes of Health (September 1997).

⁴ Article 17 of the Surrogate's Court Procedures Act governs New York State guardianship law.

⁵ Families' and Children's AIDS Network (FCAN). (1995). "HIV-Affected Children, Youth and Families in Chicago: Building an Advocacy Agenda for Permanency." This report provides an assessment of the service and policy needs of HIV-affected children, youths, and families in Chicago. It also contains recommendations for needed programs, policies, and legislation. For a copy of the report, send a written request to: FCAN, 53 W. Jackson Blvd., Suite 409, Chicago, IL 60604. There may be a nominal charge for the report.

⁶ Id. at 74.

⁷ Id. at 74-5.

⁸ Id. at 75.

⁹ Id. at 75.

¹⁰ Id. at 75.

¹¹ HHS press releases regarding the particular waiver of each state can be found by visiting <http://www.dhhs.gov>.

¹² 42 U.S.C. § 1320(a)(3)(C)(1997).

¹³ Health and Human Services, Administration for Children and Families. (1997). Child Welfare Waiver Demonstration Project for the State of Maryland, § 2.2.

¹⁴ P.A. 97-272. § 7(c)(1).

¹⁵ P.A. 97-272. § 7(c)(2).

¹⁶ Cal. Prob. Code § 2105(f).

¹⁷ CT. ST. § 45a-616(b).

¹⁹ See Randy Retkin, Gary Stein, & Barbara Draimin, *Attorneys and Social Workers Collaborating In HIV Care: Breaking New Ground*, Fordham Urban Law Journal (1997), for a discussion of the complex ethical and service questions that arise when attorneys and social workers collaborate on behalf of their clients. The article also presents various models of partnerships among the legal and social service professionals.

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Domestic AIDS / Orphans File

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(AIDSLINE) Caregiver issues and AIDS orphans: perspectives from a social worker focus group.

J Natl Med Assoc. 1997 Oct;89(10):684-8. Unique Identifier : AIDSLINE MED/98007275

Paige CY; Johnson MS; Department of Family Medicine, NJ Medical School-UMDNJ, Newark; 07103, USA.

Abstract: This study examines social workers' perceptions of the needs of families coping with acquired immunodeficiency syndrome (AIDS). This research investigates the problems of family caregivers of children orphaned by human immunodeficiency virus (HIV)-related death of their parents. A qualitative semistructured interview format was used in a focus group of 18 social workers. Four questions were designed to assess family needs and resources, as well as to evaluate the social workers' perspectives of governmental policies affecting these families. A list of four problems and two recommendations for change evolved from the focus group. Inadequate finances to house and care for the children was the primary cause for distress in these families. The major governmental policy that hindered the social workers' ability to assist families pertained to the low financial entitlement for caregivers who are related to the orphaned child. It was noted that unrelated caregivers receive substantially more money for the care of these children than family caregivers receive. Recommendations were made to change this policy and to develop guardianship laws that facilitate families' abilities to provide care to AIDS orphans. Family caregivers of AIDS orphans are bombarded with great demands and limited resources. This analysis of their situation from the social workers' perspective is a positive step toward the improvement of support services for these families. Further research should include individual qualitative interviews assessing the needs of the caregivers and AIDS orphans.

Keywords: *Acquired Immunodeficiency Syndrome *Caregivers Child *Child of Impaired Parents *Foster Home Care Human New York Public Policy *Social Welfare JOURNAL ARTICLE

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CDC NCHSTP Daily News Update Database

Accession Number: N21997

Title: AIDS and Comfort

Authors: Ifateyo, Ajowa

Source: Miami Herald (12/30/96) P. 3B

Abstract: In Broward County, Fla, grandmothers who are called on to care for their grandchildren after their children die of AIDS have formed the Family CARES Network. Members meet once a month for support, as well as to share food, clothing, and medical supplies. They also organize picnics, trips to the zoo, and other events for the children. Moreover, some of the group members take in children of members who have died. "I really consider them crusaders, taking on this incredible challenge," commented Stormy Schevis, coordinator at the Children's Diagnostic Center of the North Broward Hospital District.

Major Descriptors: Orphans. Elderly persons.

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Title

AIDS orphans in Louisiana in the year 2000: the potential economic impact on the foster care system.

Author

Parsons S; Merrick-Roddy P

Address

Dept of Public Administration, Southern University, Baton Rouge, La., USA.

Source

J La State Med Soc, 1996 Sep, 148:9, 391-8

Abstract

This study estimates the number of AIDS orphans in Louisiana and projects the fiscal demand on the state's foster care system in the year 2000. The Michaels and Levine model is used to estimate the number of orphans, and state foster care data are used to project the placement cost of those AIDS orphans. Between 1992 and the year 2000, the AIDS orphan count in Louisiana is estimated to range between 1,242 and 2,627 infants and children. Black children are estimated to comprise the overwhelming majority of this population. If only 50% of the AIDS orphans this study projects for the year 2000 require foster care services, the state of Louisiana would need additional revenues for that year alone, ranging from \$308,112 to \$624,546, to serve those new entrants. This study provides a critical starting point for state policy planning. The AIDS orphan population in Louisiana is growing each year and the needs of these infants and children must be anticipated and accommodated.

Language of Publication

English

Unique Identifier

97294995; MED/97294995



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MeSH Heading (Major)

Acquired Immunodeficiency Syndrome|*/EP/MO; Foster Home Care|*/EC/TD

MeSH Heading

Child; Female; Forecasting|MT; Human; Infant; Louisiana|EP; Male

Publication Type

JOURNAL ARTICLE

ISSN

0024-6921

Country of Publication

UNITED STATES

JAMA HIV Document

Record 1 from database: **AIDSLINE**



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Title

Ethical issues in developing policies for orphans of the HIV epidemic.

Author

Levine C

Address

The Orphan Project, New York City, NY, USA. Fax: (212) 925-5675. E-mail: clevine@fcny.org.

Source

Int Conf AIDS, 1996 Jul 7-12, 11:2, 389 (abstract no. Th.D.4874)

Abstract

Issue: The emergence of a population of children and adolescents orphaned by HIV/AIDS is a phenomenon that crosses national boundaries. Several ethical issues that transcend local conditions need fuller analysis. Project: Focusing on the ethical principles of justice and beneficence (promoting well-being and protecting from harm), the author has combined an ongoing analysis of the U.S. response to AIDS orphans with the results of an international survey, a literature review, and interviews. Results: (1) The extended family is the primary locus for orphans' care and custody. In recognizing family autonomy, how can children be protected from the potential familial exploitation that may accompany placement in a new home? (2) Societal stability is an important influence on the ability of children and families to adjust to new conditions of decreased resources. In promoting stability, how can practices that discriminate against women and children be changed? (3) Many children, including orphans of other diseases and violence, need assistance. How can the needs of AIDS orphans be addressed without taking resources away from other vulnerable youngsters? (4) Although family life may be the goal, it is not always possible. How can children who must be cared for in congregate settings be treated in ways that do not discriminate against them because of their own or their parent's HIV status? (5) HIV testing is a useful tool in identifying HIV-infected children who need special care. How can HIV testing be introduced in ways that benefit and do not harm children by stigmatizing them or denying them care? (6) Both immediate and long-term needs of orphans and their families must be addressed. How should the short-term needs be balanced against the need for sustainable programs? Lessons Learned: Ethical issues should be addressed explicitly in national and local policy development. The cultural and economic context is essential background for a comprehensive analysis. Analyses from a global and cross-national perspective should be undertaken.

Language of Publication

English

Unique Identifier

96925171; ICA11/96925171



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MeSH Heading (Major)

Child Welfare[*]; Child, Abandoned[*]; Ethics[*]; HIV Infections[*]/EP/MO

MeSH Heading

Adolescence; Child; Human; Public Policy; United States|EP; Violence

CDC NCHSTP Daily News Update Database

Accession Number: N20196

Title: Across the USA: New York

Source: USA Today (04/17/96) P. 11A

Abstract: AIDS will leave 58,000 children in New York motherless by 2001, researchers at City University of New York Medical School estimate. Nine out of 10 of the children will be black or Hispanic.

Major Descriptors: Orphans. Blacks. Hispanics. Statistics.

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CDC NCHSTP Daily News Update Database

Accession Number: N20000

Title: N Vital Statistics: AIDS Orphans

Source: Washington Post--Health (03/19/96) P. 5

Abstract: A growing number of children are being orphaned by AIDS, which has become the leading cause of death among women of childbearing age in the United States, according to a new study in the Journal of the American Medical Association. Experts project that about 144,000 children and young adults will have lost their mothers to AIDS by the year 2000, unless the current trend shifts dramatically.

