No. 93-1067

IN THE

APPELLATE COURT OF ILLINOIS

FIRST JUDICIAL DISTRICT

Estates of
MELANIE MARIE HERROD and
EBONY LYNETTE STEVENSON,

Minors,

GERALDINE JONES,

Petitioner-Appellant

Appeal from the Circuit Court of Cook County, Illinois
County Department, Probate Division
Nos. 92 P 10948 & 92 P 10949
The Honorable GEORGE W. COLE, *Judge Presiding*

BRIEF AND ARGUMENT FOR AMICI CURIÆ

JAY R. GIUSTI
525 North Ada Street
Suite 20
Chicago, Illinois 60622
(312) 455-0074
Attorney for Amici Curiæ.

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POINTS AND AUTHORITIES

ISSUES PRESENTED FOR REVIEW

1. Whether public policy of this State requires a parent stricken with the terminal illness Acquired Immunodeficiency Syndrome ("AIDS") to immediately relinquish custodial control over her minor children, in order to secure a stable environment at such time in the indeterminate future when the parent will become incapacitated or deceased?

2. Whether the court below abused its discretion in holding, against the manifest weight of the evidence, that it was neither necessary nor convenient that a competent parent of two minor children retain immediate custody, with appointment of a standby guardian who could assume custodial duties at such time when the parent becomes temporarily or permanently incapacitated or deceased?

3. Whether the decision of the court below, by refusing to appoint a standby guardian for the minor children, failed to consider their best interests for a stable environment in the future?

STATEMENT OF FACTS

In addition to those facts related in the Brief for Petitioner-Appellant, *Amici Curiæ* urge the Court to consider the following uncontroverted evidence contained in the record before the court below:

AIDS/HIV

AIDS (Acquired Immunodeficiency Syndrome) is a deadly disease spread by the transmission of the Human Immunodeficiency Virus ("HIV") through the exchange of blood and bodily fluids that occurs during sexual

contact, blood transfusions, sharing infected injected equipment during intravenous drug use, and perinatal contact between an infected mother and her fetus. AIDS leads to the destruction of the immune system, leaving its victims vulnerable to opportunistic infections which, in turn, lead to death. (R. C021, Memorandum of Amici Curiæ, n. 1 at p. 2)[1]

STATISTICS AND DEMOGRAPHICS OF AFFECTED FAMILIES

It can no longer be disputed that we face a serious challenge. Statistics regarding the virulence and effects of HIV and AIDS are by now common knowledge, but bear repetition in the face of a tide swell threatening to engulf our courts: 218,301 cases nationally had been officially reported by March 1992, with increasing proportions of the cases involving the primary caregivers for minor children who have become orphaned as a result of the epidemic. (R. C036)[2] At least 3,300 women in Chicago are infected with HIV. (R. C030, 35)[3] More than eighty percent of these women had children, with more than one-third of the women having three or more children, resulting in an estimated 8,000 children with HIV-positive mothers. (*Id.*)

The Chicago Department of Health in 1989 projected that approximately 60,000 women were at risk for infection. (R. C031-32, 35)[4] By the

[1]In this brief, citations to the Record on Appeal follow the pagination of the documents relating to Ebony Lynette Stevenson, inasmuch as the documents relating to Melanie Marie Herrod are not identically numbered.

[2]"Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States", 268 Journal of the American Medical Association, at p. 3458 [Dec. 23/30 1992]. A copy of the article is included in the Appendix to this brief.

[3]"The Health Care and Social Service Needs of HIV-Positive Women and Children in Metropolitan Chicago", Visiting Nurse's Association of Chicago [Feb. 1990] As noted at R. C035, the cited document was too volumous to incorporate into the Record but was made available to the court below. The relevant portions of the source which contain the cited material are reproduced in the Appendix to this Brief.

[4]"Aids Strategic Plan for the City of Chicago", Chicago Department of Health [Oct. 1989] As noted at R. C035, the cited document was too volumous to incorporate into the Record

end of 1995, it is estimated that up to 56,700 minors will become motherless as a result of AIDS; if present trends continue, by the end of the century, the number may reach 125,000. (R. C038)[5] The number of AIDS-related deaths will surpass those due to cancer and motor vehicle accidents, the two other most frequent causes of death among mothers of young children. (*Id.*, at R. C038-39; p. 3458-59) Of particular relevance to the issues raised by this appeal, these numbers do *not* include "HIV-affected children *who are effectively orphaned" prior to the deaths of their parents.* (R. C042) (emphasis supplied)[6]

UNPREDICTABLE COURSE OF AIDS

HIV or AIDS are conditions with unpredictable courses, frequently developing differently in various cases. (R. C069, ¶8; Supp.R. C014, ¶10; Supp.R. C006, ¶11) An infected person may well be able to function at some times, but not at other times, without predictable pattern. (R. C069, ¶10; Supp.R. C014, ¶¶11, 12; Supp.R. C006, ¶12) HIV/AIDS-infected persons are often unable to predict periods of disablement or hospitalization. (R. C069, ¶11; Supp.R. C006, ¶13) Even physicians well-experienced in caring for HIV/AIDS patients seldom are able to predict periods of incapacity or needed hospitalization. (R. C068-69, ¶¶1, 5, 7, 12; C079-81, ¶¶1-4, 6)

Many HIV/AIDS-related patients are single parents of minor children. (R. C069, ¶15) There are numerous instances where an HIV- or

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but was made available to the court below. The relevant portions of the source which contain the cited material are reproduced in the Appendix to this Brief.

[5]"Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States", at p. 3458.

[6]"The 'Silent' Legacy of AIDS: Children Who Survive Their Parents and Siblings", 268 Journal of the American Medical Association, at p. 3478 [Dec. 23/30 1992]. A copy of the article is included in the Appendix to this brief.

AIDS-infected person may be hospitalized in serious condition, but then recover with full functioning for an extended period of time. Such parents strongly desire to care for their children, but the unpredictability of their condition can be very distressing, so that they need a standby guardianship to be available. (R. C066, ¶3; C070, ¶¶17, 18) The condition of a seemingly-healthy patient can deteriorate very rapidly within a few days, and could result in death or an extended period of dementia. (R. C080, ¶5) It is very likely that the Petitioner's physical or mental health will decline suddenly. (R. C081, ¶6)

INABILITY, DESPITE NEED, OF NATURAL PARENTS TO PLAN FOR FUTURE GUARDIANSHIPS

Approximately seventy to eighty percent of HIV/AIDS-affected parents with minor children are single women heads of households, with an average of three to five children each. (Supp.R. C013, ¶7; Supp.R. C010, ¶9; Supp.R. C005-06, ¶8; R. C066, ¶2) Planning for the future care of their children is a desire of many such parents. (Supp.R. C013, ¶8; Supp.R. C010, ¶10; Supp.R. C006, ¶9)

Present procedures to obtain emergency or temporary guardianship authority only provide piecemeal solutions. (Supp.R. C006, ¶10; R. C066, ¶2) Multiple efforts may be required before a permanent guardianship is established, imposing unnecessarily burdensome financial, time and energy expenditures for families (Supp.R. C006, ¶10; R. C066, ¶2), possibly more than the already-overburdened families can handle (R. C066, ¶2).

The time required for a guardian to be appointed can result in children being unnecessarily removed from their families to be placed in emergency shelter or foster care settings (Supp.R. C014, ¶14; Supp.R. C010, ¶16; Supp.R. C006, ¶15), or even preclude being enrolled in school

(R. C066-67, ¶4). Government benefits, including Social Security, Public Aid, Section 8 housing vouchers or Chicago Housing Authority placement, may be and have been delayed or denied as a direct result. (Supp.R. C014, ¶15; Supp.R. C010, ¶17; Supp.R. C006, ¶15; R. C066-67, ¶4) The minors involved in the instant appeal reside with Petitioner in Section 8 housing, but the nominated guardian does not and would face a delay in obtaining a continuation of §8 housing for the children. (R. C082-83, ¶¶3, 5) Such children have also faced delays in receiving medical care. (Supp.R. C.014, ¶16; Supp.R. C010, ¶18; Supp.R. C006, ¶17; R. C066-67, ¶4; R. C083, ¶6) Possible harmful effects to the children include the interruption of care, and permanent estrangement from immediate and extended family members. (Supp.R. C014, ¶14; Supp.R. C010, ¶16; Supp.R. C006, ¶15) The majority of affected children live under poverty conditions. (R. C.042)[7] The future needs of children and adolescents who are orphaned as a result of AIDS-related illnesses will place heavy demands on the mental health, social welfare and educational sectors. (R. C039)[8]

Advance planning for the future welfare of minor children by permitting standby guardianships is in the best interests of the children, the guardian, the parent and the family. (Supp.R. C014, ¶¶17, 19; Supp.R. C006-07, ¶¶19, 21; R. C067, ¶5) Examples of five case histories were related to the court below where minor children were placed in emergency shelters and a series of temporary Department of Children and Family Services (DCFS) foster homes and private agency foster homes, despite the intentions and advance efforts of parents to establish guardianships.

[7]"The 'Silent' Legacy of AIDS, at p. 3478.

[8]"Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States", at p. 3459.

(Supp.R. C014-15, ¶¶18 a-e; Supp.R. C010-11, ¶¶20 a-e; Supp.R. C006-07, ¶¶20 a-e) State laws "which leave children in legal limbo at the time of a parent's death, even when a guardian has been named" should yield to solutions—such as standby guardianships—which permit a guardian to be named prior to incapacity or death. (R. C043)[9]

ARGUMENT

INTRODUCTION

A. PETITIONER'S REQUEST FOR AN ORDER ESTABLISHING STANDBY GUARDIANSHIP

Petitioner-Appellant Geraldine Jones ("Ms. Jones"), petitioned for the appointment of her sister, Charlene Gonzalez, as guardian for her two minor children, Melanie Marie Herrod, and Ebony Lynette Stevenson. Ms. Jones further made the request contingent upon allowing her to retain custody of her children until she is no longer able to care for them, as determined by her own admission, her hospitalization, or by the statement of her physician. In effect, petitioner requested that her sister be appointed as a "standby guardian".

B. SUMMARY OF THOSE ISSUES OF PARTICULAR CONCERN TO AMICI CURIÆ WHICH ARE ADDRESSED IN THEIR BRIEF ON APPEAL

Leave was granted to AIDS Legal Council of Chicago (ALCC), National Association of Social Workers (NASW), AIDS Foundation of Chicago (AFC), Families' and Children's AIDS Network (FCAN), Child Care Asso-

[9]"The 'Silent' Legacy of AIDS", at p. 3479.

ciation of Illinois (CCAI), Episcopal Diocese AIDS Task Force (EDATF), and Chicago Women's AIDS Project (CWAP), to file their Brief of *Amici Curiæ* by this Court's order of April 21, 1993.[10]

Amici will address three issues of particular concern to them.

The manifest weight of the evidence contained in the record has shown that, given the growing number of HIV and AIDS cases, the flexibility of standby guardianships will become required more frequently by AIDS-affected parents and families in order to adequately plan for the future care of their children. However, the judge below did not act in the best interests of the children when he failed to acknowledge their particular circumstances as children of a single parent whose illness will lead to disability or death, but by an unpredictable course—a scenario which will increasingly demand creative judicial relief.

Second, *amici* contend that the Circuit Court has authority to appoint a standby guardian, whether under the Illinois Probate Code (755 ILCS ¶ 5/11-5 [Smith-Hurd 1993]) and the case law interpreting the code, or under the equitable power of the probate court to structure such a standby guardianship.

Finally, *amici* believe that a standby guardianship serves the best interests of these particular children and the thousands of others in Illinois who are facing the same uncertain future and unstable environment as a result of this very traumatic experience. Guardianships in which custody immediately passes to the appointed guardian are inappropriate to Ms. Jones' situation. Although she presently has the capacity to care for her daughters, she wishes to plan for her children's care upon her incapacitation from AIDS.

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[10]The interest of *Amici* are noted in the Appendix to this Brief, at p. 23i.

I
THE OVERWHELMING MAGNITUDE OF THE SERIOUS PROBLEMS FACING AIDS-AFFECTED CHILDREN IN ILLINOIS REQUIRES STANDBY GUARDIANSHIPS

Women, long the invisible sufferers of the AIDS epidemic, now account for an increasing number of HIV and AIDS diagnosed adults in Chicago and the nation as a whole. At least 3,300 women in Chicago are infected with HIV. In a recent needs assessment of Chicago women with HIV, it was found that more than eighty percent of these infected women had children. Of those women, half had one or two children and over one-third had three or more children. These figures lead to the projection that there are approximately 8,000 children with HIV-positive mothers who will become "effectively orphaned".

> These findings warn of a serious challenge to cities and communities already staggering under the weight of faltering economies, violence, homelessness, inadequate medical care, poor education, drug use, and a host of other long-standing social problems. Yet the needs of these youngsters cannot be ignored. To do so would be not only lacking in compassion for the most vulnerable members of society: it would also invite a social catastrophe of the greatest magnitude. The death of a parent or other emotionally significant adult is one of the most traumatic experiences that any child can suffer. When that death is accompanied by stigma and isolation and is followed by instability and insecurity, as it is in AIDS, the potential for trouble, both immediately and in the future, is magnified.
>
> While more study is needed on the impact of the HIV/AIDS epidemic on the family, there is ample evidence to warrant immediate action, with appropriate evaluation and follow-up. *Children and adolescents already orphaned by AIDS cannot wait for the normally slow policy process to take account of their complex and individualized needs*. While some bereaved children and adolescents are already in foster care and others are immediately taken in by relatives willing and able to care for all the surviving youth, *many, probably the majority, face futures beset by uncertainty and instability,* separation from siblings, and unrecognized and unaddressed grief. Those who

> develop, interpret, and implement guidelines and programs of custody decisions, foster care, adoption, education, juvenile justice, health care, and institutionalization will need flexibility and creativity in addressing these immediate and urgent needs.

