

**Report of the
Subcommittee on Newborn HIV Screening
of the
New York State AIDS Advisory Council**

February 10, 1994

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EXECUTIVE SUMMARY

The New York State AIDS Advisory Council's Subcommittee on Newborn HIV Screening was constituted in June 1993 of physicians, other health care and social services providers, and community representatives. The Subcommittee held five meetings and a public hearing in the fall of 1993.

Given a broad mandate to review New York State policy options for newborn HIV testing, the Subcommittee formulated recommendations that, in its view, have the greatest potential to identify and bring into care a high number of HIV-infected infants and their mothers.

The recommendations derive from the following principles:

HIV testing as early as possible in the childbearing process, that is, prior to conception or early in pregnancy, has distinct advantages in helping to prevent perinatal transmission and maximizing the benefits of HIV treatment. All sexually active adults and adolescents should be actively encouraged to learn their HIV status.

More aggressive identification of HIV-infected women and children will require substantial expansion of counseling and treatment services. These services should be funded without diverting money from other human service programs.

Programs should emphasize accessibility, confidentiality, and family-oriented delivery of comprehensive, integrated, medical and social support services. They should be tailored to the distinct needs of urban and rural communities.

The State should be prepared to respond quickly to new developments in HIV testing and treatment for women and children.

Adoption of a new standard of care integrating HIV counseling and testing into routine medical visits for all ~~pregnant and postpartum women will require the active~~ support and commitment of every health professional, paraprofessional, community leader, administrator, and community organization that provides care to women. It is the intent of the Subcommittee that the well coordinated, interdisciplinary, and highly successful model of HIV counseling and testing at Harlem Hospital be a model for statewide efforts.

Based on these principles, the Subcommittee put forth the following policy recommendations to the New York State AIDS Advisory Council for consideration by the State Legislature.

Summary of Recommendations

1. A policy of mandatory HIV counseling and strongly encouraged voluntary testing for all pregnant and postpartum women. Providers in all prenatal, obstetrical, postpartum, and pediatric settings should present HIV testing as a standard medical recommendation.
2. Strongly encouraged HIV testing for all sexually active adults and adolescents (males and females), which should also be a standard medical recommendation in all health care settings.
3. Repeat counseling and strongly encouraged testing for pregnant women who tested negative prior to pregnancy.
4. HIV counseling for uncounseled or untested postpartum women and strongly encouraged HIV testing for mother and/or infant by postpartum and pediatric care providers.
5. Adequate funding for expanded HIV counseling and testing programs and comprehensive medical and psychosocial care for HIV-positive women, infants, and children.
6. Evaluation of the effectiveness of the new policy and programs to begin not later than one year after financing is made available to providers.
7. Adoption of policies and procedures in all hospitals, clinics, and doctors' offices to implement the new policy, note maternal HIV status in neonate's records, and assist women in returning for post-test counseling and treatment.
8. Streamlining of current HIV counseling, testing, and informed consent procedures within existing law.
9. Coverage of prenatal and postpartum HIV counseling and testing by commercial health insurance, continuation of Medicaid coverage, and exclusion of these services from Medicaid co-payments.
10. ~~The provision of culturally and linguistically appropriate~~ literature on HIV counseling, testing, medical care, and support services in all health care settings.
11. Inclusion in the curricula of health care professionals instruction on HIV counseling, confidentiality, patient disclosure, and the routine integration of counseling and testing into primary medical care.
12. Active support for these policies and public and professional educational campaigns by health professional societies and organizations.

**New York State AIDS Advisory Council
REPORT OF THE
SUBCOMMITTEE ON NEWBORN HIV SCREENING**

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INTRODUCTION

In June 1993, citing the desire to insure that all HIV-infected children are offered treatment that may delay or prevent HIV symptoms, as well as the risk of HIV transmission through breastfeeding, Assemblywoman Nettie Mayersohn of Queens introduced a bill in the New York State Assembly that would require the Department of Health to notify parents if their child tested positive on the HIV test that is currently done anonymously on every newborn in New York State. Since an infant's HIV status invariably reflects that of the mother, this policy would amount to mandatory HIV testing of all childbearing women.

In considering the bill, the New York State Assembly's Ad Hoc Task Force on AIDS invited David Rogers, M.D., Chair of the New York State AIDS Advisory Council, to appear before the Task Force to discuss the pros and cons of mandatory newborn screening. Because of the serious policy issues involved, Dr. Rogers urged the Task Force to allow the AIDS Advisory Council to convene a blue ribbon panel to examine the proposal. The Mayersohn bill was tabled by a vote of 10 to 9, pending the

recommendations of the AIDS Advisory Council (AAC) based on the report of its Subcommittee on Newborn Screening.