Major Descriptors: Orphans. Mothers with HIV/AIDS. Death or dying.

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CDC NCHSTP Daily News Update Database

Accession Number: N18474

Title: In Whose Care and Custody? Orphans of the HIV Epidemic

Authors: Levine, Carol

Source: AIDS Clinical Care (08/95) Vol. 7, No. 8, P. 66

Abstract: Most young people who survive the AIDS death of a parent are at high-risk for economic loss, as well as both behavioral and developmental problems. As teens, they are likely to engage in high-risk activities related to HIV transmission. Some of these children require new sources of financial assistance, shelter, food, and medical care. David Michaels, an associate professor at the City University of New York Medical School, estimates that by the year 2000, between 72,000 and 125,000 U.S. children and teenagers will have lost their mothers to HIV/AIDS. One study found that almost 60 percent of the children whose mothers had died went to live with their grandmothers or aunts. HIV-infected parents report feelings of extreme isolation and anxiety about their own and their children's health, as well as the financial toll of illness. A study of HIV-infected families headed by single mothers found that they were "overextended with caregiving responsibilities and confronting multiple stressors." One very difficult task for HIV-infected parents is planning for the future custody of their children. Often, for example, if a parent names guardian in a will, the choice may not be honored by the family court judge or surrogate. If a parent selects a guardianship petition, she relinquishes critical decision-making rights and perhaps actual custody of her children while she is alive.

Major Descriptors: Orphans. Families. Children. Mothers.

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AIDS Daily SummaryA small rectangular button with a dotted border containing the text "Jump to other years".**AIDS Orphans**

Journal of the American Medical Association (06/28/95) Vol. 273, No. 24, P. 1960

Callan, Monnie B.

"AIDS and the New Orphans: Coping With Death," edited by Barbara O. Dane and Carol Levine, offers a new perspective on the issue of children orphaned by AIDS. The book is a compilation of works by several authors who examine the different developmental stages in relation to coping with death. They include step-by-step recommendations on how to prepare children for parental loss, with particular understanding of the additional burdens of AIDS-related secrecy and stigma. Each chapter offers Latino and African-American cultural coping mechanisms, as well as the spiritual side of childhood loss. Both this publication and its predecessor—"A Death in the Family: Orphans of the HIV Epidemic," also edited by Levine—sensitize the reader the challenges of the children and families orphaned by AIDS, and open the door to policies and programs that might alleviate the full impact of these problems.

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AIDS Daily Summary[Jump to
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years](#)**Who Will Care for Children when Parents Die of AIDS?***Philadelphia Inquirer (02/08/95) P. H1***Martin, Antoinette**

Since late last summer, a series of public service announcements by the National Council for Adoption (NCFA) has urged parents with AIDS to arrange adoptions for their children before they die. One of the ads says, "AIDS. Kids. If you have both, maybe it's time to take a closer look at adoption." The ads have been on television and radio stations in cities including Philadelphia, New York City, Detroit, and San Francisco. "We are targeting areas where the AIDS epidemic is prevalent," says William Pierce, president of the Washington, D.C., non-profit group. Pierce says that hundreds of calls--from people with AIDS, support groups, and people wanting to adopt--have flooded the phone lines since the ads began airing last spring in the Washington area. There have been no negative responses. So far, 64 children have been adopted as a result of the national campaign. The number of children in the United States that have been orphaned by AIDS is estimated to be about 35,000. Health officials project that by the year 2000, there will be between 70,000 and 125,000 AIDS orphans, says Pierce.

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AIDS Daily Summary**Jump to
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years****Orphans of the Epidemic***Focus (12/94) Vol. 10, No. 1, P. 7***Tufel, Robert**

An outgrowth of a conference sponsored by the Orphan Project and the United Hospital Fund, "A Death in the Family: Orphans of the HIV Epidemic," explains the needs of surviving children and adolescents, their families, and new guardians. The issues raised by the increasing numbers of "AIDS orphans" are described from several perspectives including law, mental health, program development, and advocacy. The book, edited by Carol Levine, features writings by providers working with HIV-affected families as well as personal essays by HIV- infected parents and affected family members. One of the first books to systematically document the complex issues facing HIV-affected families, "A Death in the Family" represents--according to Levine--the "first steps in a long journey" in acknowledging the problem of HIV-affected orphans.

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AIDS Daily Summary**Jump to
other
years****Motherless Child***American Medical News (04/18/94) Vol. 37, No. 15, P. 11****Pinkney, Deborah Shelton***

The AIDS epidemic will leave between 72,000 and 125,000 American children and adolescents motherless by the end of the decade, calculates Dr. David Michaels, an epidemiologist at City University of New York Medical School. "Unless increased attention and resources are devoted to this vulnerable group, a social catastrophe is unavoidable," he says. Few orphans are themselves infected with the deadly virus, since children born with HIV usually die within the first four years of life. But the Centers for Disease Control and Prevention estimates that 93,000 to 112,000 healthy children will be born to HIV- positive mothers between 1992 and the year 2000. Despite these projections, little is being done and, ironically, a recent medical breakthrough could worsen the situation. A new study found that **AZT** lowered the risk of perinatal transmission of HIV to less than 10 percent. "My first reaction to this was joy at the thought of children who will be spared this disease," comments Dr. Blake Caldwell, a CDC medical epidemiologist. "But the second thought was of the number of children who will now be born uninfected and lose their mothers." AIDS orphans must confront feelings of shame, stigma, and isolation, yet a recent study by the Orphan Project found that these children are lacking services, in particular mental health and bereavement services.

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VIEW IN FRAME

Books in Print



AIDS and the New Orphans: Coping with Death

Auburn House, 88 Post Road West, Westport, CT 06881. 158p., bibliog., index. ISBN: 0-86569-220-3, 0-86569-249-1pbk. \$49.95, \$17.95pbk.

edited by Barbara O. Dane, Carol Levine. 1994. (13 contributors to this volume)

The impact of AIDS on children is enormous. This book speaks to this problem by allowing "the reader to develop a fresh, albeit sobering, perspective on the scale and nature of problems faced by orphaned children." The contributors have provided an array of articles that clearly show how important family relationships are in dealing with the death of a parent. The need for continuity is vital if the child is to develop into an adult and the contributors show this in the papers in this book. The nine chapters cover: "The New Orphans and Grieving in the Time of AIDS," "Death and Bereavement," "Suffer the Little Children: The Child and Spirituality in the AIDS Crisis," "Parental Loss and Latency Age Children," "Adolescents and Parental Death from AIDS," "Latino Communities: Coping with Death," "Black American Communities: Coping with Death," "Bereavement and the New Guardians," and "Programs for Children and Adolescents."

This is an excellent book. In some parts of our society, death from AIDS is still not socially accepted and as a result the children suffer. We have such people as Reverend Phelps from Topeka, Kansas, who pickets the funerals of AIDS victims with signs that say faggots die, good riddance, and other non-printable remarks. As long as there are individuals who do this, we will have great difficulty in counseling the children of these victims. They many times do not understand unless they have a very strong family around them. That is the message of this book. The unfortunate aspect of this entire situation is that most of the children who will be orphaned by AIDS will come from socioeconomically disadvantaged minority families. The parent may not reveal that he or she has AIDS because of all the other problems that surround the family. Here is where proper counseling is needed so that these children can understand what is facing them and help them to cope with their loss. This book is highly recommended for all counselors and should be in all libraries.

Keywords: Children of AIDS Patients, Bereavement

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AIDS Daily Summary**Jump to
other
years****A Legacy of AIDS: Orphans***Washington Post (03/29/94) P. A3***Vobejda, Barbara**

AIDS will leave 72,000 to 125,000 American children without mothers by the year 2000, reports a study released today. Conducted by the Orphan Project in New York City, it is the first study to provide estimates for the six cities hardest hit by the problem: New York; Newark, N.J.; Miami, Fla.; San Juan, Puerto Rico; Los Angeles; and Washington, D.C. "The scope of it is stunning," says co-author Carol Levine, executive director of the Orphan Project, which conducts research on policies to help children and young adults affected by AIDS. According to Levine and co-author Gary L. Stein, these children have many needs, including mental health services, housing assistance, and legal services. They note that with the loss of a parent, the child also loses an important source of financial and AIDS-related assistance. A problem arises, say the authors, when states neglect to provide assistance to relatives who take in AIDS orphans. Although they are willing to do so, relatives often cannot assume the financial burden. The report offers several suggestions, including flexible foster care programs in which the child is temporary placed when the parent is ill, returning home when health has improved. The study was based on a mathematical model of the number of women who have died from HIV-related disease. David Michaels, a professor of epidemiology, says the estimates may be conservative, since they include neither children whose parents are infected but are still alive, nor children whose fathers have died of AIDS-related causes. Related Stories: New York Times (03/29) P. B4; Philadelphia Inquirer (03/29) P. A1

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INFECTIOUS DISEASES IN CHILDREN

a SLACK Incorporated newspaper

The hidden plague: Number of AIDS orphans rising

Those orphaned by the virus could top 125,000 in next five years, public health officials say.