(R. C040-41; D. Micheals & C. Levine, "Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States", at 3460-61) (emphasis supplied).

Without any factual basis in evidence contained in the record, the judge below assumed that the present system effectively and efficiently protects AIDS-affected children. However, Petitioner's supporting affidavits documented repeated examples of the courts' inability to protect the welfare of children, the majority of whom live under poverty and who have been unnecessarily removed from their families and placed in emergency shelter or foster care settings, been unable to attend school or receive medical care, and who have experienced denials or delays in continuing to receive government entitlements. Elizabeth Monk, Director of the AIDS Project of the Illinois Department of Children and Family Services, has concluded that the best interests of the children cannot be protected without standby guardianships, an opinion shared by the Families' and Children's AIDS Network (FCAN), an organization of approximately 80 hospitals, clinics, social service and legal aid agencies in Chicago which provide services to AIDS-affected families.

II
THE CIRCUIT COURT ABUSED ITS DISCRETION IN HOLDING, AGAINST THE MANIFEST WEIGHT OF THE EVIDENCE, THAT IT WAS NEITHER NECESSARY NOR CONVENIENT THAT PETITIONER, A COMPETENT PARENT OF TWO MINOR CHILDREN, RETAIN IMMEDIATE CUSTODY, WITH APPOINTMENT OF A STANDBY GUARDIAN WHO COULD ASSUME CUSTODIAL DUTIES AT SUCH TIME WHEN PETITIONER BECOMES TEMPORARILY OR PERMANENTLY INCAPACITATED OR DECEASED

A. ALL RELEVANT STATUTORY PROVISIONS FOR APPOINTMENT OF GUARDIANS FOR MINORS WERE SATISFIED

The Illinois Probate Code provides that "a court may appoint a guardian of the person...of a minor *whenever* it appears necessary or convenient." (755 ILCS ¶ 5/11-5(a) [Smith-Hurd 1993]) (emphasis supplied). The guardianship petition should be granted if appointment would be *either* "necessary" *or* "convenient". *Stevenson v. Hawthorne Elementary School,* 144 Ill.2d 294, 302-05 (1991) A court, in deciding whether a guardianship is "necessary or convenient", looks at all relevant facts and analyzes what is in the best interest of the child. *Stevenson v. Hawthorne Elementary School*; *see e.g., In re Marriage of Russell*, 169 Ill. App. 3d 97, 523 N.E.2d 193 (2d Dist. 1988); *In re Estate of Suggs*, 149 Ill. App. 3d 793, 798, 501 N.E.2d 307 (1st Dist. 1986); *In re Estate of Stark*, 33 Ill. App. 3d 626, 628, 342 N.E.2d 234 (5th Dist. 1975). The "best interests" standard is also used in child custody proceedings brought under the Juvenile Court Act. *E.g., In re W.B., Jr., a Minor*, 213 Ill. App. 3d 274, 571 N.E.2d 1120, 1126 (4th Dist. 1991).

Petitioner's argument before the court below, and in her Brief on appeal, demonstrates that her application for appointment of a guardian satisfied all of the relevant factors set forth in Section 602 of the Marriage

and Dissolution of Marriage Act, 750 ILCS 5/602 (Smith-Hurd Supp. 1993). The crucial issue therefore becomes at what point should the guardianship become effective, and under what conditions.

B. INHERENT EQUITABLE POWERS OF THE PROBATE COURTS TO ESTABLISH GUARDIANSHIPS FOR MINORS

It is the responsibility of the trial court to provide for the best interests and welfare of minors. *In re Estate of Stark,* 33 Ill.App.3d 626, 628 (5th Dist. 1975). *Amici* contend that the appointment of Ms. Gonzalez as a standby guardian for Ms. Jones' daughters is in the best interests of these children, and therefore both "necessary" *and* "convenient" under Illinois law. Moreover, appointing Ms. Gonzalez as a standby guardian also falls within the traditional equitable powers of the Circuit Court.

A probate judge has "inherent, plenary jurisdiction to appoint guardians for minors *independent of any authority that the Probate Act or other legislation confers.*" *In re Estate of Suggs*, 149 Ill.App.3d 793, 797, 501 N.E.2d 307 (1st Dist. 1986) (emphasis supplied), *citing In re Guardianship of Smythe*, 65 Ill.App.2d 431, 441, 212 N.E.2d 609, 613 (1965). In exercising this plenary power, the court may "cause to be done whatever may be necessary to preserve their [minor's] estates and protect their interest" *In re Guardianship of Smythe*, 65 Ill.App.2d at 440-41. Furthermore, this equitable jurisdiction cannot be taken from the courts by the legislature. *Id.* at 440-41. *Amici* urge this Court to use such power to shape an appropriate standby guardianship so that all involved will benefit.

In guardianship cases, the court has the power to impose conditions upon the guardianship. According to 755 ILCS ¶ 5/11-13 (Smith-Hurd

1993), "[t]he court shall have control over the person and estate of the ward." The guardian acts under the direction of the court, which may specify the conditions of the guardianship—and the time at which the guardianship responsibilities should be activated is one such condition. *Cf. In re Marriage of Manuele*, 107 Ill.App.3d 1090, 1096, 438 N.E.2d 691, *app. denied*, (4th Dist. 1982) (court has broad powers in custody matters and may impose conditions upon custody).

III
THE COURT BELOW, BY REFUSING TO APPOINT A STANDBY GUARDIAN FOR THE MINOR CHILDREN, FAILED TO CONSIDER THEIR BEST INTERESTS FOR A STABLE ENVIRONMENT IN THE FUTURE

A. THE COURT FAILED TO PROPERLY GIVE DUE WEIGHT TO THE WISHES OF PETITIONER REGARDING CUSTODY OF HER CHILDREN

1. The Court Must Consider the Particular Circumstances of Each Case.

Case authority directs that "[i]n determining the best interest of the child, the court must consider the particular facts and circumstances of each case." *In re Custody of Bobby Krause,* 111 Ill.App.3d 604, 607 (1st Dist. 1982). In its role as a reviewing court, the Appellate Court will not hesitate to disturb the lower court's findings if the trial court incorrectly applied legal principles or if the evidence showed that an injustice had been committed. *Jenkins v. Jenkins,* 81 Ill.App.2d 67, 71 (1st Dist. 1967)

2. Appointment of a Standby Guardian Serves to Effectuate Petitioner's Wishes Regarding Custody of Her Children.

The best interests of the children would be furthered by appointing Ms. Gonzalez as a standby guardian, whose duties would become activated upon the incapacity of Ms. Jones. The standby guardianship gives

effect to Ms. Jones' wishes regarding the custody of her children. *In re Marriage of Russell*, 169 Ill.App.3d 97, 103, 523 N.E.2d 198 (2d Dist. 1988) (a parent's intent as to who should care for her minor children is an important factor to be considered in establishing guardianships). It also gives effect to Ms. Jones' desire to retain custody of her children while she is still fit.

Moreover, a testamentary nomination is merely a nomination. Since the nomination is subject to those who might contest in a hearing, Petitioner requires that the hearing occur while she is still alive and capable of providing testimony. A testamentary nomination is further inadequate because it does not provide for guardianship during the parent's incapacity: it does not take effect until the parent dies.

Although the courts usually will award custody of minors to the appointed guardian, the natural rights of a parent may be preferred, *In re Custody of Bobby Krause,* 111 Ill.App.3d 604, 606-07 (1st Dist. 1982); *Cebrzynski v. Cebrzynski,* 63 Ill.App.3d 66 (1st Dist. 1978), and so the non-parent testamentary guardian may not be given custody, which potentially may create an additional delay as a result of holding contested hearings during a time when the AIDS-infected parent is disabled or deceased.

B. THE COURT FAILED TO CONSIDER THE CONTINUING INSTABILITY IN THE MINOR CHILDREN'S ENVIRONMENT

1. Stability of the Minors' Environment Should Have Been Considered by the Court Below.

Stability in a child's environment is an important factor to be considered in an analysis of best interest. *In re Marriage of Dunn*, 208 Ill.App.3d 1033, 567 N.E.2d 763 (5th Dist. 1991). A standby guardianship

provides some stability at a time when the child's world is most tumultuous—after his parent's death. It is almost inevitable, given the nature of AIDS, that Ms. Jones' children will need a guardian. Ms. Jones is attempting, with the assistance of the court, to plan a smooth transition for the care of her children. Ms. Jones and her daughters must be assured that Ms. Gonzalez will be the legal guardian of the girls.

Testimony of knowledgeable authorities established the potentially disruptive effects of denying the petition for standby guardianship and thus requiring resort to emergency court intervention:

> 15. The period of time needed to obtain court-sanctioned powers of guardianship can mean that child(ren) from HIV-affected families will be removed from the custody of their parent(s) and may be placed unnecessarily in emergency shelter and/or foster care settings until a guardian can be appointed. This kind of placement can interrupt continuity of care for the child(ren) and may lead to their permanent estrangement from immediate and extended family members.
>
> 16. The period of time needed to obtain court-sanctioned powers can mean a delay or denial of government benefits, such as Social Security, Public Aid, Section 8 Housing vouchers, or Chicago Housing Authority placement.

(Supp.R. C006; Affidavit of Elizabeth Monk, Director of the AIDS Project of the Illinois Department of Children and Family Services, in support of Petitioner's Motion for Rehearing).

2. As Long as the Natural Mother is Capable of Caring for Her Children, Their Best Interest is Served by Remaining In Her Custody.

When the natural parents are fit, it is presumed that the best interest of a child is served by remaining with her natural parents. *In re custody of Krause*, 111 Ill.App.3d 604, 609, 444 N.E.2d 631 (1st Dist. 1982); *see also* 755 ILCS ¶ 5/11-7 (Smith-Hurd 1993) (living parent or parents competent to transact their own affairs and fit are entitled to custody of

the person of the minor). A standby guardianship addresses this presumption and helps the court serve the best interests of these children. The mother, Ms. Jones, retains custody of her children for as long as possible, until and so long as her illness results in incapacity. Ms. Jones is requesting the fullest possible participation and involvement in her children's lives; she expects that both she and her children will be enriched by doing so. Yet Ms. Jones foresees the inevitable loss of her ability to care for her children and therefore desires to establish a guardianship, while she is still alive, alert, and able to testify.

A standby guardianship is a thoughtfully-fashioned and appropriate guardianship which fulfills a very specific need. In a two-parent family, the care of the children passes to the other parent upon the incapacity of one of the parents. But, single parents with terminal illnesses such as AIDS, inoperable cancer, multiple sclerosis, cystic fibrosis or muscular dystrophy, need to be able to provide for the welfare of their children before they are incapacitated.[11]

A testamentary guardianship nomination does not suit the needs of Ms. Jones and her family. When she dies or becomes incapacitated, Ms. Jones wants her children's guardian to have immediate legal authority; she wants to eliminate the need for further legal action, such as the probating of a will. She also wants to avoid placing her daughters in a legal limbo during the period when the case is before the probate court—a limbo during which the girls might be hindered in their attempts to obtain

[11]Illinois law provides for a similar type of delayed arrangement in the context of durable powers of attorney for health care and property. Both allow a person to nominate a guardian for his own property and person in the event the court determines a guardian is necessary. Ill. Rev. Stat. ch. 110 1/2 ¶ 803-3 (property) and ¶ 804-10 (health care). If a standby guardianship is not granted, the anomalous result is that one can arrange to take better care of one's property than one's children.

medical treatment, enroll in school, or receive their government entitlements.

C. THE LOWER COURT'S DECISION NEEDLESSLY REQUIRES THIS MOTHER, WHO IS TRYING TO PROVIDE FOR THE FUTURE CARE OF HER TWO CHILDREN, TO PREMATURELY RELINQUISH CUSTODY

Typical guardianships in Illinois remove a child from the custody and care of his parent too soon: they take effect immediately upon the adjudication of guardianship. 755 ILCS ¶ 11-13(a) (Smith-Hurd 1993) ("guardian *shall have custody*" of the ward) (emphasis supplied). In this case, Ms. Jones is still capable of caring for her children. It has been the experience of *amici* that few parents wish to relinquish custody and care of their children while they remain healthy enough to care for them. The bonds of love and affection, direction and guidance, and day-to-day involvement should not be destroyed simply because a parent is nearing an untimely death.

As a result of Judge Cole's decision, Ms. Jones finds herself faced with an unreasonable dilemma: should she needlessly give up custody of her children immediately, while she is still capable and able to parent, or should she run the risk of delaying guardianship proceedings until the last moment? Unfortunately, the "last moment" can not be predicted for people suffering from AIDS.[12]

> The various opportunistic and indicator diseases, conditions and symptoms associated with AIDS can be episodic—that is,

[12]Appointing a standby guardian is especially well-suited for cases involving single-parent families in which the parent has AIDS. This is due to the nature of the disease: the physical and mental health of the individual can frequently change dramatically and suddenly. An HIV positive mother may properly remain her child's custodian for most of her illness and then quite suddenly, by reason of her sickness, be ill-prepared to establish the needed guardian arrangements.

> in some cases and for some of these individuals diseases conditions, or symptoms may very well leave them able to function one week, and not the next. By the third week they may be able to function well again.

(R. C069, ¶10; affidavit of Mardge Cohen, M.D., physician in charge of Women and Children HIV Program at Cook County Hospital, in support of Petitioner's Motion for Rehearing).

A parent may become incapacitated before guardianship proceedings are initiated or during the guardianship proceedings. In contrast, the standby guardianship allows the parent to provide for a guardianship while she is still able to participate in the proceedings. Ms. Jones should not be burdened with this unfair, and unduly harsh, choice when a more suitable alternative, a standby guardianship, can be granted by the court.