The Subcommittee on Newborn HIV Screening (the Subcommittee) was created by the Advisory Council in June 1993. (See Appendix A for list of members.) The Subcommittee held five meetings and a public hearing during the fall of 1993. (See Appendix B for list of dates and locations; see Appendices C through E for lists of presenters, public hearing testimony, and written statements submitted at the public hearing). This report, which includes a statement of principles and a set of recommendations, is based on information and materials provided to the Subcommittee by a wide variety of presenters, organizations, and individuals.

The Newborn HIV Seroprevalence Survey

AIDS cases are reported in every state and data is collected and reported at the federal level. However, monitoring AIDS cases only permits an understanding of the extent of late-stage HIV infection that meets the federal definition of AIDS. It does not indicate the prevalence of HIV infection in the population as a whole or in selected populations or geographic areas.

"Blinded," that is, anonymous, seroprevalence surveys (based on tests for HIV antibodies in the blood, not AIDS symptoms) are a method to assess the extent of HIV infection in a given population or area. Since HIV infection is not a reportable

condition in New York, the Department of Health conducts a number of blinded studies of HIV infection rates, including the Newborn HIV Seroprevalence Survey, which began in 1987 to test for HIV antibodies in the blood of all newborns in New York State.

However, the test cannot distinguish between maternal and infant antibodies. Since maternal antibodies freely cross the placenta, infants carry their mother's HIV antibodies at birth but may not be infected themselves. Thus, newborn HIV status reflects HIV infection rates and epidemiological trends in childbearing women. New York uses the data from this Survey to inform decisions about allocation and funding of HIV prevention and treatment services for women, infants, and families.

The Newborn HIV Seroprevalence Survey is part of a nationwide program administered by state departments of health and funded by the Centers for Disease Control and Prevention (CDC), the National Institute of Child Health and Human Development, and the states. Newborn HIV seroprevalence surveys are currently conducted in 44 states and territories.

The survey is an epidemiological research study, not a public health screening program. Since the survey is a research tool, it has no legal authority to do HIV screening. Moreover, because the survey has no information that could identify the infant or mother and is not a screening program, no informed

consent is required from parents and no pre- or post-test counseling of the mother is done as is required for HIV testing by New York State Public Health Law, Article 27-F.

Currently, an HIV antibody test is done on the blood of each newborn after the seven legally mandated screening tests for congenital diseases are complete. HIV test results take about one month and, in the absence of identifying parental information, cannot be linked to individual newborns. (See Appendix F for information on the current process of newborn testing for congenital diseases and the Newborn HIV Seroprevalence Survey and Appendix G for types of HIV testing.) Thus, the ongoing Newborn HIV Seroprevalence Survey could not simply be "unblinded" to notify parents of results. Mandatory newborn HIV screening with parental notification would require a number of changes in law and procedure, including revisions in the New York State HIV confidentiality statute, laboratory protocols, and hospital and parental follow-up.

Charge to the AAC's Subcommittee on Newborn Screening

~~The Subcommittee was charged by the New York State AIDS Advisory Council to take a broad look at the issue rather than focusing narrowly on whether New York State should institute mandatory HIV screening of newborns. The Subcommittee was asked to assess the latest medical and scientific knowledge on clinical care and transmission of HIV, including transmission by breastfeeding; to~~

provide guidance on the best ways of identifying infants with HIV infection; and to determine the best means of getting them, their mothers, and other infected family members into early treatment.

EPIDEMIOLOGY

AIDS Cases in Women and Children

As of December 31, 1993, New York State had a cumulative total of 69,921 AIDS cases, 82.5 percent of them in New York City. Women with AIDS totaled 12,657, 18 percent of the adult and adolescent cases. The use of injection drugs is the predominant risk factor for HIV exposure in women, accounting for 60 percent of cases; heterosexual sex accounts for an additional 27 percent. Nearly 83 percent of women with AIDS are women of color: 52 percent are black and 30.6 percent are Hispanic.

Except for a small number of AIDS cases caused by infected blood products, pediatric AIDS cases (in children less than 13 years) mirror those among women, since perinatal transmission of HIV (from mother to fetus or infant) accounts for 93 percent of pediatric cases. By December 31, 1993, there were 1,395 cases of pediatric AIDS in New York State, more than 87 percent of them in New York City. About 75 percent of pediatric AIDS cases are attributable to the mother's injection drug use (IDU) or sexual relations with an IDU partner. Almost 90 percent of pediatric AIDS cases are among black (53.3 percent) and Hispanics (35.1

percent).