[Staggering numbers] [Microcosms of the orphan problem]
[What is being done]

[Your turn]

February 1998

NUTLEY, N.J. - AIDS is known in many parts of the country as the disease of mothers and fathers, whose legacies are the growing number of orphaned children left behind, forcing state and federal health officials to face yet another aspect of the epidemic.

Staggering numbers

By 2000, between 72,000 and 125,000 children and teenagers in this country will have lost their mothers to HIV. An additional 60,000 young adults 18 years and older will have lost their mothers. The hardest-hit cities will be New York City; Newark, N.J.; Miami; San Juan, Puerto Rico; Los Angeles; and Washington, D.C. According to the non-profit organization Orphan Project in New York, the estimates for the number of children and young adults who will be orphaned by the epidemic in these cities by 2000 are:

- New York City - 30,000
- Newark, N.J. - 7,200
- Miami - 4,900
- San Juan, P.R. - 4,200
- Los Angeles - 1,900
- Washington, D.C. - 1,200

"AIDS really breaks the rules when one thinks of dying," said Gwen Scott, MD, director of pediatrics at the University of Miami's Project Cradle, a program designed to assist those orphaned by the epidemic. "It strikes the young rather than old and decimates entire families and communities, which is leaving as a legacy a growing generation of orphans."

Almost unnoticed, the epidemic has been responsible for the creation of a new, large and especially vulnerable group of parentless children. Right now, there are more than 45,000 orphan victims of AIDS living in the United States. Not surprisingly to activists and health officials, the majority of AIDS orphans are concentrated in those urban areas where the virus is most prevalent. And, as with other urban problems, the greatest proportion of these motherless and fatherless children live in minority communities. In fact, African-American and Hispanic groups account for close to 90% of AIDS orphan cases.

"While AIDS becomes more entrenched in the inner cities, it's also fanning out into the countryside," said Scott. "Studies from Rhode Island and North Carolina on women with HIV describe the emerging problems of motherless children. Wherever there are women with AIDS, there will be motherless children."

The epidemic has come to rival or surpass other important causes of death in taking the lives of mothers of young children. Looking at women under the age of 50, cancer is the cause of death of mothers of about 4,200 children and 8,700 adolescents annually. Motor vehicle accidents are responsible for the deaths of mothers of an additional 3,200 children and 1,900 adolescents a year. But in contrast, the numbers of children and adolescents annually orphaned by AIDS are predicted to reach 3,900 children and 3,400 adolescents by the turn of the century.

Microcosms of the orphan problem

New York and New Jersey have the largest AIDS populations in the country, serving as microcosms for what the rest of the country is weathering, said Carol Levine, executive director of the Orphan Project in New York City.

In New York state, through the influx of immigrants and the density of its population, AIDS has become a major problem for the state's already overburdened health care system. Of New York state youth with mothers under the age of 50 dead from any cause by the end of 1996, an estimated 35% were children of women who died from HIV/AIDS. The proportion attributable to HIV/AIDS were higher in the younger age groups: The mothers of 44% of newly orphaned young children (0-6 years old) died of HIV/AIDS. For older children (7-12) adolescents (13-17), and young adults (18-21), the proportions were 39%, 34%, and 21%, respectively.

Reflecting distribution of AIDS deaths, children and teenagers orphaned by HIV/AIDS are concentrated in communities of color in New York state. More than half (54%) of all youth left motherless by HIV/AIDS are African American, about one-third (35%) are Hispanic, and the remainder (12%) are white. The proportion of maternal deaths from HIV/AIDS compared with those from other causes will be even greater in the African American and Hispanic communities. In 1996, HIV/AIDS were the cause of maternal death for 63% of all Hispanic youth orphaned that year, 49% of all orphaned African American youth, and 9% of all orphaned white youth, said health officials.

In New Jersey, 44,673 people have been diagnosed with AIDS since 1985, and almost 5,986 of them are women. For many years, the Garden State has had the highest percentage of infected women in the nation. Minority women make up about three-quarters of that number. At the time of their AIDS diagnosis, about 87% of these minority women were in their child-bearing or child-rearing years (13 through 49 years of age).

Children left motherless in New Jersey due to AIDS over a 10-year-period are estimated to number 10,000. By 2001, the predicted numbers indicate a dramatic rise to 18,000 children. During a comparable time, low estimates of motherless youth range from 9,000 to 14,300 and high estimates range from 11,600 to 20,500. Recognizing that women of color represent 79% of the total of reported cases of HIV-infected women in New Jersey, it's projected that a similar percentage of motherless children would be of African American or Hispanic heritage, said health officials.

What is being done

The death of a parent is one of the most traumatic experiences any child can suffer. But when that death is accompanied by stigma and isolation, followed by instability and insecurity, as it is in AIDS, the potential for social trouble is magnified, said Levine.

Two ways individuals and organizations are assisting HIV orphans are through standby guardianships and AIDS-focused organizations. Standby guardianships enable terminally ill parents with HIV to designate a surrogate to care for their children immediately upon their incapacitation or death. Guardians can be appointed in one of two ways - through a court petition or a written designation. The petition has the advantage of court approval, which is important if a relative contests guardianship. So far, seven states have enacted standby guardianship laws - Connecticut, Maryland, Florida, New York, New Jersey, Illinois and North Carolina among them.

Places like the St. Francis Center in Washington, D.C., and the Henry Street Settlement House in New York, are helping orphans with health, social and psychological services, getting them to face their depression and fear of abandonment. These organizations say many parents simply don't make plans because many times they are in denial over their illness, fearing retribution if their condition is disclosed. The parent's loss also means the disappearance of financial support for the child. Up until recently, the federal government has provided much of the funding for these orphans, but with the increasing numbers of children needing support, the government has placed much of the burden on the individual states. New York now has cash grants available for children living with new caregivers. Several other states are considering similar measures as they watch their orphan populations climb.

"There is a challenge to cities and towns already staggering under the weight of faltering economies, violence, homelessness, inadequate medical care, poor education, drug use and a list of other social problems," said Scott. "But we can't ignore the needs of these children unless we want a catastrophe."

For more information:

- Levine, C. Stein, G. Orphans of the HIV Epidemic-Unmet Needs in Six Cities. Published by the Orphan Project, 1995. Levine, C. Michaels, D. Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States. *JAMA*. 1992. 268: 3456-61.

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cmoore@aidspolicycenter.org**DATE:** 11/25/98**TOTAL PAGES:** 3**SUBJECT:** World AIDS Day**COMMENTS:**

Additional article of potential interest.

1996 June, BETA - HIV/AIDS in Children: Overview and Guidelines for Disease Management

By the end of 1995, the World Health Organization Global Programme on AIDS had received reports of nearly 1,300,000 cumulative cases of AIDS in 193 countries. The estimated number of actual cases is closer to 6 million. Nearly 40% of reported worldwide cases occur in the U.S., and, while the majority occur among gay and bisexual men, women and children are increasingly affected. By 1995, the U.S. Centers for Disease Control and Prevention (CDC) had received reports of 58,000 AIDS cases in women and over 5,500 AIDS cases in children. The National Center for Health Statistics (NCHS) estimates that there are approximately 10,000 HIV-infected children living in the U.S.

The first U.S. case of pediatric AIDS was reported in 1982. Early reports attributed HIV/AIDS in children to perinatal (vertical) transmission, transfusion and the use of contaminated blood products. Since the implementation of screening protocols for blood products and donor self-deferral, the proportion of children infected postnatally through transfusions and use of blood products has decreased substantially. Today, nearly 90% of cumulative pediatric AIDS cases and nearly 100% of new HIV infections in children result from perinatal transmission. Each year, an estimated 1,750 children in the U.S. are infected with HIV. AIDS is now the fifth leading cause of death for all children under 15 years old, and the leading cause of death for children 1-4 years of age, according to the NCHS.