CONCLUSION

Children and adolescents already left parent-less by AIDS should not have to face a future which is fraught with uncertainty and instability. *Amici* have found that many ill HIV-infected women do not establish future custody plans for their children, partly due to denial and fear of disclosure, and partly because they fear they will lose custody—and too many of their parental rights—too soon. Appointing standby guardians provides much-needed flexibility and creativity in addressing the immediate and urgent needs of these children. The law should be shaped by experience, and judgments rendered in such a way as to recognize the dignity of individuals. Guardianship laws in particular can be crafted to meet what will be, sadly, an ever-growing need.

> It is revolting to have no better reason for a rule of law than that so it was laid down in the time of Henry IV. It is still more revolting if the grounds upon which it was laid down

> have vanished long since, and the rule simply persists from blind imitation of the past.

Justice Oliver Wendel Holmes, *The Path of the Law,* 10 Harv.L.Rev. 457, 469 (1897).

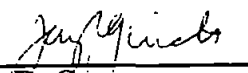
This Court can act now, given the authority granted circuit judges under the case law, the Probate Code, and the equitable powers of the probate court.

For the foregoing reasons, *Amici* respectfully urge this Court to reverse the decisions of the court below, and remand with instructions to enter the Petitioner's order for a standby guardianship. The circuit court should appoint Ms. Gonzalez as guardian, but allow Ms. Jones to retain custody of her children until such time as she is no longer able to care for them, as determined by her own admission, her hospitalization, or the statement of her physician.

In the alternative, the Appellate Court should reverse the order of the court below, and remand with instructions to enter an order awarding joint custody to Ms. Jones and Ms. Gonzalez.

Respectfully submitted,

JAY R. GIUSTI
525 North Ada Street
Suite 20
Chicago, Illinois 60622
(312) 455-0074
Attorney for Amici Curiæ.



JAY R. GIUSTI

IN THE APPELLATE COURT OF ILLINOIS
FIRST DISTRICT

Estate of MELANIE MARIE HERROD, Minor and Estate of EBONY LYNETTE STEVENSON, Minor Petitioners-Appellants.	No. 93-1067 Hon. George W. Cole, *Judge Presiding*

NOTICE OF FILING

TO: Linda M. Rio
SIDLEY & AUSTIN
One First National Plaza
Chicago IL 60603

PLEASE TAKE NOTICE that I have caused to be filed with the Clerk of the Court on May 10, 1993 the Brief and Argument of Amici Curiæ, a copy of each of which is herewith served upon you.

Attorney for *Amici Curiæ*

CERTIFICATE OF SERVICE

The undersigned attorney certifies that he caused the foregoing Brief and Argument of Amici Curiæ to be served on the person(s) above designated by causing three copies thereof, properly sealed and addressed, to be delivered to Linda M. Rio, SIDLEY & AUSTIN, One First National Plaza, Chicago IL 60603, before 5:00 p.m. on May 10, 1993.

Attorney for *Amici Curiæ*

Name	Jay R. Giusti
Attorney for	Amici Curiæ
Address	525 N. Ada St., No. 20
City	Chicago IL 60622
Telephone	(312) 455-0074

APPENDIX TO BRIEF OF AMICI CURIÆ

Interest of *Amici Curiæ*

AIDS Legal Council of Chicago (ALCC)
National Association of Social Workers (NASW)
AIDS Foundation of Chicago (AFC)
Families' and Children's AIDS Network (FCAN)
Child Care Association of Illinois (CCAI)
Episcopal Diocese AIDS Task Force (EDATF)
Chicago Women's AIDS Project (CWAP)

Each of the *Amici* are considered to be highly knowledgeable within their particular areas of concern about the affect of HIV/AIDS upon parents and their children.

The *AIDS Legal Council of Chicago* ("ALCC") and the *Families' and Children's AIDS Network* ("FCAN") were granted leave by the court below to participate as *Amici Curiæ*, and filed a joint brief in support of the petitioner. The petitioner sought assistance with her guardianship petition from the AIDS Legal Council of Chicago. ALCC referred petitioner to Linda Rio, of Sidley & Austin, who is also a volunteer attorney for ALCC. Ms. Rio represents the interests of Petitioner before the Appellate Court.

1. ALCC is a non-profit corporation dedicated to ensuring the fair treatment of people with the HIV infection and with AIDS. With the assistance of 70 volunteer attorneys, the ALCC provides legal representation and advocacy to individuals affected by HIV and AIDS. The ALCC also supports the public policy interests of individuals infected with the virus. The ALCC, the recipient of private and public funds, has also helped lead a coalition of social service agencies studying the problems faced by ill parents who are planning for the future care of their children. Last year the ALCC represented over 906 clients, 32 of whom required legal advice and assistance in establishing guardianships for their children.

2. FCAN is a coalition of hundreds of individuals and organizations working on behalf of families and children affected by HIV. Its membership includes medical and social service agencies that provide services to children and families affected by HIV in Chicago. FCAN promotes and develops family-centered, community-based care through coordination of services to fill gaps, advocacy for the needs of HIV-affected families and children, and education on HIV infection in children and families to providers and to the general public. FCAN is a non-profit agency, receiving private donations and public funds.

3. The *National Association of Social Workers* ("NASW") is the largest association of professional social workers in the world, with over 145,000 members in 55 chapters throughout the United States and abroad. The Illinois chapter of NASW has over 8,400 members. Founded in 1955 from a merger of seven predecessor social work organizations, NASW is devoted to promoting the quality and effectiveness of social work practice, advancing the knowledge base of the social work profession and improving quality of life by utilizing social work knowledge and skills. Many of NASW's members work with children and families, including persons who are HIV positive, who are ill with AIDS or whose lives are directly impacted by the disease. NASW believes that allowing standby guardianships would promote family stability, foster greater security for all parties, and would be in the best interests of the children involved.

4. The *AIDS Foundation of Chicago* ("AFC") represents more than 100 AIDS service providers in the Chicago area. Among AFC's principal activities is the development and support of a citywide system of case management services. In the past year, more than 2,000 HIV-positive people received case management services funded by AFC; among them

were a substantial number of women and children. The number of case managers who work specifically with women and children has doubled in the past year. As the cases increase, case managers often report that the long-term welfare of their children is the parent's primary concern. AFC also provides grants to establish innovative programs that address the unique needs of women and children living with HIV/AIDS. AFC is a non-profit agency receiving public and private funds.

5. The *Child Care Association of Illinois* ("CCAI") is a state-wide association of 75 member agencies across the State of Illinois. CCAI provides a wide variety of child welfare services, including helping secure institutional, group home, foster care, and relative care placements, and CCAI is actively involved in advocacy efforts before the Illinois General Assembly on issues addressing child welfare. CCAI also provides a wide spectrum of counseling services for individuals, groups and families; members of CCAI often work with individuals affected by HIV and AIDS.

6. The *Episcopal Diocese AIDS Task Force* ("EDATF") exists as a ministry of empowerment, service and advocacy. In its work, EDATF assists people who are struggling with issues raised by AIDS. The Task Force also provides the following programs: workshops, direct services (providing direct physical and pastoral care to people affected by HIV and AIDS), and information and referral for individuals and families affected by HIV and AIDS.

7. The *Chicago Women's AIDS Project* ("CWAP") is dedicated to serving the needs of women with HIV/AIDS and their families. The Project provides support groups for women, including child care and therapy groups for children. Through its care management services and through individual, couples, and family counseling, CWAP addresses many

HIV/AIDS-related issues, among them: custody and guardianship planning, custody changes, reuniting families, and other parenting issues. CWAP consistently seeks to establish means by which women may more appropriately plan for the future care of their children. CWAP is a non-profit agency receiving private donations and public funds.

Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States

avid Michaels, PhD, MPH, Carol Levine, MA

Objective.—To estimate the number of youth in the United States who have ɔen or will be left motherless by the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic, in order to project the need for ımily supports, age-appropriate foster and congregate care, and mental health and ocial services.

Design.—Orphans are defined as youth whose mothers (the usual caregiving arent) die of HIV/AIDS-related causes. A mathematical model was constructed to stimate the number of such motherless youth. Cumulative fertility rates were applied to the number of reported AIDS deaths (1981 through 1990) and projected eaths (1991 through 1995) of adult women less than 50 years old. The results were djusted for underreporting of HIV/AIDS-related mortality, pediatric AIDS deaths, ıfant mortality, ethnic and racial variation in fertility, and decreased fertility assoɔiated with late-stage HIV disease. Estimates were made for the number who were ɔhildren (less than 13 years of age), adolescents (13 to 17 years of age), or young ıdults (18 years of age or older) at the time of their mothers' death.

Results.—By the end of 1995, maternal deaths caused by the HIV/AIDS epidemic will have orphaned an estimated 24 600 children and 21 000 adolescents n the United States; unless the course of the epidemic changes dramatically, by .he year 2000, the overall number of motherless children and adolescents will exɔeed 80 000. In 1991, an estimated 13% of US children and 9% of adolescents whose mothers died of all causes were children of women who died of HIV/AIDS-related diseases. These proportions will surpass 17% and 12%, respectively, by 1995. The vast majority of these motherless youth will come from poor communities of color.

Conclusions.—A large and rapidly growing number of American youth are being orphaned by the HIV/AIDS epidemic. Unless increased attention and resources are devoted to this vulnerable population, a social catastrophe is unavoidable.

(*JAMA*. 1992;268:3456-3461)

NOW in its second decade, the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic is reverberating in ever-widening circles. From 1981 through March 1992, 218 301 cases of AIDS had been reported to the Centers for Disease Control and Prevention (CDC). Of these, 22 607 (10%) were women.[1] However, while 9% of the first 100 000 persons with AIDS were women, women comprised 12% of the second 100 000, and the proportion of women among all persons with AIDS will continue to rise.[2] The proportion of women among all AIDS cases is significantly higher in some locations, reaching 27% in New Jersey (oral communication, J. Piel, MPH, New Jersey Department of Health, Newark, April 13, 1992) and 20% in New York City for calendar year 1991.[3] By 1989, AIDS had become the sixth leading cause of death nationwide among women 25 to 44 years of age.[4] In New York City, it is the leading cause of death among women 15 to 44 years of age,[5] and since 1987, HIV/AIDS has been the leading cause of death among African-American women of that age group in New York State and New Jersey.[6]

Half of the women with AIDS nationally are injecting drug users (IDUs) and an additional quarter have been infected through heterosexual contact with infected drug users.[1,7] Studies of family structure among IDUs show that in these families, women are the primary caregivers.[8-10] When these women die, they leave children of different ages, some of whom need shelter, food, and medical care, and all of whom need emotional support and guidance.

For editorial comment see p 3478.

This study addresses a fundamental question: How many children, adolescents, and young adults will be orphaned by the HIV/AIDS epidemic in the United States?

Because there are no data that directly answer the fundamental question (in itself an indication of the relative lack of attention this population has received), this study attempts to synthesize information from other sources to produce ranges of estimates. These

From the Department of Community Health and Social Medicine, CUNY Medical School/Sophie Davis School of Biomedical Education (Dr Michaels) and The Orphan Project, New York, NY (Ms Levine).

Reprint requests to The Orphan Project, 121 Avenue of the Americas, 6th Floor, New York, NY 10013 (Ms Levine).

estimates can be used to project the need for family supports, foster and congregate care, and mental health and social services.

METHODS

For the epidemiological purposes of this study, orphans of the HIV/AIDS epidemic are defined as youth whose mothers die of HIV/AIDS-related disease. Within the broad category of youth, we distinguish among children (0 to 12 years of age), adolescents (13 to 17 years of age), and young adults (18 years of age and older). Although in recent years the term "orphan" has been used most commonly to describe a child who has lost both parents, throughout Western history it has been used to define a child who has lost one or both parents.

A definition that focuses on motherless youth was chosen for several reasons. First, it conforms to the realities of family life, since for the vast majority of youth whose caregiving parent dies of an HIV/AIDS-related disease, the mother is that parent. There are, of course, families in which an uninfected father is willing and able to serve as primary caregiver when the mother dies of HIV/AIDS-related complications. These situations appear to be rare. There are also families in which the death of the father due to an HIV/AIDS-related disease, even if the mother is uninfected, is a traumatic event that occasions family breakup and subsequent placements of the children. While both such scenarios are important in developing programs to meet the range of individual needs, they do not affect the broad epidemiological picture. Second, this definition conforms to the realities of epidemiological analysis, since there are few data on the offspring of men dying of HIV/AIDS-related disease. For these reasons, this definition is used by the CDC,[11] the World Health Organization, and the United Nations Children's Fund (UNICEF).[12] A mathematical simulation model, similar to one used to project the number of AIDS orphans in Africa,[13] was constructed using the following steps:

1. Estimate the number of women who die of HIV-related disease.

Data on women 13 to 49 years of age, who died of AIDS-related diseases from 1981 through 1990, were abstracted from the CDC's Public Information Data Set, containing information on individuals meeting the CDC's AIDS case definition reported through December 1991. For the purpose of this analysis, the women were divided by race/ethnic group, and stratified by year of death and 5-year age group. Women over the age of 49 years were not included, since it is assumed that virtually all of the children born to these women would be over 18 years of age. For the years 1991 through 1993, the number of projected deaths due to all HIV-related causes was derived from CDC projections,[14] assuming that the age, race, and gender distribution of these deaths is the same as that seen among deaths of reported AIDS cases in 1990. While the CDC has not issued projections of AIDS mortality beyond 1993, recent mathematical models project that overall AIDS incidence is likely to level off in 1993 and 1994, while the number of cases transmitted through heterosexual sex and injecting drug use will continue to rise.[15,16] For the purposes of this model, annual AIDS-related deaths among women beyond 1993 have been assumed to plateau at the projected 1993 number.