Newborn HIV Seroprevalence Survey Data

The Newborn HIV Seroprevalence Survey has shown that HIV-infected women in New York State give birth to about 1,800 infants each year who test positive for HIV antibodies. According to currently accepted estimates of maternal-infant transmission rates, only 15 to 25 percent of these infants are actually infected with HIV; the remainder carry maternal HIV antibodies, which disappear some months after birth.

Survey data report that 9,249 HIV-infected women in New York State gave birth from November 1987 through December 1992. Preliminary data record an additional 1,074 women through August 1993. (These figures may include women who gave birth more than once during the study period.) Almost 80 percent of HIV-infected women giving birth are either black or Hispanic.

Table 1 (below) indicates that the total number of HIV-infected women giving birth peaked in 1990 and has decreased 12.5 percent over the last two years. New York City accounted for most of the previous increase and recent decline in the State's maternal seropositivity rate. In New York City, both the total number of HIV-positive births and the proportion of HIV-positive births out of all births have decreased. In areas outside New York City, there was an increase of 7.8 percent in HIV-positive

births in 1991. In 1992 the increase was 0.3 percent.

**Table 1. Infants Born with HIV Antibodies
New York State, 1988-1992***

Year	NYC	(% HIV+)	Rest of NYS	(% HIV+)	Total**	(% HIV+ of All Births)
1988*	1,570	(1.25)	240	(.16)	1,816	(.66)
1989	1,537	(1.21)	260	(.17)	1,822	(.64)
1990	1,619	(1.23)	269	(.17)	1,909	(.65)
1991	1,535	(1.17)	290	(.19)	1,842	(.64)
1992	1,391	(1.08)	291	(.19)	1,691	(.59)
1993	--	--	--	--	1,074***	--
Total	7,775	(1.19)	1,380	(.18)	10,333***	

* HIV Seroprevalence Study began on November 30, 1987 (figures for 1988 include data for December 1987).

** Totals include out-of-state cases that could be attributed neither to New York City nor the rest of New York State.

*** The figure for 1993 is based on unpublished seroprevalence data representing the number of infected mothers giving birth from January to August, 1993; this figure is also included in the Total.

Source: New York State Newborn Seroprevalence Study in *AIDS in New York State, 1988-1992*.

In New York City, the average rate of HIV-positive births (that is, the HIV infection rate among women giving birth) since 1987 is about 1.2 percent. This rate is lower in upstate New York (less than 0.2 percent). Counties closer to New York City have higher rates. The total New York State maternal seropositivity rate has declined slightly from 0.66 percent to

0.59 percent, despite a sharp increase in the number of AIDS cases reported among women each year.

Forty-four (or 25 percent) of the 179 hospitals reporting births in New York State account for 89 percent of all HIV-positive births. Of these 44 hospitals, 36 are in New York City and 8 are in other urban areas. These 44 hospitals are located in 12 (19 percent) of New York State's 62 counties/boroughs. Maternal HIV infection shows the same geographic distribution as drug use, low birth weight, and low level of maternal education. There has been no substantial change in geographic distribution of maternal seropositivity in New York State since 1987.

PERINATAL TRANSMISSION

The data in Table 1 (above) show the numbers of infants who test positive for HIV antibodies at birth in New York State. The percent of children who actually have the virus is unknown. Published studies from around the world, which are summarized in Table 2 (below), indicate a range of 14 percent to 45 percent for "vertical" (mother-to-child, or perinatal) transmission of HIV. The lowest rates of mother-to-infant transmission of HIV have been reported in Europe, where they range from 15 percent to 25 percent. The highest rate, about 45 percent, was reported in Kenya. Unpublished data from a New York State Department of Health research study on early diagnostic testing methods in a

sample of more than 200 HIV-positive newborns show a 15.5 percent transmission rate.

Table 2. Summary of Published Mother-to-Child Transmission Rates

Site (Year)	Number	Rate
North America:		
New Haven (1990)	43	16%
Bronx, NYC (1991)	33	21%
Brooklyn, NYC (1989)	55	29%
Miami (1991)	82	30%
Caribbean:		
Haiti (1990)	230	25%
Continental Europe:		
Europe (1992)	721	14%
France (1992)	263	23%
Italy (1992)	551	24%
Africa:		
Rwanda (1991)	218	30%
Zaire (1989)	92	39%
Kenya (1991)	361	45%

Source: Centers for Disease Control and Prevention, 1993.