Increasingly, perinatal infections are traced to women who report acquisition of the virus through heterosexual contact with a partner whose HIV status and risk factors were unknown. Heterosexual contact is the mode of HIV transmission increasingly responsible for new infections in women. In the U.S. Northeast and South, women of color are predominantly affected by rising rates of infection; thus, children of color likely will be disproportionately affected in years to come. In 1994, the annual rate of adult female AIDS cases per 100,000 population was: Caucasian, 3.8; African American, 62.7; Latina, 26.0; all women, 12.8. The rate among African American women was 15 times that for Caucasian women, and 3 times higher than among Latinas. The median age at AIDS diagnosis for women was 35. Urban areas with high seroprevalence rates among women may in turn be predicted to have high seroprevalence rates among children. In New York City and in Oakland, CA, in 1990-1991, seroprevalence of HIV among women of childbearing age was 40/1,000.

Defining children as persons less than 13 years of age is important for medical research and practice. The official CDC definition of pediatric AIDS for the purposes of case diagnosis and reporting pertains to children under 13. Clinical trial data specifies age group or developmental stage, and drug approvals and package insert labeling agrees with data gathered in rigorously conducted studies. Adults are persons 18 years of age and over, and adolescents are those from 13-17. (Some adult studies include adolescents 13-17.)

Statistics gathered on Americans under age 20 indicate that the rate of HIV infection in this group is increasing. In addition to children with perinatally transmitted HIV infection, this group includes adolescents at risk. A related topic that will not be a focus of this article is often termed "youth and HIV/AIDS," which tends to refer to HIV/AIDS in older children or adolescents. According to the March 1996 "Youth & HIV/AIDS: A Report to the President," increased access to HIV counseling and testing for adolescents will be key elements in improving prevention and treatment efforts for this group. In this article, pediatric infection refers to HIV in children less than 13 years of age.

Identification of HIV Positive or At-Risk Children

Since mother-to-child infection is by far the most common route of transmission for children, intense research is underway to develop methods for reducing the risk of perinatal transmission. AZT (Retrovir) is now approved for use during pregnancy as a risk reduction strategy, according to the regimen used in AIDS Clinical Trials Group (ACTG) 076. (See BETA, June 1995, for a review of ACTG 076, the study that showed that use of AZT by mother and child could substantially reduce the risk of mother-to-child transmission.) An ACTG study currently underway is evaluating the utility of HIV immune globulin (HIVIG) and pooled intravenous immune globulin (IVIG) regimens for reducing transmission rates. Other antiretroviral agents, such as nevirapine (Viramune), are candidates for this use as well. A study of nevirapine has begun in which mothers and infants receive a single dose; another perinatal transmission reduction study evaluating ddI for this purpose is now beginning to enroll. Much has been written and

publicized elsewhere about public health and policy issues associated with maternal HIV treatment.

Perinatal exposure to HIV is the backdrop, but infected children and their treatment are the focus of this article. In order to initiate prompt, optimal healthcare for perinatally exposed children, the CDC adjures healthcare providers to promptly identify infants born to HIV positive women in order to begin monitoring, diagnostic procedures and *Pneumocystis carinii* pneumonia (PCP) prophylaxis (recommendations appear later in this article). Approximately 1 in 4 children born in the U.S. to HIV positive mothers who use no perinatal transmission reduction strategy (AZT) will have confirmed HIV infection; since children routinely carry their mothers's antibodies for up to 18 months, various strategies have been implemented for HIV testing and care before that time.

The best way to identify at-risk children is to diagnose women with HIV before pregnancy, which is also critical for initiating care for the women themselves. To this end, the CDC has recommended that HIV counseling and voluntary testing be routinely offered to all pregnant women. If the mother's HIV status is not determined before delivery, pediatric healthcare providers should attempt to identify infants born to HIV positive women as soon as possible after birth. Symptoms of illness in all infants should be taken very seriously, since they may be signs of serious, life-threatening conditions (e.g., PCP) and HIV infection.

Diagnosis of Pediatric Infection

All infants born to HIV positive women should be monitored for HIV status as close to birth as possible. If test results at birth are negative by polymerase chain reaction (PCR), HIV culture and p24 antigen, testing should be repeated either at 1, 3 and 6 months of age (Dorenbaum), or before 1 month and again before 4 months (CDC). PCR and HIV culture are the preferred methods for HIV detection. If results are negative for HIV on at least 2 occasions, ELISA testing (HIV antibody test) should be performed at 12, 15 and 18 months of age. HIV ELISA and Western blot antibody tests are used as screening tools; confirmatory tests include HIV culture, PCR, immune-complex dissociated (ICD) p24 antigen and IgA assay. A positive HIV test result in an infant should be confirmed by repeat testing.

For at-risk infants who are being monitored for HIV status and for infants who have tested positive, CD4 cell counts should be obtained as an adjunct diagnostic tool. Although PCP prophylaxis is not initiated on the basis of CD4 count, the count is still clinically useful. For example, the CD4 count may help determine prognosis or risk for disease progression and guide decisions about whether or not to continue PCP prophylaxis after 1 year of age. The CDC recommends obtaining CD4 counts and percentages for HIV-exposed infants at 1 and 3 months of age, and for infants and children who are HIV indeterminate or HIV positive at ages 6, 9 and 12 months.

Recently, a University of South Florida study showed that a commercial PCR test was quicker and less expensive than HIV culture for detecting HIV in newborns. PCR results are available in 3-10 days compared with 3-4 weeks for HIV culture results; PCR costs about \$175, compared to \$300-600 for HIV cultures. This study is considered one of the first to establish the accuracy of PCR as a tool for diagnosing pediatric HIV infection. The investigators suggest that PCR be regarded as a standard, rather than investigational, clinical test for pediatric infection. In this study, PCR was performed in a commercial laboratory on blood samples from 286 newborns older than 1 week and children at risk for HIV infection. Samples were collected and mailed for testing. Among infants between the ages of 1 week and 1 month, PCR accurately detected HIV infection 95% of the time and correctly ruled it out 100% of the time. Standard HIV IgG antibody tests can diagnose HIV in children older than 18 months.

Pediatric HIV Classification

The CDC case definition for pediatric AIDS pertains to children through 12 years of age. Initially created in 1983, the definition was last revised in 1987 (unlike the adult AIDS case definition, which was revised most recently in 1993). The pediatric HIV/AIDS definition is similar to the adult definition in terms of HIV disease staging, but also contains conditions specific to children such as lymphoid interstitial pneumonitis (LIP) and recurrent serious bacterial infections. In the U.S. and Europe, an AIDS diagnosis requires a positive diagnostic test result for HIV infection. In developing nations or places where diagnostic tests for HIV are not readily available, pediatric AIDS diagnoses are based on clinical

criteria published by the World Health Organization.

The CDC has established an HIV classification system to define the spectrum of pediatric HIV disease. HIV-infected children are first grouped into 3 immunologic categories: no evidence of immunosuppression, moderate immunosuppression or severe immunosuppression. There are also 4 clinical categories: N, A, B and C.

Children in category N have no signs or symptoms. Those in clinical category A may have lymphadenopathy, splenomegaly (enlarged spleen), hepatomegaly (enlarged liver), parotitis (inflamed salivary glands), dermatitis (skin condition), recurrent upper airway infections, bilateral otitis media (BOM, an ear infection) or sinusitis (sinus infection).

Those in category B may have recurrent herpes simplex virus (HSV), herpes zoster/varicella (VZV, chickenpox, shingles), bacterial infections, chronic fever, cardiomyopathy (heart muscle disease), cytomegalovirus (CMV), chronic diarrhea, hepatitis (liver infection), anemia (low red cell count), leiomyosarcoma (muscle tumor), neuropathy or LIP. Finally, those in category C may have classic AIDS-related opportunistic infections (OI) such as PCP, *Mycobacterium avium* complex (MAC), cryptosporidial diarrhea, severe failure to thrive, toxoplasmosis, lymphoma, encephalopathy (brain disease), severe recurrent bacterial infections or cryptococcal meningitis.

Pathogenesis of Pediatric HIV Infection

Because HIV-related immunosuppression is imposed upon still-developing immune, nervous and other systems, HIV disease tends to be more aggressive in children than in adults, and leads to a range of unique problems.

Among children as a group, 2 patterns of HIV disease progression have been observed. The first is characterized by rapid progression, with 10-25% developing AIDS by 2 years of age. Mortality in rapid progressors approaches 100% by 4 years of age.

The second pattern is characterized by slower progression. Earlier studies that evaluated the mode of HIV acquisition found that children who were perinatally HIV-infected progressed more rapidly than children who were infected after birth, e.g., by transfusion. As perinatal transmission increasingly becomes the predominant route of pediatric infection, children in the latter group will account for progressively fewer infections.