Deaths among reported AIDS cases represent only a fraction of all HIV-related deaths. The CDC estimates that before 1987, when it modified its criteria for identifying cases of AIDS, between 46% and 72% of all deaths due to HIV-related disease had been reported as cases to its national AIDS surveillance system.[17] To adjust for this underestimate, the estimated range's midpoint (59%) was selected, and deaths for those years were multiplied by 1.69 (1/0.59).

For the period since the change in case definition, the CDC estimates that between 61% and 89% of HIV-related deaths were reported as AIDS cases.[17] Applying the midpoint of this estimate (75.5%), the multiplier of 1.32 was employed in deaths that have occurred between September 1987 and December 1990. The number of HIV-related deaths projected to occur after 1990 were not multiplied, since these figures were already adjusted for the estimated undercount.

2. Estimate the number of children born, adjusting for HIV-related decreased fertility.

Annual race-specific cumulative fertility rates (CFRs), representing the total number of children born 1980 through 1989 per 1000 women of that 5-year age stratum, published by the National Center for Health Statistics, were used to estimate the number of children that white and African-American decedents would have had if their fertility experience were identical to that of the US standard. Cumulative fertility rates for 1989 were used for all subsequent years. For Hispanic women, comprising 21% of the women with AIDS in the United States, the rate for white women was multiplied by 1.312, the ratio of the total fertility rate (TFR) of Puerto Rican-origin women to the TFR of white women in the United States in 1989.[18] (This rate was chosen because 62% of adult Hispanic women who died of AIDS-related diseases in New York City were born in Puerto Rico, and a significant proportion of the remainder are likely to be women of Puerto Rican origin.[19])

Calendar year and 5-year age-specific CFRs were constructed with a 1-year lag, based on the assumption that no children were born to women in the year before they died of AIDS-related causes. (For example, the CFR for 19- to 23-year-olds in 1985 was applied to the 20- to 24-year-old stratum in 1986, using the same group's CFR of 1 year earlier, when they were 1 year younger.) The numbers of women dying of AIDS-related causes in each year and 5-year age stratum were multiplied by the lagged fertility rates.

Women for whom the race/ethnicity category was listed as "other/unknown" were assigned to the three groups using a weighted system that distributed cases proportionally within each age stratum.

3. Adjust for infant mortality and pediatric AIDS deaths.

In order to take into account the small number of infants who die in the first year of life, infant mortality rates (IMRs) were estimated and applied. For women in the white and Hispanic categories, the IMR selected was 15 per 1000, and for African-American women, the IMR was 20 per 1000, representing the highest historical IMRs recorded nationally for these groups in the 1980s.[20]

While the rate of pediatric AIDS incidence and mortality associated with disease in mothers is not available, the authors of a study of 161 HIV-infected women in Rhode Island[21] have reported that 0.9% of the total children of mothers in the cohort had died of AIDS (oral communication, C.C.J. Carpenter, MD, Providence, RI, February 12, 1992). This estimate of 0.9% pediatric AIDS mortality was applied to the study's projections; this represents 300 children who died of AIDS-related causes through 1991, or 15% of pediatric AIDS deaths reported through the end of that year.[1] Although the multiplier of 0.991 (1−0.009) was applied to the total group, its entire effect was assigned to the children (0 to 12 years of age), since it appears that few children infected perinatally with HIV are likely to live beyond 12 years of age.[22]

4. Determine the age distribution of motherless youth.

In order to determine the proportion of motherless youth who are children, adolescents, or young adults, one sample year (1989) was selected and the proportions of the CFR for each race

5-year year-of-birth specific strata CFRs were calculated for each year 1 through 1989. This permitted estimation of the proportion of all offspring women who died in a given year who were children (0 to 12 years of age), adolescents (13 to 17 years of age), or young adults (18 years of age and older) that year. The proportions were then applied to each race-specific 5-year age stratum, for every year studied, adjusted for the hypothesized drop in fertility the year before death. Assignment to child or adolescent category is therefore made at the time of the mother's death. By definition, as time progresses, children will reach adolescence and adolescents will become young adults.

The overall model can be summarized in the following formula:

$$= \sum_{ijk}\left[(D_{ijk}\cdot CFR_{ijk})(1/DC_i\%)(1-IMR_k)(1-P_{AIDS})\right]$$

which: O = the total number of motherless children, for all calendar year and 5-year age-specific strata, for each race/ethnicity group; D_{ijk} = the number of deaths for each calendar year$_i$, 5-year age$_j$, and race/ethnicity group$_k$–specific stratum; CFR_{ijk} = calendar year$_i$, 5-year age$_j$, and race/ethnicity group$_k$–specific adjusted CFRs; $DC_i\%$ = proportion of all HIV/AIDS-related deaths listed as dying of AIDS-related causes on death certificate; IMR_k = race/ethnicity group-specific IMR; and P_{AIDS} = cumulative pediatric AIDS deaths proportion (estimated AIDS deaths per 100 children of HIV-positive women).

The model was then elaborated to calculate the following:

1. Upper and lower bounds for the point estimates in the model.

All mathematical estimates are based on the application of a series of assumptions to known or predicted data points. In order to ascertain upper and lower bounds to the point estimates, alternative assumptions were substituted for several of the variables. For the lower bound of the range, the following assumptions were applied:

- Before 1987, 72% of HIV-related deaths were identified through the national AIDS reporting system, and since then, 89% have been identified. These represent the upper bounds of the CDC's estimates.[17]
- The IMR of offspring of half of the women in the study was 46.3, the reported IMR of children born to narcotic-addicted women in New York City, 1979 through 1981.
- The proportion of children who die of AIDS-related complications before their mothers die is 2.7% of all offspring. This is three times higher than the proportion chosen in the main model. As before, this entire effect is assigned to the age category 0 to 12 years.

The upper range was calculated in a similar manner, applying these assumptions:

- Before 1987, 46% of HIV-related deaths were identified through the national AIDS reporting system, and since then, 61% have been identified, representing the lower bounds of the CDC's estimates.[17]
- The number of deaths after 1993 continues to increase at the rate of 10% per year, reflecting the earlier increase in incidence and the projected continued rise of the number of new cases attributed to heterosexual contact.[13]

2. The number of youth made motherless by maternal deaths from other causes and the proportion attributable to the HIV/AIDS epidemic.

Estimates for the total number of new motherless youth in the United States were made by multiplying the total number of women dying each year, for the years 1981 through 1989, by age and race-specific fertility rates, also lagged for 1 year (assuming decreased fertility in the year). Overall, US infant mortality rates for the decade (10 per 1000 for whites and Hispanics, 15 per 1000 for African-Americans) were applied, and the estimated number orphaned by the HIV/AIDS epidemic was subtracted. The number of deaths for the years subsequent to 1989 were assumed to remain constant, augmented only by the number of new HIV-related cases (estimated deaths times the undercount multiplier). The proportion of these motherless youth who are children and adolescents was determined using the technique described above. The estimated numbers of motherless youth orphaned by AIDS were divided by the estimated total motherless youth in order to approximate the proportion of motherless youth orphaned by AIDS among all motherless youth.

In order to estimate the relative contribution made by HIV/AIDS to the number of motherless youth in the United States, a similar method was employed to estimate the number of youth left motherless following maternal death attributed to cancer (*International Classification of Diseases, Ninth Revision* [*ICD-9*] codes 140 through 208) and to motor vehicle accidents (*ICD-9* codes E810 through E825) in 1988, the last year for which complete statistics have been published.[21]

3. The number of motherless youth orphaned by AIDS in New York City.

A similar mathematical simulation model was constructed for New York City, the city with the largest number of women with AIDS. For this model, the results of which will be reported elsewhere, the number of women who were identified by the New York City Health Department to have had AIDS as an underlying cause of death was used, and similar assumptions were applied, including the CDC's estimates of the proportion of all HIV/AIDS-related deaths identified through analysis of the underlying cause of death listing.[17]

RESULTS

The number of children and adolescents made motherless by the HIV/AIDS crisis in the United States is large and rapidly increasing. As illustrated in Fig 1, by the end of 1991, an estimated 18 500 children and adolescents (range, 15 200 to 22 200) in the United States had been orphaned by AIDS. Through the year 1995, the cumulative number of motherless children and adolescents orphaned by HIV/AIDS will reach 45 700 (range, 39 200 to 56 700). The cumulative total (Fig 2) through 1991 includes 10 100 children (range, 8600 to 12 200) and 8400 adolescents (range, 7100 to 10 100). By the end of 1995, the total will include 24 600 children (range, 20 500 to 30 600) and 21 000 adolescents (range, 18 600 to 26 100).

As projections move into more distant time, they inevitably become less precise. Unless the course of the epidemic changes dramatically, however, by the year 2000, the overall number of motherless children and adolescents will reach 82 000 (range, 72 000 to 125 000).

The number of young adults whose mothers die of HIV/AIDS-related causes is also large and growing (Fig 2). Through 1991, there have been 13 900 young adults (range, 11 800 to 17 000) in this category; the total is estimated to rise to 35 100 (range, 31 200 to 43 600) by 1995 and to reach 64 000 (range, 57 000 to 98 000) through the year 2000.

In 1991, an estimated 13% of US children whose mothers died of all causes (and 9% of adolescents orphaned) were offspring of women who died of HIV/AIDS-related complications. These proportions will surpass 17% and 12%, respectively, by 1995. More than 80% of all youth whose mothers died of HIV/AIDS-related complications are offspring of African-American or Hispanic women.

The HIV/AIDS epidemic has come to rival or surpass other important causes of death in taking the lives of mothers of young children. Including only women under the age of 50 years, cancer is the cause of death of mothers of approximately 4200 children and 8700

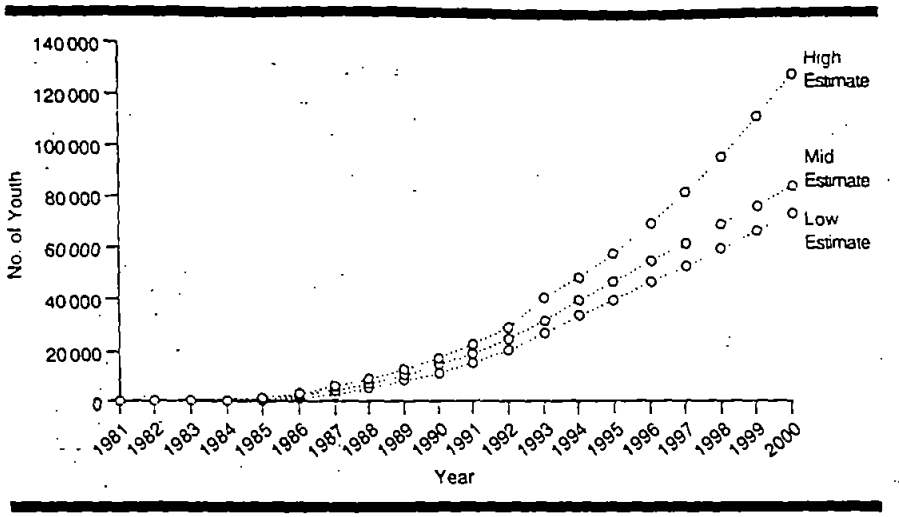


Fig 1.—The range of estimates of the cumulative number of children (less than 13 years of age) and adolescents (13 to 17 years of age) left motherless by the HIV/AIDS epidemic, for the years 1981 through 2000, using different estimates for selected parameters used to construct the model.

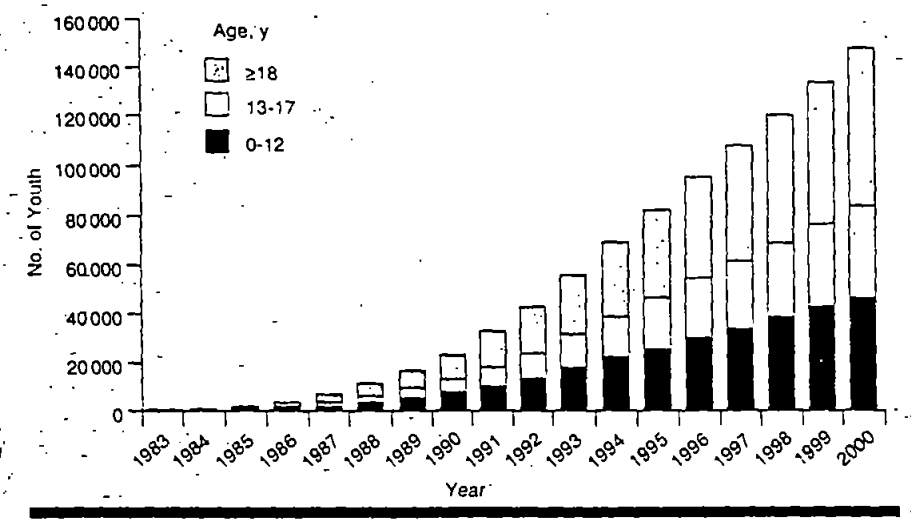


Fig 2.—The cumulative number of motherless children, adolescents, and young adults estimated to be orphaned by the HIV/AIDS epidemic in the United States, 1983 through 2000.

adolescents annually. Motor vehicle accidents are responsible for the deaths of mothers of an additional 3200 children and 1900 adolescents. In contrast, the numbers of children and adolescents annually orphaned by AIDS are predicted to reach 3900 and 3400, respectively, by 1993.

New York City has the largest number and proportion of youth whose mothers have died of HIV/AIDS-related causes of any city in the United States. Through 1991, 3900 children (39% of the country's total) and 3600 adolescents (42% of the total) orphaned by AIDS were from New York City (Fig 3).

The total number of children and adolescents orphaned by the HIV/AIDS epidemic in New York City in 1995 will more than double to 8200 and 8000, respectively, representing 34% and 38% of the national totals.