Table 3 (below) lists estimates of HIV-infected infants born in New York State from 1988 to 1993. Using the currently accepted transmission risk of 15 to 25 percent, it is estimated that between 1,550 and 2,584 infected infants were born in New York State between November 1987 and August 1993.

**Table 3. Estimated HIV-Infected Newborns
New York State, 1988-1992***

Year	Range:** NYC	Range: Rest of NYS	Range: Total
1988*	236-393	36-60	272-454
1989	231-384	39-65	273-456
1990	243-405	40-67	286-477
1991	230-384	44-73	276-461
1992	209-348	44-73	254-423
1993	--	--	161-269***
Total	1166-1944	207-345	1,550-2,583***

- * HIV Seroprevalence Study began on November 30, 1987 (figure for 1988 includes data for December 1987).
- ** Ranges of truly infected infants were calculated by applying low (15%) and high (25%) estimates of maternal HIV transmission to the number of newborns testing HIV antibody positive each year.
- *** The figures for 1993 are based on unpublished seroprevalence data representing the number of infected mothers giving birth from January to August, 1993; this figure is also included in the Total.

Source: Based on data in *AIDS in New York State, 1988-1992*.

Variations in maternal-infant transmission rates are not well understood, but the possible risk factors can be divided as follows: prepartum (before birth), including maternal infection stage, immunologic factors, and placental factors; intrapartum (during birth), factors that expose the infant to HIV during labor and delivery; and postpartum (after birth), the risk of HIV transmission through breastfeeding.

Prenatal HIV transmission involves passage of HIV through the placenta, although it is not clear whether the infectious agent is cell-free or cell-associated virus. Prenatally, maternal factors such as advanced illness, a low CD4+ cell count, high viremia/antigenemia (high levels of virus in the blood), and increased infectivity immediately after seroconversion are thought to present an increased risk of HIV for the infant. Immunologic factors that increase risk are related to the absence of specific neutralizing antibodies in the mother. In one African study, chorioamnionitis, infection of the amniotic sac, has been identified as a placental risk factor.

Intrapartum transmission could occur through exposure of the infant's skin and mucous membranes to maternal blood and vaginal secretions or due to fetal scalp trauma from electrodes or other intrusive procedures that cause breaks in the infant's skin. Vaginal delivery and premature delivery have thus been cited as possible factors increasing transmission risk. In the postpartum period, breastfeeding is a mechanism of HIV transmission.

~~There is evidence that transmission may occur at any of these stages.~~ Virus has been detected prenatally in fetal tissue and at birth. Both hepatitis B and cytomegalovirus are transmitted intrapartum and it is possible that HIV may be as well. Studies of twins born to HIV-infected women indicate that the first-born is more likely to be infected with HIV, perhaps

because the first infant "cleans out" the birth canal, reducing the exposure of the second-born twin to blood and maternal secretions. In the postpartum period, HIV has been isolated from breast milk. HIV transmission from breastfeeding has been demonstrated in cases in which mothers acquired HIV infection after giving birth; and there is an elevated HIV seroprevalence rate among breastfed infants born to HIV-positive women.

Table 4 (below) lists data on HIV transmission from infected mothers to breast and bottle-fed infants. The average difference in transmission rates between these two groups shows a 14% additional risk of HIV transmission due to breastfeeding.

Table 4. Breastfeeding and the Risk of HIV Transmission

Region	Breast	Bottle
Europe	32%	14%
Miami	28%	32%
France	44%	17%
Switzerland	15%	16%
Zaire	20%	0%
Australia	50%	17%
Summary estimate of additional risk = 14%		

Note on the duration of breastfeeding: The odds ratio increases from about 1 at birth to about 3.65 by 300 days, meaning that at 300 days of breastfeeding, an infant is almost 4 times as likely to be infected as at birth. The transmission risk increases most dramatically in the first month of life.

Source: Centers for Disease Control and Prevention, 1993.

Considering the possible mechanisms and timing of transmission, there are in theory a number of ways to prevent perinatal infection. It is thought that most transmission occurs before and during delivery, and most of the possible interventions would be used during the prenatal or intrapartum periods. Prenatally, the mother and fetus could be treated to decrease viral load; a clinical trial is currently underway to determine if pregnant women who receive zidovudine (AZT) have a lower perinatal transmission rate. During the intrapartum period, cesarean section, passive immunization (with hyperimmune globulin or a neutralizing antibody), treatment of the infant, and washing the vagina and the baby have all been proposed, but their benefits are as yet inconclusive. Postpartum, breastfeeding could be avoided.