In the case of the perinatally infected child, the timing of transmission also impacts the child's health. Perinatal transmission may occur in utero (during pregnancy), intrapartum (during delivery) or postpartum (after birth), primarily through breast-feeding. Studies suggest better clinical prognoses for children infected relatively late, e.g., during childbirth or through breast-feeding. Children infected during pregnancy, particularly earlier during pregnancy, tend to progress much more rapidly. Infants infected in utero who are positive by HIV culture or by PCR at birth often develop symptoms by 4-8 months; PCP is frequent in these babies and LIP is rare. They often develop AIDS by 1 year of age and their prognosis is poor. Infants infected during delivery usually are negative by PCR or HIV culture at birth; in these babies, LIP is frequent and PCP less common. They are more likely than those infected in utero to have lymphoid hyperplasia (increased amounts of lymphoid cells and tissue) and to survive longer.

Neurological Concerns

Neurodevelopmental delays and neurological complications often occur in children with HIV, especially after an AIDS diagnosis. HIV infection itself may cause developmental delays in the areas of speech and fine and gross motor skills. Progressive cognitive impairment may be due to central nervous system (CNS) effects of HIV. Children may even lose pediatric milestones already passed. They may experience short-term memory loss or have attention deficit disorder. Acquired microcephaly (abnormally small brain) is another neurological condition found in children with HIV/AIDS. Computerized tomography (CT) scans reveal cerebral atrophy (brain tissue wasting), calcifications (calcium deposits) in basal ganglia (nerve structures deep inside the brain) and white matter changes.

Psychosocial Considerations for Children

In addition to their medical problems, children also are likely to have enormous social and emotional problems. Many have parents who are ill or dead; many are in foster care and thus are involved in the social service or juvenile justice systems. Many HIV-infected children are economically disadvantaged and likely to have poor access to health care.

HIV-related neurodevelopmental impairment may impact daily functioning. Children may have extra difficulty expressing themselves; they may perform poorly on intelligence tests taken, e.g., at school. All of these factors are likely to affect an HIV positive child's overall socialization and growth.

Older HIV-infected children are also at risk for depression, which may manifest as apathy, withdrawal and loss of appetite. Moreover, children often lack the coping skills or defense mechanisms more mature people have developed. HIV-related dementia may also occur in children or adolescents, with symptoms similar to those in adults with AIDS-related dementia or encephalopathy. Although the psychology of children with HIV/AIDS has not been well studied, psychotherapy and psychopharmacology (use of drugs) may be helpful.

Complications of HIV Disease in Children

While the clinical categories that define stages of pediatric and adult HIV infection are similar, the clinical manifestations of HIV disease in children can differ greatly from those in adults. Children develop OI at much higher CD4 counts than do adults. They also have a somewhat different pattern of clinical manifestations, e.g., children have a much higher rate of recurrent and serious bacterial infections. Certain developmental problems are also uniquely pediatric; e.g., failure to grow and to thrive at an early age is common in HIV-infected children, albeit somewhat parallel to the adult problem of HIV-related wasting. However, while wasting occurs late in HIV disease for adults, failure to grow and thrive may occur early for children.

Children are more likely than adults to have enlarged livers, spleens and lymph nodes. LIP, common in children, is uncommon in adults. Malignancies are uncommon in children but more common in adults. CNS abnormalities may occur early in the course of HIV disease in children, whereas AIDS dementia complex (ADC), a specific HIV-related CNS condition, occurs late in HIV disease for adults. Parotitis is another primarily pediatric concern. At one time, HIV-infected children were considered at risk for a disability called HIV-related dysmorphic syndrome. Researchers have since attributed this condition to alcohol use by the mother, and now generally relate the condition to fetal alcohol syndrome rather than to HIV.

Pediatric infections common among all children are exacerbated in children with HIV, including chronic ear infections and respiratory tract infections. Chronic infection of both middle ears, known as bilateral otitis media (BOM), is common in HIV-infected children without AIDS, as is thrush (oral candidiasis). In children with an AIDS diagnosis, thrush has been estimated to occur in more than 80%. Thrush is frequently the initial clinical sign of HIV disease. It is rarely disseminated but frequently involves the esophagus.

The top 4 AIDS-defining conditions in children are, in order of decreasing frequency: PCP, other OI, LIP and recurrent bacterial infections. PCP is often diagnosed in the first few months of life, and actually may occur at CD4 cell counts considered normal for the child's age. Often, PCP occurs before a child's HIV infection has been identified.

Gastrointestinal pathogens commonly found in children with AIDS include protozoa (*Cryptosporidium*, *Isospora*, *Giardia*), viruses (CMV, HSV, Epstein-Barr virus [EBV], adenovirus, hepatitis viruses), bacteria (*Salmonella*, *Shigella*, *Mycobacterium tuberculosis*, *Mycobacterium avium*, *Clostridium difficile*) and fungi (*Candida albicans*, *Histoplasma gondii*, *Coccidioides immitis*, *Cryptococcus neoformans*).

HIV Disease Management Guidelines for Children

Optimal management of HIV disease in children often requires a team approach which involves physicians, nutritionists, social workers and psychotherapists.

Diligent primary care is essential. According to Ho and Wei (1995), several features of pediatric HIV disease make a compelling case for aggressive HIV treatment. Newly infected infants usually have a very homogenous population or type of HIV-1 virus, which means that the virus is very sensitive and thus relatively more responsive to antiretroviral treatment. Today, scientists know that HIV replication in the body is a continuous, dynamic and rapid process. Tests now available to measure viral RNA (viral load) in plasma can be used after primary infection, when the viral RNA concentration reaches a plateau, to try to predict longer-term clinical progress or outcomes. Finally, there are powerful anti-HIV inhibitors now available, such as the protease inhibitors and combinations of other antiretroviral agents, that have been shown in studies of adults to reduce the concentration of virus in blood serum by as much as 2-3 logs, or 100- to 1,000-fold. Although protease inhibitor data in children are sparse, it is hoped that these powerful compounds will be as important for pediatric as for adult treatment.

The goals for antiretroviral treatment are to slow or eradicate viral replication, which is likely to mean life-long therapy for children. Prophylaxis and treatment, when necessary, for OI are also essential. Acute medical care may be necessary at times. Pain management as well as nutritional and psychosocial support are extremely important aspects of HIV disease management in children.

Antiretroviral Treatment

Antiretroviral therapy is warranted in children who have developed an AIDS-defining condition such as PCP, failure to thrive, HIV-related progressive encephalopathy, recurrent serious bacterial infections, thrombocytopenia (low platelet count), hypogammaglobulinemia (low antibody levels) or low CD4 cell count, even without symptoms. Antiretroviral drug choices for children are nearly the same as for adults, with a few important qualifications and exceptions. In some cases antiretroviral drugs involve different side effect profiles for children, or there are insufficient pediatric data to substantiate their use.

An important pediatric antiretroviral treatment update came on February 28, 1996, with the official release of final data from ACTG 152. The large nationwide trial enrolled nearly 900 children with AIDS, aged 3 months to 18 years, who had little or no prior antiretroviral treatment. The study's goal was to compare the efficacy of 3 different antiretroviral treatment regimens for delaying disease progression when used as initial or first-line antiretroviral strategies. Originally, participants were randomized to receive one of 3 treatments: AZT monotherapy, ddI monotherapy or combination AZT/ddI. However, an interim analysis about a year ago indicated that children receiving AZT monotherapy were faring much worse than children in either of the other 2 arms. Children receiving AZT alone had "more rapid rates of disease progression as measured by growth failure, new opportunistic infections, neurologic and neurodevelopmental deterioration or death." A Public Health Service press release dated February 13, 1995, states that interim results show that "zidovudine (AZT) alone was the least effective as an initial therapy to prevent HIV disease progression." In February 1995, the AZT monotherapy arm was discontinued, and the study continued with the 2 remaining arms.

Therefore, final results compare ddI monotherapy to combination ddI/AZT treatment. At this time, the data suggest that there are no significant differences in disease progression or survival between the 2 treatment strategies. Even though AZT is believed to penetrate the CNS better than ddI, children taking ddI alone did not fare worse than those taking combination ddI/AZT in terms of neuropsychological dysfunction or deterioration (experienced by about 19% of all participants). Although some physicians feel that clinically stable children may fare well on AZT monotherapy, others feel that the results of ACTG 152 argue strongly against the use of AZT monotherapy in any HIV-infected child. Thus, the emerging trend for antiretroviral treatment in children is similar to that for adults, with providers and advocates on the "cutting edge" proposing that first-line treatment for children, like adults, should consist of combination antiretroviral therapy.