COMMENT

Almost unnoticed, the HIV/AIDS epidemic has been responsible for the creation of a new, large, and especially vulnerable group of motherless youth—children, adolescents, and young adults whose mothers have died of HIV/AIDS-related complications. This study estimates that there are already more than 18 500 motherless children and adolescents of the epidemic in the United States, and that number will more than double by 1995. Similar estimates have been made by CDC scientists using a somewhat different method.[11] The future is even more ominous, bringing with it a mounting cumulative total of affected youth.

Not surprisingly, these motherless youth will be concentrated in those urban centers where AIDS and HIV infection are most prevalent. The majority will come from poor communities of color. In New York City through 1991, 5357 cases of CDC-defined AIDS had been reported among women of child-rearing age (13 to 49 years). Other cities with large numbers of reported cases of CDC-defined AIDS among women are Newark, NJ (1271), Miami, Fla (924), San Juan, Puerto Rico (676), Los Angeles, Calif (354), and the District of Columbia (254).[24] Children affected by the epidemic will not be limited to these metropolitan areas. While the epidemic becomes more deeply entrenched in inner cities, it is also spreading outward. Studies from Rhode Island and North Carolina on women with HIV/AIDS describe the emerging problems of motherless children in these regions.[18,25] Wherever there are women with AIDS, there will be motherless youth.

As the HIV/AIDS epidemic unfolds, some changes may occur in the age distribution. For example, the women represented in mortality statistics so far were mainly in their 30s and 40s. As younger women become HIV-infected and develop AIDS, the proportion of children who are orphaned may be expected to increase.

Many youth in this study were likely to have been born before their mothers were infected with HIV, and as a result were not at risk for perinatal infection. In addition, of those children born to HIV-infected women in the United States, at most 36%, and perhaps as few as 13%, will themselves be infected with HIV.[26,27] The absolute number of children infected with HIV is likely to increase dramatically with time, necessitating allocation of substantial medical and social services. However, they will remain a relatively small proportion of all children of mothers who die of HIV/AIDS-related causes.

The primary emphasis of this study is on children and adolescents, who have the most pressing needs for direct services. Data on young adults are included because many members of this group, whose needs may be less immediately emotionally compelling than those of their younger brothers and sisters, will face serious psychosocial, financial, and legal problems. Their needs will place heavy demands on the mental health, social welfare, educational, and employment sectors.

The various categories of youth who are infected with or affected by HIV can be likened to a pyramid. At the top are reported pediatric AIDS cases (including the small number of reported

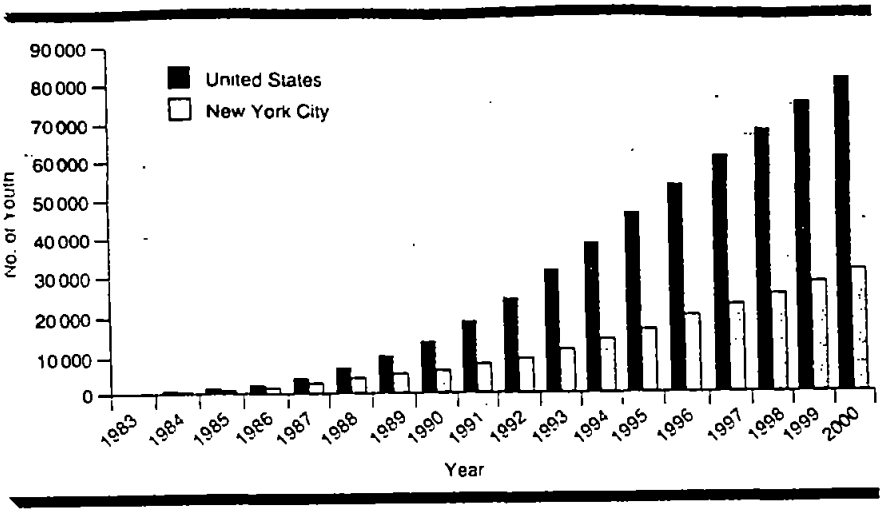


Fig 3.—The cumulative number of motherless children and adolescents estimated to be orphaned by the HIV/AIDS epidemic, 1983 through 2000, comparing the United States and New York City.

adolescent cases). Pediatric AIDS has received the most public and professional attention, understandably enough, since these very sick children and their families have urgent medical and social service needs. Just below this group are known cases of HIV-infected children and adolescents.

At the base of the pyramid are the uninfected siblings of the pediatric AIDS cases and uninfected youth whose parent or parents, or another adult relative, has either died of an HIV/AIDS-related disease or is living with AIDS or serious HIV disease. It is not uncommon for a child to experience the loss of several members of a family due to HIV/AIDS. The communities in which these families live are engulfed by violence, homelessness, drug abuse, poverty, discrimination, and societal neglect.

In considering these estimates of motherless youth, it should be noted that several aspects of this simulation model were selected to provide conservative estimates and therefore are likely to result in an underestimate of the number and percentage of motherless youth:

1. No attempt is made here to measure the number of orphans resulting from fathers' HIV/AIDS-related deaths. Nor do we attempt to measure the effects on youth of living with parents with AIDS or serious HIV disease, a population much larger than that of persons with AIDS.[28]

2. Similarly, in calculating these proportions, it is assumed that women who die of non–AIDS-related causes such as cancer are as likely to be primary caregivers as women with HIV disease. However, since women who die of non–AIDS-related causes are less likely to be IDUs or their sexual partners, it is possible that these women (who die of other causes) also are more likely to share active parenting with another person. This will result in an overestimate of the number of youth whose mothers' deaths were unrelated to HIV, and therefore an underestimate of the proportion of motherless youth attributable to HIV.

3. It is assumed here that the fertility rates of IDUs are equal to that of the national population. There are limited data, however, suggesting that IDUs have higher than average fertility rates.[10] This would result in a larger number of youth orphaned by HIV. Further, it is possible that women who die of non–AIDS-related causes have lower fertility associated with other chronic disease. Alternatively, it is plausible that injecting drug use may be associated with an increased risk of miscarriage, resulting in lower fertility rates for these women. This is an area that requires further study.

4. In calculating the number of youth orphaned by all diseases, we assume that deaths from non–AIDS-related causes remain stable for the years 1990 through 1995. In fact, non–AIDS-related mortality rates for women have been dropping for many years and are likely to continue to do so.[17] This results in an underestimate of the proportion of motherless youth attributable to the HIV/AIDS epidemic.

5. While not all Hispanic women with HIV/AIDS are of Puerto Rican origin, fertility rates for Puerto Ricans living anywhere in the United States were used in calculating the number of children born to Hispanic mothers. If overall Hispanic fertility rates had been applied, the estimated number of Hispanic motherless youth would increase by 12%. However, the overall rates include the large Mexican-origin population,[17] a group at much lower risk of HIV/AIDS than Puerto Ricans.[29]

This study is only a beginning. More systematic data collection and analysis should be undertaken to describe children orphaned by the HIV epidemic. The model outlined in this study can be used by researchers to describe the population of motherless youth in particular regions. Other studies could, for example, link death certificates with birth records, to quantify more precisely the number of children born to women with HIV. Other studies could examine a particular population, families receiving social or medical services for example, to determine how many children and adolescents (HIV-infected and HIV-uninfected) are in that family and who is caring for them. Anthropological studies could examine in detail caregiving arrangements and placement of children and adolescents after death.[30] Investigators could study HIV-positive men and their relationships with their offspring. Such studies would create a more accurate picture of the needs and problems of families.

These findings warn of a serious challenge to cities and communities already staggering under the weight of faltering economies, violence, homelessness, inadequate medical care, poor education, drug use, and a host of other long-standing social problems. Yet the needs of these youngsters cannot be ignored. To do so would be not only lacking in compassion for the most vulnerable members of society; it would also invite a social catastrophe of the greatest magnitude. The death of a parent or other emotionally significant adult is one of the most traumatic experiences any child can suffer. When that death is accompanied by stigma and isolation and is followed by instability and insecurity, as it is in AIDS, the potential for trouble, both immediately and in the future, is magnified.

While more study is needed on the impact of the HIV/AIDS epidemic on the family, there is ample evidence to warrant immediate action, with appropriate evaluation and follow-up. Children and adolescents already orphaned by AIDS cannot wait for the normally slow policy process to take account of their complex and individualized needs. While some bereaved children and adolescents are already in foster care and others are immediately taken in by relatives willing and able to care for all the surviving youth, many, probably the majority, face futures beset by uncertainty and instability, separation from siblings, and unrecognized and unaddressed grief. Those who develop, interpret, and implement guidelines and programs of

custody decisions, foster care, adoption, education, juvenile justice, health care, and institutionalization will need flexibility and creativity in addressing these immediate and urgent needs.

There is, in addition, much to do to prepare for the expected wave of future motherless youth. The CDC recently commented that the emergence of a disease and its appearance as a leading cause of death in the same decade is without precedent.[4] The emergence of a new group of motherless youth because of that disease may also be without precedent. Unless increased attention and resources are devoted to this vulnerable population, a social catastrophe is unavoidable.

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VNA The Visiting Nurse Association of Chicago

322 South Green Street
Chicago, IL 60607-3599

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THE HEALTH CARE AND SOCIAL SERVICE NEEDS OF HIV-POSITIVE WOMEN AND CHILDREN IN METROPOLITAN CHICAGO*

February, 1990

Andréa Carr, Ph.D.

The Visiting Nurse Association of Chicago

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TABLE 1.
ESTIMATES OF AIDS AND HIV-POSITIVE STATUS
AMONG WOMEN AND CHILDREN IN CHICAGO, FALL, 1989

	THOSE WITH AIDS		THOSE WHO ARE HIV-POSITIVE	
	CURRENTLY	EVER	PER YEAR	CURRENTLY EVER
CDOH, AIDS Surveillance Program				
Women	44[a]	119[b]		
Children	10[a]	29[b]		
IDPH and CDOH Seroprevalence Studies				
Women	150[c]		1890[d]	
Children	60[c]			
CDOH, Projections from the Strategic Plan				
Women	100-125[e]	225-275[e]		1968-2352[f]
Children				492-588[f]
VNA-C				
Women	51		227[g]	
Children	27		80[g]	

[a]Source: Chicago Department of Health, Office of AIDS Prevention, AIDS Surveillance Program, October, 1989. Estimates are 37 percent (100% minus the overall fatality rate

of 63%) of the cumulative reported AIDS cases.
[b]Source: Chicago Department of Health, Office of AIDS Prevention, AIDS Surveillance Program, October, 1989.
[c]Source: Chicago Department of Health, AIDS Strategic Plan,
October, 1989. Reports a .27% seropositivity rate for live births in Chicago and that there are approximately 55,000 live
births each year. Estimate for women, then is .27% of 55,000.
[d]Based on the assumption that the seropositivity rate of .27% applies to all women of childbearing age, not just those who give birth each year -- some 700,000 women of childbearing age.
[e]Source: Chicago Department of Health, AIDS Strategic Plan, October, 1989. These figures correct for underreporting of the AIDS Surveillance Program.
[f]Source: Chicago Department of Health, AIDS Strategic Plan, October, 1989. The Strategic Plan provides projections for cumulative HIV infections. Our projections are based on the assumption that the proportion of HIV-positive women (and children) to HIV-positive men is the same as the proportion of AIDS women (and children) to AIDS men. Women have represented 4.8% of cumulative reported AIDS cases and children have represented 1.2% of cumulative reported AIDS cases.
[g]Includes a small number of metropolitan Chicago-area women and children.

II. EXECUTIVE SUMMARY.

In this section we present the major findings of our research. First we present demographic results and findings about the women's current resources. Second, we present our findings on their health care and social service needs. More detailed analyses are presented in Section IV and information about the sample and data collection are presented in Section III. Third, we summarize the recommendations derived from our research. Again, more detailed discussion of these recommendations is contained in Section V.

A. DEMOGRAPHICS AND RESOURCES OF THE WOMEN

* Of the 298 women in our sample, 227 are HIV-positive; 71 have been diagnosed with ARC or AIDS.
* The women in our sample have a total of 592 children.
* About one-third (36 percent) of the women in the sample have three or more children; only 16 percent have no children.
* We know the HIV status of only 350 children in the sample (many are too old to be considered at risk):
    * 42 children are positive, but asymptomatic
    * 49 children are infants who have tested positive
    * 6 children are positive and symptomatic

  - 5 children have been diagnosed as having ARC
  - 27 children have been diagnosed with AIDS.

* Most of the women in our sample are young and in their child-bearing years (average age, 34 years); about half the sample women (49 percent) are between 30 and 39 years of age.
* The average age of the women's children is about nine years, but the average age of the HIV-infected children (including infants who have tested positive) is much younger -- three years. The children who have been diagnosed with AIDS are, on average, nearly six years.
* Two-thirds of the women in the sample are minority women: 44 percent are black; 22 percent are Hispanic; 31 percent are white.
* Sixty-three percent of the women are at risk due to their own IV drug use, although some of these women may actually have been infected through heterosexual relations with an IV-drug-using man or a bisexual man.
* Twenty-two percent of the women are at risk because of heterosexual contact with an infected man (for 13 percent of the women the heterosexual contact was with an IV-drug-user and for seven percent more it was with a man who was either an IV-drug-user or a bisexual).
* Few women in the sample are at risk due to transfusions (six percent) or hemophilia (five percent).

* Only a fifth of the women live in the traditional family of husband (or partner) and children; nearly half the women do not live with their children although over four-fifths of the women have children.
* Twenty-three percent of the women have been threatened with the loss of their homes and another 16 percent have actually lost their homes.
* The women live in all parts of Chicago, but there is a concentration of women in zipcodes 60640 (Uptown), and 60612, 60622 and 60647 (Logan Square, Humboldt Park and West Town); while a significant number of the women live on the south side of Chicago, no one south side zipcode has a disproportionate number of the women in the sample.
* Over two-thirds (68 percent) of the women in our sample are on some form of public aid and for 59 percent it is their only source of income.
* Only ten percent of the women have their own personal income.
* Twenty-two percent of the women have "other income," that is income primarily from prostitution or other illegal activities.
* Nearly one-half (49 percent) the women do not have a high school diploma.
* Fewer than one-fifth (19 percent) of the women have private health insurance and two-thirds of the women rely on Medicaid or disability for

their health insurance. Almost ten percent of the women have no health insurance at all.