AZT, the first antiretroviral approved for children, is available in tablet, intravenous (IV) and raspberry-flavored syrup formulations. The dose recommendations are 2-3 mg/kg (180 mg/m²) every 6 hours for children older than 3 months. Children absorb oral AZT well (about 65% absorption). AZT,

which penetrates the blood-brain barrier to the CNS, is found in cerebrospinal fluid at amounts equal to about 25% of serum concentration. Another advantage of AZT is its ability to readily cross the placenta. HIV resistance to AZT develops as a function of length of time used, not dose; in children, resistance correlates with disease progression.

ddI is also approved for pediatric use. At 40%, its oral bioavailability is lower than that of AZT or ddC (87%). ddI must be taken on an empty stomach, during fasting, which may be difficult for children. It is available in chewable tablet, powder and pediatric oral solution forms. The dose is 200 mg/m² twice daily. ddI fails to penetrate the CNS well. Pancreatitis, peripheral neuropathy, retinal damage and diarrhea may result from its use.

ddC is 10 times as potent against HIV as AZT in vitro. It is available on the market in tablet form, and in clinical trials only in syrup form. The suggested dose is 0.005-0.01 mg/kg orally, every 8 hours. ddC has poor CNS penetration. Side effects include neuropathy, stomatitis (mouth sores), esophageal ulcers and rash.

d4T is considered to have good bioavailability and CNS penetration. There are limited Phase I data in children; a Phase II/III trial is in progress.

Other drugs being studied in children include the new class of protease inhibitor drugs. Nevirapine and delavirdine, also under study, belong to a class of drugs that seems to be powerful in vitro and minimally toxic, although HIV mutates extremely quickly to become highly resistant to them.

Other agents used in pediatric antiretroviral therapy include those that diminish HIV stimulation, those that decrease antigen stimulation and those that block mediators that stimulate HIV infection. Agents used to stimulate the immune system include certain hormones and growth factors, certain cytokines, immunizations, bone marrow transplants and gene therapy.

Prophylaxis and Treatment of OI and Childhood Conditions

Since PCP is the most common serious OI in children with AIDS, prevention is of paramount concern. While recommendations for beginning prophylaxis in adults are based on a CD4 cell count of fewer than 200 CD4 cells/mm³, the CD4 count is an inadequate marker for infants and children. CD4 counts vary more from child to child than among adults, and thus are not particularly helpful indicators of when to begin PCP prophylaxis. Because PCP kills many infants younger than 1 year, recommendations are to begin prophylaxis at 4-6 weeks of age in all infants, regardless of CD4 count, born to HIV positive mothers. (Prophylaxis is delayed until 4 weeks of age because it takes about that long for an infant to develop the necessary ability to metabolize bilirubin.) Infants who are identified as HIV positive after 6 weeks of age should immediately begin PCP prophylaxis.

Currently, the National Pediatric and Family HIV Resource Center and the CDC recommend PCP prophylaxis for all "at-risk" infants 1-4 months of age, until HIV status can be firmly determined, and for all HIV-infected infants 4-12 months of age. After 12 months of age, recommendations for PCP prophylaxis for infected children are based on CD4 cell counts and history of PCP. Because CD4 percentages vary less than CD4 counts, some physicians prefer to use them as a marker. Generally, PCP prophylaxis is recommended for children 1-2 years of age with fewer than 750 CD4 cells/mm³ or 15%; children 2-5 years of age with fewer than 500 CD4 cells/mm³ or 15%; and children 6-12 years of age with fewer than 200 CD4 cells/mm³ or 15%.

The first-line choice for PCP prophylaxis is trimethoprim/sulfamethoxazole (TMP/SMX, Bactrim or Septra) at an oral combined dose of 150 mg/m² TMP and 750 mg/m² SMX 3 times a week. For children who cannot tolerate TMP/SMX, alternative regimens are oral dapsone, 1-2 mg/kg once daily; aerosolized pentamidine, 300 mg monthly (only for children over 5 years of age); and parenteral (by injection, bypassing the gastrointestinal tract) pentamidine, 4 mg/kg every 2-4 weeks. Breakthrough PCP has been documented in infants on dapsone and pentamidine. Also, the CDC currently recommends that infants who received AZT for the prevention of vertical transmission not begin prophylaxis with TMP/SMX until AZT has been discontinued at 6 weeks, per the ACTG 076 regimen, because of potential liver toxicity. (Some physicians feel that the high risk of PCP before 1 year of age warrants

beginning PCP prophylaxis with TMP/SMX at 4 weeks, even while infants finish the AZT regimen.)

Prophylactic use of TMP/SMX also protects against bacterial infections. IVIG has also been used to prevent bacterial infections and related hospitalizations. IVIG has been used at a dose of 400mg/kg every 28 days in HIV-infected children, especially those with hypogammaglobulinemia, thrombocytopenia or recurrent infections not ameliorated by routine use of antimicrobial agents. Prophylaxis for other OI depends on the child's age, degree of immunosuppression and other individual factors, such as physician and parent preferences. In general, different dose levels of the same drugs that are used to prevent OI in HIV-infected adults are used for children.

In the February 1996 issue of Pediatrics, the American Academy of Pediatrics (AAP) published an updated policy on tuberculosis (TB) skin testing for children. The AAP now recommends that children's risk level for TB be assessed, and that testing schedules complement risk level determination. For example, children who have recently come into contact with a TB-infected person should be tested immediately. Children with HIV should be tested annually.

HIV-infected children are at elevated risk for more severe versions of common childhood illnesses like measles and chickenpox, which may be fatal. Common, minor symptoms like cough and fever must be taken very seriously in HIV-infected children, for they may herald potentially life-threatening infections.

Certain immunizations routinely given to HIV negative children are also recommended for HIV positive children; others are not (see chart). The main caveat about routine vaccinations is the possibility that consequent immune system stimulation may activate CD4 cell activity and, in turn, enhance HIV replication. For example, the wisdom of vaccinating HIV-infected adults and children against influenza has been widely debated. Some researchers have argued that HIV positive children tend to be at even greater risk for the flu than adults, e.g., through contact with large numbers of other children in daycare or at school. In a recent study at the University of Texas Medical Center in Dallas, Octavio Ramilo and others used viral load tests to investigate the effects of flu vaccines on HIV activity in infected children. Investigators found that 5 of 16 children experienced significant post-vaccination viral load increases. However, viral load changes were transient, with levels returning within 2 months to baseline in 4 of the 5 children. Investigators concluded that children, relative to adults, were less likely to experience increases in HIV burden (but demurred, recommending further studies in children with different disease stages taking different treatment regimens). The debate is likely to continue.

RECOMMENDATIONS FOR IMMUNIZATIONS IN THE CHILD WITH HIV/AIDS FROM THE AMERICAN ACADEMY OF PEDIATRICS

Vaccine: DPT (diphtheria, tetanus, pertussis)

Known Asymptomatic: Yes

Known Symptomatic: Yes**

Vaccine: OPV (Sabin, oral polio vaccine)

Known Asymptomatic: No

Known Symptomatic: No

Vaccine: IPV (Salk, inactivated polio vaccine)

Known Asymptomatic: Yes

Known Symptomatic: Yes**

Vaccine: BCG (Bacille Calmette-Guerin, for tuberculosis)

Known Asymptomatic: No

Known Symptomatic: No

Vaccine: MMR (measles, mumps, rubella -- live-attenuated)

Known Asymptomatic: Yes

Known Symptomatic: Yes

Vaccine: Hibc (Haemophilus influenza type b/c)

Known Asymptomatic: Yes

Known Symptomatic: Yes**

Vaccine: Pneumococ cal*

Known Asymptomatic: Yes

Known Symptomatic: Yes**

Vaccine: Influenza*

Known Asymptomatic: Yes

Known Symptomatic: Yes**

NOTES:

* Pneumococcal vaccines should begin when a child reaches 2 years of age. Flu vaccines should be given annually starting at 6 months of age.

** Inactivated vaccines are recommended, although patient responses may not be optimal. Definitely, HIV positive children and even HIV negative children residing in the same household should receive the killed polio Salk vaccine and not the live attenuated Sabin product.

Nutritional Considerations and Therapy

Competing theories on the role of nutrition in HIV disease abound. Important research continues to delineate the roles played by nutrients and micronutrients, and will permit the formulation of recommendations for diet and nutritional supplementation. Associations between nutritional deficiencies and disease stage in adults have been fairly well established; as disease advances, so does the extent of nutritional depletion. While malnutrition enhances disease-related immunosuppression in persons of all ages, the nutritional requirements of any child differ significantly from those of any adult. So far, little data exist to establish the impact of HIV infection on nutritional status in children. The known catabolic and metabolic problems experienced by HIV positive children, as well as endocrine problems and failure to grow and thrive, underscore the importance of optimal nutrition. Adequate dietary intake of nutrients is the most important, first-line approach to nutritional management; children must receive adequate calories and protein. However, supplementation should be considered for children who fail to grow despite adequate oral intake.

In France, a recent study evaluated nutritional abnormalities in 21 generally healthy children with HIV. The prospective study involved a group of HIV positive children and a matched control group of HIV negative children. Investigators assessed health history (e.g., fever, diarrhea), height, weight, dietary intake and nutritional status, including total calories, protein, fiber, fat, cholesterol, vitamins, calcium,

iron, zinc, copper and fatty acids. All children were relatively well-nourished. Measures of nutritional status appeared unaffected by origin of maternal infection (injection drug use versus heterosexual contact), ethnic background, or socioeconomic or educational status. Within the HIV positive group of children, about half were symptomatic but "non-AIDS." The remainder had AIDS diagnoses, and a lower average CD4 cell count that was associated with lower vitamin A levels. There was no correlation between CD4 cell count and vitamin E, beta carotene, zinc, copper or selenium. CD8 levels were significantly correlated with zinc levels.

HIV positive children did not differ from HIV negative children in dietary intake, nor was their ability to absorb nutrients impaired. Generally, study data suggest that, as HIV disease progresses, so does the extent of vitamin level depletion (with the exception of beta carotene, levels of which did not appear to change after receiving an AIDS diagnosis). This finding was particularly true for the micronutrients known to influence immune status--vitamins A and E and the carotenoids, zinc, copper and selenium--and mirrors the same phenomenon known to occur in HIV-infected adults.

Although more significant as HIV progressed, micronutrient deficiencies were noted even in children with early-stage HIV disease. However, remedial supplementation is not automatically recommended; for example, iron supplementation to address the low iron levels often seen in people with infections often exacerbates infectious complications by providing fuel for the pathogens. Essential findings indicated that, despite adequate diets, notable micronutrient alterations were common in these children, even though none of them manifested signs of malnutrition. Research into the utility of nutritional interventions early in the course of pediatric HIV disease remains to be done.

Various studies have demonstrated that vitamin A supplementation benefits immune status in HIV-infected children. In a study from South Africa, researchers studied the effects of vitamin A supplementation on morbidity (sickness) in 118 children born to HIV positive mothers. Vitamin A plays various roles in optimizing immune function and maintaining the health and integrity of epithelial tissues, which include the mucosal tissues of the gastrointestinal tract and the eye. These characteristics led to dubbing vitamin A the "anti-infective" vitamin. (Durban, the study locale, is not considered a vitamin A deficient area.) The study was randomized, double-blind and placebo-controlled. At 1 and 3 months of age, children received 50,000 International Units (IU); at 6 and 9 months, 100,000 IU; and at 12 and 15 months, 200,000 IU of vitamin A. HIV status was determined at 15 months, and data on health status were collected up to 18 months of age. HIV negative children had roughly the same number of illnesses and hospitalizations, whether or not they received supplemental vitamin A. However, HIV positive children who received supplemental vitamin A had less diarrhea, fewer hospitalizations for diarrhea and less severe illnesses overall (e.g., respiratory infections, rashes) than those who received placebo. The researchers hope that vitamin A supplementation in HIV positive children, especially economically disadvantaged children, may be an effective and inexpensive means for reducing illness. (See the report "Mother-to-Child HIV Transmission," by Leslie Hanna, on vitamin A levels and vertical HIV transmission in the September 1994 BETA.)

A Clinical Research Agenda for Children

According to pediatrician Paula Botstein, MD, Deputy Director of FDA's Office of Drug Evaluation, FDA is encouraging clinical trials in children. She explains that the majority of approved drugs have been studied in and labeled for adults, and that package inserts commonly rely on disclaimers that explain that safety and efficacy have not been established for children. Historical reasons for lack of pediatric research include little financial incentive on the part of pharmaceutical companies and the difficulties inherent in pediatric research. Parents and guardians as well as children must understand what involvement in a trial means and must provide informed consent. The collection of data on a drug's safety and efficacy is important because children may metabolize drugs differently than adults; adult doses cannot simply be reduced for use in children. Botstein says FDA is trying actively to encourage drug companies to test drugs in children during the drug development process, and that FDA reviews of new drug applications (NDA) include consideration and evaluation of pediatric data. FDA is also creating ways to evaluate a drug's post-marketing use in children.

Recently, however, the Office of AIDS Research called for dramatic cuts to the pediatric research budget through the nation's largest research mechanism, the ACTG. There are 2 rumored reasons for the

proposed cuts: 1) the pediatric ACTG has in the past been too generously supported, relative to adult studies, and 2) now that AZT has been officially approved for use in pregnant women, fewer children will be HIV-infected so less research will need to be done.

Conclusion

Early identification of children at risk for HIV infection and especially HIV positive children is essential for optimal treatment, defined as early, aggressive treatment. Quality counseling about HIV disease and testing should be routinely offered to all pregnant women. Counseling ensures that women have adequate information to make informed choices.

Infants of women considered "at risk" should be monitored so that infants and children who develop lymphadenopathy (lymph node swelling) or frequent bacterial infections, or who have low platelet counts or other unusual clinical findings may be promptly attended. Mothers of such children must be integrally involved in their children's medical care, one reason being that HIV testing of such children guarantees revelation of the mother's serostatus.

The epidemic in children less than 13 years of age reflects the epidemic in women. According to the CDC, the proportion of cases among women has increased steadily over the past decade. The official hope of government and medical researchers is that Public Health Service recommendations for routine counseling and voluntary prenatal HIV testing for women, and the use of AZT and forthcoming antiretroviral strategies (e.g., protease inhibitors) for interrupting perinatal transmission will minimize the pediatric epidemic. Nevertheless, new pediatric infections are likely at least in the near future. It is important for research to go forward to better understand HIV disease in children and to learn how best to treat it.

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Protease Inhibitor News for Children

Important recent news in antiretroviral treatment for persons with HIV concerns protease inhibitors and combination antiretroviral therapy, often including a protease inhibitor. Most new drug approvals have been granted for adult HIV infection; unfortunately, there is relatively little news about protease inhibitors for children.

Abbott Laboratories' protease drug, ritonavir (Norvir), FDA-approved on March 1, 1996, was widely hailed because data showed a survival benefit in people with advanced HIV disease. The clinical studies that led to ritonavir's approval have also been denounced for failing to gather safety and efficacy data in children. In late February, when FDA advisory committee meetings which led to FDA approval were held, no pediatric data were reported. Part of the approval agreement between FDA and Abbott was a plan that requires Abbott to conduct trials to provide additional data, including a pediatric trial of ritonavir to provide safety and efficacy data for children. A small pediatric study is currently underway at the National Cancer Institute (NCI), and other protocols are being developed.

Hoffmann-La Roche's (Roche) protease inhibitor saquinavir (Invirase), which received FDA marketing approval in December 1995, is indicated for use in adults and children over 16. Currently, Roche will only say that it is committed to developing a sprinkle formulation for use by children, and that the process is underway.

Merck's protease inhibitor indinavir (Crixivan) was FDA-approved on March 14, 1996, on the basis of studies in over 2,000 volunteers with AIDS. Study participants showed improvements in markers of HIV disease such as CD4 count increases and viral load decreases, especially when indinavir was used in combination with AZT. The indicated use is for adults older than 18 years of age only. There are no current indications for pediatric use; the adult dose cannot be adjusted or altered. "With Crixivan, it is very, very important, in order to keep viral load down and to erect and maintain a wall against resistance, to start with and maintain the optimal, approved dose: 800 mg 3 times daily. You cannot titrate up or down, you cannot try drug holidays. Timing and conditions around taking doses are important, too; Crixivan must be taken every 8 hours, in a fasting state or with a very light meal, in order for maximum absorption," says Kyra Lindemann of Merck Corporate Public Affairs. Therefore, until studies establish the optimal dose(s) for children, there will be no indication for pediatric use. A pediatric dose-ranging study using a capsule form of indinavir is currently underway at NCI, where safety and efficacy data for the different doses are being gathered. Meanwhile, Merck is working to develop an oral suspension formulation for pediatric use.

by Leslie Hanna

Leslie Hanna is Associate Editor of BETA.

Bulletin of Experimental Treatments for AIDS

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Issues on Women and Children with AIDS or HIV Infection

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I. Where are we in Latino HIV/AIDS research?

National statistics of AIDS cases reported to the Centers for Disease Control (CDC), in Atlanta, provide a grim framework to our discussions of issues related to Hispanic women and children infected with HIV. Whereas Latino children represent 13% of the total U.S. population (1990, U.S. Census Bureau), they represented 25% of all children reported to the CDC with AIDS for the years 1992 and 1993. In fact, Latino women and children are one of the fastest growing groups of AIDS cases reported for the past three consecutive years. The impact of the HIV pandemic in the Hispanic population living in the U.S., particularly on Latino women and children, is unfolding and will have significant consequences for the forthcoming years.