* Over one-fifth (22 percent) of the women have no friend or relative who is willing to help them cope with their disease; another 32 percent have only one such person.

* While four-fifths of the women in our sample have children, only about half have their children living with them. For these women, about half (45 percent) have help with child care often; over one-quarter (28 percent) never have help with child care.

* Only a third (35 percent) of the women often have access to a reliable car for transportation, and nearly one-half (47 percent) the women never do.

* Overall, the informal supports available to these women are relatively weak: only 36 percent have at least one friend to help them cope, at least infrequent help with child care (if any is needed), and at least infrequent access to a car.

* As a further indicator of the weak systems of informal support available to these women, over one-third (36 percent) of the women are known to have a substance abuser living in their households.

* More than one-half (54 percent) the women in our sample have no formal support; that is, they are not in a drug treatment program, are not receiving individual counseling and are not in a support group.

* One-third (34 percent) of the women in the sample are involved in a support group. This is the most frequent source of formal support for these women.
* Although the need for drug treatment among these women is presumably great, only 13 percent are currently involved in a drug treatment program.

The women in our sample are, by and large, poor, minority women with few resources. Most are not yet diagnosed as having ARC or AIDS, but this does not mean that these women have not experienced some illness due to HIV infection. These are young women, most of whom already have children, and as they are of child-bearing age a number of them can be expected to bear more children. The women have overwhelmingly become infected because of their own IV drug use or because of their connection, through their husbands or partners, to the IV-drug-using community. The women are poor and rely on public entitlements for income and health insurance; they are not well educated. The women reached through outreach programs to the IV-drug-using community are particularly poor and without resources. Over half the women have inadequate informal support systems, and half have no formal supports.

B. HEALTH CARE AND SOCIAL SERVICE NEEDS OF THE WOMEN AND CHILDREN

* More than two-fifths (42 percent) of all women in the sample and three quarters of the women with ARC or AIDS have needed acute, in-hospital care in the last

six months. About one-third (31 percent) of the children have needed in-hospital care.

* Three-quarters (73 percent) of all women in the sample and 92 percent of the women with ARC or AIDS have needed outpatient hospital care in the last six months. This great need for outpatient care probably reflects the greater emphasis on monitoring the course of HIV-related illness and the greater number of available treatments. Over two-thirds (68 percent) of the children have needed outpatient hospital care, perhaps reflecting that until very recently treatments for children have been less available and utilized.

* Skilled nursing care at home has been needed by 15 percent of all the women and children in the sample, and by 42 percent of the women with ARC or AIDS. While smaller percents have needed high tech nursing at home, still a significant 21 percent of the women with ARC or AIDS have needed this service in the last six months.

* The need for hospice care is less than for the other health care services, but we would expect this to be a less needed service partly because it is not a usual service for young women and children, partly because it is reserved for those who are terminally ill and close to death. Still, four percent of the women overall have needed this service as have four percent of the HIV-positive children. Fully 15 percent of the women with ARC or AIDS have needed this service.

* Medical equipment delivery at home has been needed by seven percent of the women overall and by 20 percent of the women with ARC or AIDS. Eleven percent of the HIV-positive children have needed this service.

* Thirty-seven percent of the women overall and almost half (49 percent) the women with ARC or AIDS have needed health education in the last six months. Twenty-one percent of the HIV-positive children have needed health education, an unexpectedly high level as many of the children are too young for such education.

* While the need for occupational, physical or respiratory therapy is less than for the other services, still about ten percent of the women overall and close to fifteen percent of the women with ARC or AIDS have needed these services. The HIV-positive children are particularly likely to have needed physical therapy (19 percent), while the ARC or AIDS women are more likely to have needed respiratory therapy (17 percent).

* Generally, if a woman needed one type of home care, she needed all types of home care.

* About one-quarter of the women overall have needed help with home care in the last six months.

* Nearly forty percent of the women with ARC or AIDS have needed home care in the last six months.

* The women in the sample showed little need for help with pet care.
* Day care was needed by 19 percent of the women overall, but by only just over ten percent of the women with ARC or AIDS.
* Babysitting was needed by 29 percent of the women overall, but by only 21 percent of the women with ARC or AIDS. Because the women with ARC or AIDS have probably experienced more, and more severe, illness these women may have already made arrangements for child care.
* Few of the children have needed tutoring in the past six months, undoubtedly because on average the children are so young. However, as treatment for children becomes more effective and children with AIDS live longer (in our sample the children with AIDS are, on average, older than other HIV-positive children) we can expect the need for tutoring to increase.
* Thirty-seven percent of the families with an HIV-positive child have needed foster care in the last six months, and in some cases there has been a need for foster care for more than one child in the family. Many more of the children are probably living with relatives who may or may not be able to care for the children permanently. We can expect that the need for foster care will increase as more of the women become unable to care for their children.

* Thirteen percent of the women have needed emergency housing (one or two days) in the last six months, with the ARC or AIDS women showing a slightly greater need (16 percent). Few of the HIV-positive children have needed emergency housing.

* The women have experienced little need for short-term housing (7 percent of the women overall; 6 percent of the women with ARC or AIDS).

* Twenty-four percent of the women (generally, and among those with ARC or AIDS) have had a need for long-term housing in the last six months. This is clearly the most pressing housing need for these women. As before, the HIV-positive children do not show this same level of need for housing.

* Over half (55 percent) of the women in the sample have needed some transportation in the last six months, and almost half (45 percent) the women with ARC or AIDS have needed transportation. In fact, transportation is the third highest need area for the women generally in the sample.

* Over half (54 percent) the women in the sample have needed individual counseling in the last six months, and 47 percent have needed family counseling. Over three-quarters (78 percent) of the women have needed a support group. Among the women with ARC or AIDS, an even greater proportion have needed each of these services. Much smaller proportions of the women's HIV-positive children have needed these services, especially family counseling (many of these

children are currently too young to benefit from these services).

* Forty-one percent of the women overall have needed drug treatment in the last six months, and over one-third (37 percent) of the women with ARC or AIDS have needed it. It is likely that some women with ARC or AIDS may already be too sick to continue their drug use and therefore no longer need drug treatment; however, there is still a great need among these sicker women.[8]

* Family planning is needed by about one-third (31 percent) of the women overall, and about one-quarter of the women with ARC or AIDS.

* Two-fifths of the women overall, and over one-half (53 percent) the women with ARC or AIDS, have needed financial planning services in the last six months. For the women with ARC or AIDS the need for financial planning is probably a result of the great cost of their care and, for some, their inability to work.

* One-third of the women overall, but more than one-half (54 percent) the women with ARC or AIDS, have needed legal services in the last six months. The higher need among the women with ARC or AIDS probably reflects a greater need to prepare wills and to address guardianship issues as they become more ill.

[8]The need for drug treatment may be even greater because some women in need of drug treatment may be in denial and may report that they do not need drug treatment, and some social workers, perceiving that women are not "ready" for drug treatment may have reported that for such women drug treatment is not needed, even though the women, once "ready" would indeed benefit from drug treatment.

* Funeral services are a less needed service, but nine percent of the women overall and 21 percent of the women with ARC or AIDS have needed these services in the last six months, as have one percent of the families with HIV-positive children in the sample.

* Respite care has been needed by 16 percent of the women overall and by 20 percent of the women with ARC or AIDS. This probably underestimates the need for respite care, for some respite care is needed not by the woman with ARC or AIDS, but by her caretakers -- we did not ask about this form of respite care.

* Twenty-six percent of the women have needed employment counseling in the last six months, and over twenty percent have needed job development and job training services.

* Women with ARC or AIDS have needed these employment services at about one-half the rate of the women overall, probably reflecting that they are more ill and less likely to consider working.

* The level of need for employment services is quite high given that many of the women have children for whom they must care. We can anticipate that the level of services needed will be quite intense, for nearly half the women have not graduated from high school and probably have never worked outside the home.

* Sixty-five percent of the women overall have needed six or more different health

care and/or social services; 35 percent have needed eleven or more different services.

C. RECOMMENDATIONS

There are several major themes that have come up over and over in our research, and any recommendations must address these themes. First, drug treatment is an overwhelming need of these women. Second, most are minority women who live in poverty. Third, they are not women or families with single, isolated needs, but rather they have multiple needs. Fourth, for these women HIV infection is a family problem: often their husbands or partners are infected, and one or more of their children may be infected. Fifth, they are a population that has difficulty accessing necessary services due to lack of personal resources. Finally, the nature of HIV illness as a chronic condition with acute episodes of serious illness should guide service planning.

The recommendations below are based on the findings of our research and address the over-arching themes we have mentioned above, as well as some of the more specific results we have presented. There is no priority order implied by the numbering of the recommendations nor are they presented in any priority order. Each recommendation is research-based and should be considered important for service planning and implementation. A more detailed discussion of each recommendation is presented in Section V (Discussion, Conclusions and Recommendations).

CITY OF CHICAGO OCTOBER 1989

AIDS STRATEGIC PLAN

Chicago Department of Health
50 West Washington Street
Daley Center, Room 228
Chicago, IL 60602
(312) 744-9654

CHICAGO AIDS STRATEGIC PLAN

Contents

EDUCATION AND RISK REDUCTION

WOMEN

Target Population

While prevention efforts directed towards women have tended to be broad-based and general, there are groups of women whose memberships, which often overlap, may be at increased risk of HIV infection and consequently in need of more specific approaches.

Intravenous (IV) drug use is the primary source of HIV infection among women in Chicago, accounting for nearly 45% of the City's female AIDS cases. The Illinois Department of Alcoholism and Substance Abuse and the Illinois Alcoholism and Drug Dependence Association estimate there are between 70,000 and 90,000 IV drug users in the City. Applying current figures which suggest 15%-25% of IV drug users are women, then there are between 10,500 to 22,500 women at risk of infection through IV drug use.

A large percentage of IV drug users in the City reside in lower-income communities. While HIV-infected IV drug using females reside in 19 of the City's 77 communities, 27% live in the West Town area and 17% in Uptown (Community Areas 24 and 3). Female IV drug users include long time users, new addicts, and addicted prostitutes.

Many women in Chicago who do not inject drugs are placed at increased risk of infection by the drug using behaviors of their sexual partners. Drawing on the above estimates, if half of the male IV drug users in the City have heterosexual relationships with non IV drug using women, then there are an additional 27,650 to 37,500 women at risk through sexual transmission from their IV drug using partners. These numbers may be low, however, as they assume only one sexual partner per male drug user.

Using the community areas in which HIV-infected male IV drug users reside as a rough indicator of where IV drug use is most prevalent, and assuming that people tend to have sexual partners who are of the same race and live nearby, we can infer the communities of women at risk through their partners drug using behaviors. The communities with the majority of drug related AIDS cases are Logan Square and West Town (CA's 22 and 24), while other cases are spread out across communities on the City's South, North and Northwest Sides.

The sexual partners of bisexual men constitute another group of women at increased risk of infection due to their partners' behaviors. Unlike women who are at risk through their partners' drug using behaviors, members of this sub-population may be less likely to be aware of their partners' risk behaviors. Although it is difficult to identify members of this subpopulation, one might begin by looking at those communities which most openly condemn homosexuality.

Black and Hispanic women are at disproportionate risk of HIV infection, due primarily to their large representation in the IV drug using and "sexual partners of IV drug users" subpopulations. Black residents tend to reside on the West Side of the City (Community Areas 25, 26, 27, 28, and 29) or on the South Side (CA's 33, 35-40, 42-51, 53, 54, 67, 71, 73, and 75). Hispanics live primarily in the central west portion of the City (CA's 30, 31, 58-61) or on the near north side (CA's 3, 5, 6, 20-24).

The Chicago Crime Commission reports there are an estimated 25,000 adult female prostitutes in Chicago. Local service providers estimate 80% of these women are Black, 10% Hispanic, and up to 50% are believed to engage in IV drug use. It is possible, however, that these figures may be more a reflection of those prostitutes who are getting arrested than of the total subpopulation.

Identifying the neighborhoods in which these women live is difficult as many commute to work in other areas to avoid being found out by friends or family. Street prostitution is most common in the lower-income neighborhoods on the City's South and West Sides. In other areas, such as Lake View, a community response to prostitution has resulted in a decrease in street workers but an increase in the less visible escort services.

In addition to preventing AIDS among women, the education of subpopulation members will effect future cases of pediatric AIDS. The majority of women with AIDS in Chicago are of childbearing age. While there are too many unknowns to realistically estimate the number of women infected with HIV, it seems reasonable to assume that the women infected are also of child-bearing age. There is no way to prevent AIDS in babies other than by keeping women uninfected.

Lesbians are generally thought to be at lowest risk for AIDS, while the risks to bisexual women are usually not considered at all. Since risk is associated with activities engaged in and not with how one identifies oneself, lesbians and bisexual women may have a false sense of security.

Many lesbians have had sexual contact with men prior to identifying as lesbian; this contact may have included high risk behaviors. Additionally, some women who identify as lesbian also have sex with men. Lesbians and bisexual women who use IV drugs may be more likely to have sex with a man than a woman in exchange for drugs or money.

Education and Service Delivery Issues

There are a number of factors that must be considered in the development and implementation of educational programs for women.

Perceived Risk: Low perceptions of risk for many women have resulted from an initial lack of prevention campaigns targeted to women, the failure of some women to identify themselves as belonging to a risk group, and a failure to translate a partner's previous risk behavior into current risk. Additionally, women who are unaware of their sexual partners'

risk behaviors may consequently be unaware of their own risk. A necessary first step in many interventions, therefore, may be to increase perceptions of risk.

Self-esteem: Low self-esteem may serve as an obstacle to safer behavior among many subpopulations of women. AIDS prevention messages often ask women not to carry out a behavior themselves, but rather to insist that their male partners do. Many women at increased risk of infection, however, come from emotionally abusive backgrounds, and consequently lack the emotional strength and feelings of self worth necessary to insist on condom use. For some, this insistence may threaten a relationship, a risk women with low self-esteem are not likely to take.

Interventions targeted to female subpopulations should not assume that women possess the self-esteem required to engage in AIDS preventive behaviors. Risk reduction efforts might benefit by including components designed to assess and, when necessary, increase feelings of self worth.

Gender Roles: Social systems supportive of male dominance may make it difficult for women to respond to AIDS prevention messages. The behaviors in which women engage are often the result of firmly established gender roles and one cannot expect women to change patterned behaviors without considering how that change will affect their relationships. For some women, of all backgrounds, assertive behavior is a violation of norms. Insistence that a partner use a condom may evoke responses ranging from acquiescence to surprise and even violence.

Hispanic communities are typically male dominant and deference is a normative behavior for women. It is seldom acceptable for women to initiate discussions of sexual issues. Women in Hispanic cultures define themselves primarily by their roles as mothers, wives and girlfriends, and condoms may be seen as a threat to those roles. Furthermore, a woman who carries condoms may be labeled as "loose," as condoms are most often associated with prostitutes.

When Hispanic men seek drug treatment it is viewed as a positive step towards addressing an acknowledged community problem. Substance use among Hispanic women, however, is viewed as unacceptable; therefore efforts to get treatment are interpreted as an admission to engaging in unacceptable behavior.

Established gender roles may also influence AIDS preventive behavior in the Black community. Black women are often raised to protect the family at all costs and they tend to be very trusting of their male partners. If questioning a partner about past behaviors might threaten a relationship, some Black women may choose not to ask questions.

Normative gender roles must also be addressed in interventions targeted to members of IV drug using populations. The IV drug using subculture is male dominated and be it for selfish or protective reasons, in a group of users the woman is typically the last to get the needle, and consequently at greater risk of HIV infection. It may be unrealistic to expect that a woman will challenge the norm and in doing so risk losing her "fix".

Community Issues: The family serves as the primary social unit in many Hispanic communities and there is a great degree of loyalty to that unit. Consequently, educational messages which emphasize familial responsibility (i.e., the husband's responsibility to his wife, or a mother's to her child) may be the most effective means of reducing risk among Hispanic women.

Women who may be unlikely to insist on safer behaviors for their own protection may be much more likely to do so to protect their unborn children. All women who are pregnant and at increased risk of infection should be targeted for education with emphasis on their maternal roles.

While importance is also placed on the family in the Black community, there is often also a great sense of responsibility to the community itself. Risk reduction efforts which appeal to one's duty to the community may be well received among members of this subpopulation.

In both Hispanic and Black communities there may be a reluctance to trust 'outsiders' and a tendency to resolve problems within the community. Education efforts that come from within the community will likely be better received than those that are brought in from another area.

Religion: The role of religion and the church has many implications for the development of HIV risk reduction initiatives. Conservative religious beliefs in many communities present major challenges to AIDS educators. Because birth control, and thus condoms, may be proscribed by the church, interventions may prove more successful if they focus on the need for condoms as a barrier to a virus rather than a barrier to procreation.

IV Drug Using and Prostitution Subcultures: Because of emotionally and physically abusive backgrounds from which many prostitutes and IV drug users come, these subpopulations characterized by low self-esteem, emotional instability, low educational attainment, and economic dependence on their partners. Additionally, the legal and societal condemnation of the behaviors characteristic of these subpopulations often result in an isolation from and mistrust of mainstream prevention and health care services.

Elements of risk related to health and safety have been inherent in the lives of both IV drug users and prostitutes since long before the onset of the AIDS epidemic. Consequently, efforts designed to evoke fear may have less effect on behavior than those which address barriers other than low risk perceptions.

Risk reduction efforts targeted to prostitutes should be based on at least two considerations. First, the majority of prostitutes who have become HIV-infected have a history of IV drug use, so interventions should address both sexual and drug using behaviors. Second, although prostitutes may be at increased risk of sexual transmission due to exposure to multiple partners, research suggests that these women are often more willing to use condoms in their business relationships than in their personal ones. Risk reduction efforts, therefore, must

not assume that a prostitute's greatest risk comes from her profession, and should address the barriers to safer behavior in her personal relationships.

The lives of female IV drug users may well be embedded in a culture of drug use that is resistant to adopting safer drug using behaviors. In many areas, the sharing of works (the needles and syringes used to inject drugs) is as much an expression of trust between users as it is a means of saving money on needles. Where needle-sharing serves social bonding functions a request by health professionals to stop the behavior may be viewed as a threat to the users' strongest relationships.

Reaching Intended Recipients: Delivery of risk reduction interventions to women at increased risk of infection may be impeded by difficulty in locating intended program recipients and/or gaining access to them. Unlike gay men, women are not organized as a community and therefore present different issues of access. Programs may be successful at overcoming these two potential barriers if they are based at sites frequented by subgroup members.

The overwhelming majority of women arrested in Chicago are charged either with drug possession or prostitution. IV drug users tend to require emergency medical services more frequently than members of many subpopulations, and lower-income women at increased risk are likely to use the health services provided by public hospitals and reduced-fee clinics.

Consideration of these factors suggest that in Chicago, women at increased risk are likely to be reached through court or jail-based educational programs, hospital emergency rooms, Cook County Hospital, and Department of Health neighborhood and prenatal clinics.

Additional Considerations: Lack of child care and transportation may prevent program utilization by many women, especially those with lower incomes. Risk reduction programs must be designed to encourage and facilitate use by persons most in need. Programs which require women to arrange for child care may be underutilized. Similarly, agency-based interventions should not assume that all women have transportation available to get to a program.

There are several issues to consider in the development of educational services to lesbians and bisexual women. These include a resistance to heterosexually-biased information, a resistance by some to identify with gay-oriented information, perceptions of immunity, and for some, a lack of awareness of the bisexual behaviors of their partners. Finally, educational materials which discuss persons who might be at risk include just about every segment of the population except lesbians.

Overview of Educational Approaches

Outreach Education. The most common approaches to providing risk reduction information to female IV drug users as well as prostitutes are street and court outreach. Educational street outreach is provided by either health professionals or trained peer educators.

Outreach workers provide risk reduction information and, where appropriate, distribute condoms and bleach, demonstrate needle-cleaning methods, and make referrals for support or drug treatment programs.

Court outreach efforts target drug users and/or prostitutes at the time of an arrest or court hearing. Programs range from the provision of risk reduction information to recruitment into support groups or treatment programs. While this approach has merit, it is limited in that it only reaches those women who have been arrested, probably a small percentage of those engaging in risk behaviors.

Drug Treatment Programs. Drug treatment programs may be one of the most effective ways to reduce risk of HIV infection. In addition to the obvious fact that cessation of drug use will eliminate future risk through needle-sharing, persons who undergo treatment in Chicago, regardless of their success will receive mandated AIDS education and risk reduction information.

Drug treatment programs have typically been designed to address male needs and have failed to consider issues most relevant or unique to women. Additionally, long waiting lists, limited financial resources, lack of child care options, or a desire to continue drug using behavior may eliminate the option of treatment for many women.

Drug treatment programs and drop-in centers have also served as a vehicle for the identification and education of the sexual partners of IV drug users. Men in treatment may provide educators with the names of women they know to be at risk (either from them or another man) and these women are then contacted and recruited into risk reduction programs. Programs focus on identifying and decreasing barriers to safer behaviors.

"Safer Sex" Parties. Safer sex parties provide an arena for women to discuss sexual practices and ways to make them safer. This approach allows women to become familiar with condoms in a non-threatening environment prior to incorporating them into their sexual lives. The purpose of these parties is to foster an environment conducive to safer behavior. These functions have jokingly been likened to Tupperware parties, however, it may very well be the party atmosphere which enables some women to discuss condoms.

While safer sex parties appear to be effective for some segments of the population, the name of these functions may inhibit attendance by women from areas where gender roles are rigidly defined and may also be viewed negatively by potential funders. Members of the Hispanic community have addressed the former issue by labeling the parties as 'girls night out.'

Support Groups. Structured support groups provide another forum for conveying risk reduction information to women. Incorporation of AIDS education into support groups might consist of a presentation of prevention information and discussions of barriers to engaging in safe behaviors.

A major advantage of this approach is that it is most often a continuous process. The feelings of trust that some women might need to discuss personal issues may not emerge until after a group has convened several times. Additionally, it allows for the discussion of issues as they arise over time.

While members of support groups for female IV drug users and for prostitutes may be most in need of this type of education, new mothers, single or married women, and members of other groups may also benefit from risk reduction information.

Natural Helpers. This approach utilizes the existing relationships between members of a community and the persons they use as resources. By training persons who serve as natural helpers to provide AIDS education, this approach ensures the provision of information through trusted and familiar channels of communication. An example of this approach has been the training of beauticians who then pass along risk reduction information to their clients.

Recommended Approach: Many of the above approaches have proven effective among various subpopulations. As the behaviors and educational needs of women will continue to diverge, the need will remain for a multi-faceted approach to risk reduction.

Because an understanding of the multiple issues influencing behaviors of subpopulation members is critical to effective education, and because mistrust of 'outsiders' is common across subgroups, a community-based approach which includes peer outreach components is most strongly recommended.

Peer outreach workers often have greater knowledge of where women at risk are located, they are better able to understand the subcultural barriers to safe behaviors, are able to communicate in the language of the subculture and consequently are viewed as more credible by the targeted population.

While street outreach may be appropriate, the recommended approach also includes outreach through the organizations that women routinely come in contact with. These would include outreach through CDOH neighborhood and maternal and child health clinics, other family planning providers such as Planned Parenthood, and hospitals and courts.

Although outreach is probably the most effective means of reaching women at risk, when possible, it should be supplemented by more intensive behavior change efforts. Both street and institutionally-based outreach should attempt to recruit women into more structured risk reduction programs. Interventions should be designed to empower women to engage in and insist on safer behaviors. This might be achieved through support groups or the inclusion of self-esteem building components into current efforts.

Because mistrust is so common among many subpopulations of women, it is imperative that educational services be provided, when possible, by qualified persons and agencies already established in these areas.

The role of the church in delivering AIDS education messages should be considered and when possible, local efforts should seek the participation of the church. Distribution of literature should be limited not only because of low literacy levels but also because a lack of information about what AIDS is and how to prevent it appears to be less of a barrier than more psychosocial issues.

Resource Assessment

There are currently three programs in Chicago which target prostitutes for HIV risk reduction. Genesis House, located in the Lake View neighborhood (Community Area 6) provides street and court outreach and conducts informational support groups. Approximately, 80% of Genesis House clients are Black and most are alcohol or drug dependent.

Six two-person teams of former prostitutes distribute literature, offer brief AIDS education and provide referrals for counseling to women on Chicago's West Side, (CA 26 & 27), South Side (CA 38) and northwest side (CA 20)). Genesis House also subcontracts out to the Northside Ecumenical Night Ministry which provides outreach to female prostitutes in the Uptown community.

Genesis House also conducts daily outreach to approximately 200 women per month in lock-up at three different branches of the Cook County Circuit Court. These branches, (29, 40, and 46), handle the majority of the City's prostitution arrests. Through both its court and street outreach, Genesis House is able to reach over 450 women a month. With new federal grants, Genesis House plans to reach 10,000 prostitutes next year. Genesis House has been recognized nationally as a successful model of risk reduction.

The Northside Ecumenical Night Ministry is a longstanding organization in Chicago's Lake View community. In addition to their contract with Genesis House, they provide outreach to the gay communities and to youth at increased risk. They estimate that approximately 10% of their 2,200 yearly contacts are women. Because this program currently has only male outreach workers, they are limited in their ability to reach women. In efforts to address this limitation, the Ministry is planning to hire women in the near future.

The Garfield Women's Project on Chicago's West Side (CAs 26 & 27) provides AIDS risk reduction counseling to approximately 250 women a month in their outpatient drug treatment program. The Project also employs former drug users and prostitutes to distribute condoms and bleach, and provide brief AIDS education to a minimum of 100 prostitutes a month. Although women reached through street outreach are encouraged to seek treatment, the Garfield Women's Project has a waiting list from one to three months long.

Interventions, an organization which provides both in- and out-patient drug treatment, provides AIDS education to approximately 2,100 women a year. This figure represents not only those women using Interventions' treatment services, but all those entering methadone

maintenance programs, all of whom go through intake at Interventions. Education includes the distribution of literature and condoms, videos and lectures.

The AIDS Outreach Demonstration Research Project at the University of Illinois in Chicago identifies and educates IV drug users through their social networks. Through their work in the Logan Square, Humboldt Park, and West Town neighborhoods (CA's 2,23, and 24), the project reaches between 150-250 women a month. Outreach includes the distribution of condoms, dental dams, and bleach. The Project's Uptown (CA 3) center has approximately 400 contacts with prostitutes a month, although many contacts are with the same person.

The Chicago Addictions Treatment Center, run by the Chicago Department of Health has 23 of its 70 available beds for women, and is usually 95% filled. Women undergoing treatment receive HIV risk reduction information twice during the four-week program. The Center has between 70-90 persons on its waiting list.

The Brass Foundation, a drug treatment program located on Chicago's South Side, provides risk reduction information to IV drug users through on-site education and, to a limited degree, street outreach. Just over half of the Foundations' 620 monthly contacts are female, and 95% of their clients are Black. Following risk assessment of new clients, staff tries to elicit the names of the drug users sexual partners. Partners are encouraged to come in and receive risk reduction information.