Much of the epidemiological research conducted by CDC and academic centers across the United States has focused on behaviors that place people at risk of acquiring HIV infection. A composite picture now emerges defining clearly that for women, heterosexual transmission of HIV will become a major transmission route. This has been apparent in Puerto Rico since 1990 where heterosexual transmission surpassed sharing of needles among Intravenous Drug Using (IVDU) women as a transmission factor.

Puerto Rico was impacted early during the initial phase of the world's HIV pandemic. Though the initial groups at highest risk were homosexual and bisexual males, users of IV drugs who shared needles and their sexual partners quickly became the predominant at-risk section of society. For women in Puerto Rico, this has had far-reaching consequences. The effectiveness and ease in transmission through the IV route and from male to female increase the pool of women HIV infected early in the course of the epidemic throughout the island.

As a direct consequence, transmission from mother to infant; prenatal or vertical transmission of HIV, increased the number of infants born with HIV infection from as early as 1978 and increasing numbers through the years 1985-90. Thus, we are seeing a steep rise in the number of children reported with AIDS for the years 1990-93. As of March 27, 1994, over 12,000 AIDS cases in adults and adolescents had been reported to the Puerto Rico AIDS Surveillance Unit of CDC in San Jan. These statistics place Puerto Rico in the upper/centiles in distribution of AIDS cases among States and San Juan as a major epicenter among cities in the United States.

There is ongoing research on factors that influence HIV transmission from mother to infant. More significantly, clinical trials designed to interrupt this transmission are being conducted by the National Institute of Allergy and Infectious Diseases, part of the National Institutes of Health.

Recently released reports of a Clinical Trial - ACTG076 promise hope of reversing some of the epidemiological trends. The ACTG076 was a randomized, placebo controlled use of Zidovudine (ZDV) by pregnant HIV infected women with CD4 counts over 500 designed to decrease the number of infants born with HIV infection. This

study was recently stopped by its Data Safety Monitoring Board because of highly significant differences in transmission between the placebos and study drug arm. Of over 600 women enrolled, 25% of those taking placebo and only 8% of those taking ZDV transmitted HIV to their infants. This difference in the number of HIV infected infants born to the two groups of women was of high statistical significance ($p < .03$). These study findings were disseminated through the national news media and its implications on the care of pregnant women infected with HIV are currently undergoing implementation across the U.S. The University of Puerto Rico School of Medicine participated actively in the implementation and accrual of this trial. It is unclear at this date what impact these results will have in developing regions highly affected by the HIV epidemic like Africa, Asia and the Caribbean.

II. What are the gaps in research?

Much is still needed on research focusing on prevention of HIV transmission. Going on to a second decade of this epidemic we still have gaps on our knowledge of how to sustain and maintain behavior change to decrease the risk of acquiring HIV infection.

Effective, sustainable, culturally appropriate and community-based efforts to prevent transmission among Hispanic homosexual, bisexual males, among intravenous drug using men and women and among their sexual partners are as urgently needed as they were during the first decade of the epidemic. Acceptable ways to empower women into a more active, assertive role in preventing sexual transmission of HIV are critically needed.

Research on barriers to care and accessibility to comprehensive, state-of-the-art health care services to Hispanic populations, and migrant workers and their families continues to be a priority. From research centers to clinics, the implementation of knowledge acquired during the preceding years on how to break those barriers and make accessible anti-retrovirals, as well as multi-disciplinary case management to infected persons and their families needs to be an on-going effort.

Preventing transmission of mothers to infants through the use of ZDV during pregnancy, labor and delivery needs to be established as a high priority public health policy issue. We need to develop ways to implement access to prenatal transmission prevention as part of the care delivered to pregnant women. Foremost, we need to increase the awareness of Hispanic women to the potential benefits of determining HIV sero-status early in the course of pregnancy. Only by doing this will the results of the ACTG076 trial have a real impact on the number of infants born yearly infected with HIV that will eventually develop AIDS. These results give a new meaning and underscore the need to universally offer all pregnant women, particularly from minority populations, the option of HIV testing early in their pregnancies. In my opinion, mandatory testing is not the best public health policy. In our experience, with appropriate counseling and frank discussions of risk/ benefits for women and their infants of such prenatal testing, the overwhelming majority will choose strategies that prevent transmission to their offspring's.

III. What are the most pressing obstacles to research?

Lack of funding is still, in my opinion, the foremost obstacle to research. Highly competed-for funds for research are not distributed yet, in my opinion, to the Hispanic

community in proportion to the magnitude of the issues surrounding the HIV epidemic in our society.

Lack of communication and linkage among Latino researchers in the community, health care centers and academic centers across the U.S. is still evident. Networking and joining of capabilities, expertise and experience among Latino researchers would prove fruitful in our efforts to fight this epidemic. Efforts promoted and sustained by governmental agencies (NIH, CDC and others) are needed to integrate researchers into a national agenda. Efforts such as this conference need to transcend and sustain change that will impact health care policy. Hispanic AIDS researchers are still a minority within the broad group of Latino researchers, a minority themselves across the U.S.

Well designed and conducted research on AIDS is not feasible without an infrastructure capable of sustaining such research. In our experience, the major obstacles in conducting our research had to do with this lacking infrastructure. Recruitment of staff, access to state-of-the-art, retrovirology laboratories, adequate access to anti-retroviral therapy were all impeding factors that needed resolution prior to the establishment of a quality research program. Continued efforts to mainstream into the national research agenda are needed.

IV. What are priority research issues?

A partial listing would include:

1. Effective dissemination of current knowledge on HIV prevention: Aggressive, community-based strategies that would include risk diminution strategies, empowerment of women and clean needle

exchange programs in the major urban centers affected by HIV.

2. Research on effective prenatal counseling to HIV infected women to decrease transmission of HIV to their infants.
3. Research on effective anti-retroviral therapy to prolong the asymptomatic phase of HIV infection among adults and children. Clinical trials of nucleoside analogs in combination and in conjunction with non- nucleoside analogs and immuno-modulators that halt or diminish the probability of HIV disease progression or risk of transmission of HIV to sex partners and offspring's are urgently needed.
4. Research on ways to implement alternative modes of care such as home-based care, primary health care setting based care management, are complimentary and important in our efforts to make care accessible and affordable.

V. What is needed to begin to implement a national research agenda on Latinos and HIV/AIDS?

A partial listing would include:

1. Access to institutions, organizations, officials that actually determine the research agenda and priorities in funding for research across the United States.
2. Linkage of academic based centers, private industry based centers and community based centers currently conducting research on Latino HIV/AIDS issues.
3. Initiate multi-disciplinary teams of researchers with complimentary goals and approaches and promote their interaction in order to plan and conduct studies directed to Latino communities across cities in the U.S. Provide a framework or milieu in which productive discussions can take place and will lead to effective fund-seeking strategies.
4. Disseminate and promote funding opportunities to conduct high quality research.
5. Encourage involvement of young, promising researchers with more established investigators aiming to increase the number of researchers conducting AIDS research.

These recommendations are only a partial listing of possible priorities in research and needs to establish a national agenda for Hispanic AIDS researchers. I hope the collective input accomplished during the upcoming conference can galvanize effective action that translates into health care policy attention to the formidable challenge that the AIDS epidemic represents to all of us.

PEDIATRIC TALKING POINTS:

A cursory review of statistical information on Pediatric AIDS cases over the six years reveals the following insights:

1) The annual rate of increase in pediatric AIDS cases in the ten cities with largest NEP's showed a 61% reduction in the rate of new cases reported. (1992-93 = 24.7% increase compared to 1996-96 = 9.7%).

2) In the ten cities with the largest NEP's there was a 36% reduction in new pediatric AIDS cases.

(1993= 383 new cases compared to 1996= 244 new cases).

If you compare other US cities that do not have NEP's the percent of reduction is just 27%. Therefor, you can argue that the pediatric reductions are not due only to AZT but rather one third of pediatric AIDS cases are avoided due to NEP's.

3) Comparing six large U.S. cities with a NEP with six large cities without an NEP using 1996 data, the percentage of pediatric AIDS cases to overall AIDS cases was 24% lower in those cities with NEP's.

Cities with NEP's: New York, Chicago, LA, San Francisco, Philadelphia, Baltimore.

Cities without: San Juan, Washington DC, Newark, Houston, Miami, Ft. Lauderdale.

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