Cook County Hospital provides HIV risk reduction information to all women who present with STD or HIV concerns, and to those who are otherwise deemed at increased risk. Education is also provided in the perinatal clinic. About 60% of the women reached at the Hospital are Black and 20% are Hispanic. In June, 1989, the program reached 110 women.

Stop AIDS recruits people off the street to participate in a small group educational discussion regarding AIDS and safer behaviors. The program, although based in Lake View (CA 6) outreaches to people in Lincoln Park, Logan Square, Lower West Side, and Grand Blvd (CA's 7, 22, 31, and 38). The program currently conducts one small group of approximately 8 women each month.

Kupona Network provides AIDS information to members of the Black community. Two female health educators provide risk reduction information to groups of women in any community at increased risk of infection. The health educators reach women both on the street and by working through established community organizations. Educators may reach between 200 to 400 women monthly.

The Chicago Women's AIDS Project provides outreach to women in communities at increased risk of infection. Educational programs include safer sex parties, presentations to mothers groups and setting up informational tables at neighborhood fairs, etc. The Project provides education to between 30 and 40 women a month in the Roseland, Uptown, and Near West Side communities (CA's 49, 3, and 28).

There are currently no programs in Chicago which target AIDS education services to lesbians and bisexual women.

Genesis House, Interventions, the Brass Foundation, and the Chicago Women's AIDS Project are Chicago Department of Health delegate agencies, and as such have received CDOH funds for their programs. Genesis House is a participant in the CDC CAPEP program.

The women at greatest risk of infection, IV drug users, are most likely to receive AIDS risk reduction information if they enter a drug treatment program. Assuming a woman wants treatment, however, because most programs are operating at full capacity she would likely be placed on a waiting list for up to several months. A lack of child care options may further deter some women from either entering treatment or continuing in out-patient follow-up services.

Although drug treatment programs are mandated to provide AIDS education, they are not funded to do so. As a result, there is likely a great deal of variance across treatment programs in terms of both the content and the context of education. Finally, as mentioned earlier, because a majority of IV drug users are men, most treatment programs are not designed to address in any detail those issues unique to women.

The only other current means of providing risk reduction information to female IV drug users is through street outreach programs. While these programs are available in specific geographic areas in the City, drug use is not limited to these areas and consequently there are women who are not being reached. Only one program appears to be reaching women in the West Town community, the area with the majority of female IV drug using AIDS cases.

Regarding the content of programs for IV drug using women, it appears that few, if any, efforts include more than the distribution of literature, condoms and bleach. Subcultural issues which may prevent some women from engaging in safer behaviors are not adequately addressed.

There is currently only one program, the Brass Foundation, which provides risk reduction information to the sexual partners of IV drug users. The nature of the program limits these services to the partners of drug users who are seeking treatment. Services are also limited to women on the City's South Side. No other programs in Chicago are targeting members of this subpopulation, women very much in need of risk reduction information.

Current efforts to provide outreach to prostitutes appear to be successful; however, they are limited in a number of ways. Although court outreach is an effective means of reaching some members of this subpopulation, the setting limits both the types and length of information provided. Additionally, there are many prostitutes who do not get arrested and are therefore not accessible through the courts.

Prostitutes who do not go through the court system are most likely to receive outreach education if they work in Community Areas 3, 6, 22-24, 26, 27, and 38. Prostitutes on the City's South Side are not targeted for risk reduction.

The nature of outreach often limits the interaction between educator and prostitute to the provision of information and materials. Street outreach is not usually conducive to lengthy discussions of obstacles to safer behaviors and methods of over-coming those barriers. Nonetheless, outreach does seem to be the most efficient and effective means of reaching prostitutes.

Finally, of the three programs which include prostitutes in their target populations, only one, Genesis House is designed specifically to address and meet the needs of this subpopulation. Because there are so few organizations reaching prostitutes, existing programs must outreach into communities other than those in which they are based.

Overall, the greatest lack of education and risk reduction services is on the City's South Side. Although there are a few organizations who do serve the South Side, the area is made up of close to 40 community areas and requires the response of more than just a few agencies.

Although women are often included as recipients of general educational services, there are very few programs which consider and meet the different educational needs of the various subpopulations. Furthermore, those agencies which have a stable funding base are not in a position to reach the women most in need of risk reduction information.

Conclusions and Recommendations

The fact that many of the female subpopulations have overlapping membership makes it difficult to determine the level of unmet need. The problem is exacerbated by a lack of information on the effectiveness of certain programs. The fact that a program reaches 3,000 women tells us little about the effect that program has had on their behaviors. We know, however, that there are at least 27,000 women who are the sexual partners of IV drug users and it is likely that only a small percentage of these women have received risk reduction information.

If Genesis House is able to make the 10,000 contacts it is aiming for in 1990, and the Garfield Women's Project and AIDS Outreach Demonstration project each reach 1,200 prostitutes a year, then according to the conservative estimate of 25,000 prostitutes in Chicago, there will still be at least 12,600 prostitutes in need of risk reduction information. Furthermore, these figures are based on the assumption that each contact is made with a different prostitute, and this is probably not the case.

It is even more difficult to determine the unmet need of the possible 25,000 female IV drug users in Chicago. Although many may receive risk reduction information either through

treatment or outreach, the effectiveness of that information on subsequent behavior is not known.

1. Risk assessment and appropriate risk reduction information should be provided to all female clients at all Department of Health facilities serving Hispanic, Black, and low-income women, with particular emphasis on the West Town and Uptown Neighborhood Health Centers, and the Maternal and Child Health and STD Clinics.

2. Drug treatment programs designed specifically to meet the needs of female IV drug users should receive higher priority by public and private funding agencies, including IDASA. Programs which provide child care services and consider the HIV educational needs of the partners of IVDUs should also receive higher priority.

3. Current outreach approaches should be expanded to reach prostitutes on the City's South and West Sides, preferably through funding indigenous agencies.

4. Female IV drug users and prostitutes at the time of their first arrest should be sentenced to participate in a multiple session AIDS risk reduction and behavior change program.

5. Funding should be provided both to drug treatment centers and other agencies for the development of risk reduction programs targeted to the sexual partners of IV drug users.

6. Educational materials should include lesbians and bisexual women in discussions of persons who might be at risk.

ıe 'Silent' Legacy of AIDS

ıildren Who Survive Their Parents and Siblings

r the past decade, efforts to improve the organization and vision of health care for families affected by the human unodeficiency virus (HIV) have focused primarily on in-ed individuals. However, from the start it has been clear t children who were or would be orphaned as a result of epidemic would add unique complexities to the equation.

See also p 3456.

v many children have been or will be orphaned by the uired immunodeficiency syndrome (AIDS) epidemic? In issue of *JAMA*, Michaels and Levine[1] estimate that 18 500 ldren and adolescents have already been orphaned. By 6, this number will increase to 45 600 and by the year 2000 82 000 orphans. Additionally, tens of thousands of young lts will become motherless.

These estimates, which are similar to recent Centers for sease Control and Prevention (CDC) estimates,[2] are based a set of reasonable assumptions that, if anything, appear be deliberately conservative. As discussed by the authors, fertility rates of intravenous drug users may very well be her than the age- and race-adjusted cumulative fertility e. The authors also assumed that the rate of AIDS deaths ong women will plateau after 1993. Unfortunately, this is ely to be overly optimistic, not only because of a lack of atment options, but more pointedly because there is every son to believe that the majority of the estimated 80 000 IV-infected women[3] in the United States are unaware of ir diagnosis.[4,5] Therefore, even if a therapeutic break-ough occurred tomorrow, most HIV-infected women would t receive potentially life-prolonging or saving treatment or propriate health care.

The study by Michaels and Levine did not address those IV-affected children who are effectively orphaned prior to eir parents' deaths. This phenomenon is best reflected by ıe living arrangements of HIV-positive children (which we elieve parallel those of uninfected siblings): only 45% of all HIV-positive children who received health care in New York during 1990 lived with a biologic parent (the vast majority were single mothers, without a father in the home); 16% lived with a relative; and 33% lived with unrelated foster or adoptive parents.[6] In 1989, 39% of the HIV-positive children born at Harlem Hospital went into foster care directly from the newborn nursery because of an inability by the mother to provide adequate care (S. W. Nicholas, MD, unpublished data, 1989).

The sobering estimates by Michaels and Levine, which probably underestimate the true extent of the problem, are noteworthy because of the tragic aura that surrounds these young survivors. Most of them, living in that complex place called poverty, have a whole range of unmet social, educational, and health needs. Many have already experienced a variety of personal losses unrelated to AIDS. Ironically, AIDS orphans are themselves at high risk of HIV infection because of early sexual activity, unsafe sexual practices, and experimentation with drugs. Finally, many of these children will not only experience the loss of a parent from AIDS, but will also witness the illness and death of one or more infected siblings. The ultimate legacy of the AIDS epidemic is a deafening silence.

What is to be done? Axiomatically, to prevent children from becoming motherless, the debilitation and death of HIV-infected mothers must be prevented. This cannot be accomplished unless HIV-infected women are diagnosed and given appropriate treatment and health care.

Children orphaned by the AIDS epidemic need improved health, social, and, in particular, psychosocial support services. They often need help from a variety of sources within the community, such as schools, churches, YMCAs or the juvenile justice system. Because of the secrecy that results from the stigma of AIDS, from the fear that someone will discover the "family secret," many potential sources of help are not sought. How best to disclose HIV-related information, while still protecting confidentiality, is a dilemma that must be addressed immediately on behalf of these children. Some pilot programs have begun working on ways to facilitate the disclosure of AIDS-related information to schools, day-care, and other community programs. More programs like these are desperately needed.

While some ill HIV-infected women establish future custody plans for their children, most do not. Lack of planning results from denial, fear of disclosure, lack of a potential

From the Department of Pediatrics, Harlem Hospital Center (Drs Nicholas and rams), the Babies Hospital (Dr Nicholas), and the Incarnation Children's Center Dr Nicholas), College of Physicians and Surgeons of Columbia University, New York, Y.

Reprint requests to Incarnation Children's Center, 142 Audubon Ave, New York, Y 10032 (Dr Nicholas).

guardian, lack of any formal counseling or legal advice, and inflexible laws. Not infrequently, elderly grandmothers in ill health become guardians by default when the mothers die. The health care team, with the assistance of legal counsel, should discuss future custody plans with every HIV-infected parent. Every state should review its existing guardianship laws, many of which leave children in legal limbo at the time of a parent's death, even when a guardian has been named in the parent's will. One solution to prevent such limbo is the "stand-by guardianship law," enacted in New York in 1992, which allows an ill or dying woman to name a guardian for her children prior to mental incapacitation, physical debilitation, or death.

Ultimately, the majority of HIV-affected children will end up in formal or informal foster care or adoptive care. A variety of innovative foster care programs to meet the complex needs of HIV-positive children have been created throughout the country. Few programs, however, have focused adequately on the needs of uninfected siblings. Special HIV units designed to track and oversee the care of HIV-infected foster children should expand their programs to include all HIV-affected children. Model programs designed to augment early permanency planning are urgently needed. Such programs would train, certify, and supervise a future guardian (typically identified by an ill HIV-infected mother) to provide respite care, home assistance, and other help in caring for HIV-affected children. As the mother becomes more ill, the role of this individual would expand as necessary. Ultimately, at the time of maternal debilitation, mental incapacitation, or death, the individual would become either a foster parent or an adoptive parent. As with many of the successful AIDS programs established to date, such model programs very likely will need to cross traditional boundaries, improve interagency communications, and establish new collaborative relationships.

Michaels and Levine have taken the silence that surrounds AIDS orphans and have transformed it into an audible sound. But this sound must now be amplified into a voice that can clearly articulate the federal, state, and local actions that are needed to meet the needs of every person in this nation affected by the AIDS epidemic.

Stephen W. Nicholas, MD
Elaine J. Abrams, MD

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Law and Medicine in *JAMA*

In this issue of THE JOURNAL we introduce a new editor of the Law and Medicine section (L.G.). Although the section has appeared for a number of years on an occasional basis, it is hoped that with new leadership, it will be a regular feature. Our goal is to publish timely and scholarly articles devoted to emerging issues of importance in health law and ethics. Manuscript submissions of potential interest to us would include those on traditional law and medicine topics such as confidentiality, consent to treatment, malpractice, access to health care, and the withdrawal of life-sustaining treatment. The interrelationship of law, ethics, and innovative scientific technologies—for example, the ethical use of information from the Human Genome Project—is another important topic that merits attention. We anticipate that articles in the section will review public health law and government policies relating to tobacco, illicit drug and alcohol use, and communicable and sexually transmitted diseases.

See also p 3468.

It is appropriate that the teaching of health law and ethics is becoming an ever more important aspect of medical education and that these principles are being incorporated into clinical practice and in the development of national and state policy. The Law and Medicine section will take readers beyond the negative connotations of law relating to malpractice to an appreciation of the benefits that the law can bring to American medicine. Importantly, the section will explore how current constitutional interpretation, jurisprudence, rights analysis, and bioethics can contribute to ensuring high standards of care, greater access to health care, and improved public health.

There exists no more important issue at the intersection of law and medicine than the urgent need for health care reform to ensure high-quality medical services for all Americans. This becomes a particularly compelling subject with the election of a new President, who has promised to place health care reform at the forefront of his domestic policy agenda. We think it fitting, therefore, that we publish in this issue the article by Parmet,[1] which explores the potential impact of health insurance reform on the physician-patient relationship.

Larry Gostin, JD
Helene M. Cole, MD

From the American Society of Law, Medicine, and Ethics, Boston, Mass (Mr Gostin), and the Department of Editorial Affairs, *JAMA*, Chicago, Ill (Dr Cole).
Reprint requests to American Society of Law, Medicine, and Ethics, 765 Commonwealth Ave, 16th floor, Boston, MA 02115 (Mr Gostin).

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