Thus, HIV screening is likely to be useful at any stage of pregnancy, with the earliest knowledge of maternal serostatus yielding the greatest opportunity to prevent perinatal transmission. Determination of maternal serostatus before or early in pregnancy would allow the mother the fullest range of treatment and planning options for herself and her family.

BENEFITS OF EARLY HIV IDENTIFICATION IN INFANTS

The goals of identifying infants who are or will be born to HIV-infected mothers, and are thus at high risk of HIV infection, are to prevent transmission of HIV to those who carry only maternal antibodies and to provide the earliest possible care and treatment for infants actually infected.

Concerning prevention, although it is possible that a number of interventions (discussed in the section on Mother to Infant Transmission) can prevent the transmission of HIV from mother to child, they have not, with the exception of breastfeeding, been sufficiently studied to make formal recommendations or establish policy.

However, the New York State Department of Health currently makes specific recommendations concerning breastfeeding. Formulated in consultation with the Centers for Disease Control and Prevention, the National Institute of Medicine, and the American Academy of Pediatrics, New York's policy states that a woman known to be HIV-infected is to be informed of the risks of HIV transmission through breastmilk and counseled not to breastfeed. Women who are not HIV-infected are encouraged to breastfeed. The policy promotes voluntary HIV counseling and testing as early as possible prior to or during pregnancy.

Since women typically make the decision to breastfeed before

delivery and begin breastfeeding in the first few days after delivery, the risk of transmission via this route can be reduced if women know their HIV status before delivery. According to the CDC, HIV transmission through breastfeeding has not been a major problem in the U.S. because many HIV-infected women do not breastfeed for reasons other than HIV, such as drug use.

Care and treatment of infected infants includes prevention of pneumocystis carinii pneumonia (PCP), prevention of other potentially fatal opportunistic infections, including the use of immune globulin to prevent serious bacterial infections, monitoring of immunity-preserving CD4 cells (which can decrease precipitously in infants), changes in standard childhood immunization practice, and use of antiviral drugs that may retard the onset of AIDS symptoms.

In general, about 10 percent of children with HIV infection die within one year of life. PCP is the most common serious opportunistic infection among children with HIV and is the primary cause of death for HIV-infected infants. It strikes very young ~~HIV-infected infants~~ and is more swiftly and frequently fatal than in adults. Recent data suggest that half of all PCP cases in children occur in infants between 3 and 6 months of age. The failure to recognize HIV status and lack of PCP prophylaxis are associated with an increased risk of early death among HIV-infected infants.

Trimethoprim/Sulfamethoxazole (TMP/SMX), a common antibiotic, is usually effective in preventing PCP in children as well as in adults. Studies have shown significantly less PCP in HIV-infected infants under one year of age who have been treated with TMP/SMX compared to those who did not receive TMP/SMX prophylaxis.

In 1991, the CDC published guidelines, based on age and CD4 count, for the use of TMP/SMX as prophylaxis against PCP in children with HIV. However, some children develop PCP who have not met the CDC guidelines for prophylaxis. PCP can occur at higher CD4 counts or when the level of CD4 cells drops precipitously. Therefore, frequent pediatric practice is to begin TMP/SMX administration regardless of CD4 count at one month of age in infants born to mothers with HIV infection and continue until the infant has been definitively diagnosed as not HIV-infected. Review of the CDC guidelines is being planned.

Nationwide, approximately 70 percent of pneumocystis pneumonia occurs in children who have not had the benefit of prophylaxis (227 of 299 reviewed cases of PCP). Half of these children were not previously diagnosed with HIV or were diagnosed only in the preceding month. Others were not treated despite CD4 counts below the recommended level for prophylaxis.

Among infants in New York City identified as HIV-positive

prior to PCP diagnosis (by review of the records of 56 children less than one year old, diagnosed with PCP from 1991 to mid-1993), 22 of 29 had not received prophylaxis. The reasons for this are being studied, but it appears that factors other than lack of knowledge of HIV status may also be responsible for the fact that PCP prophylaxis is not available to all infected children.

Other recent New York City data on PCP incidence in HIV-infected children under one year suggests that PCP incidence may be decreasing (29 infants with PCP in 1991, 22 in 1992, and 5 as of mid-1993). Further, early diagnosis of HIV may be increasing. In 1991, 45 percent of these children had been diagnosed as HIV-positive prior to PCP diagnosis, while in 1992 and early 1993 that figure was 60 percent.

Since the CDC guidelines on PCP in infants were only published in 1991, the long term effects of PCP prophylaxis on HIV-infected and on antibody-positive, non-infected infants are not known, but anecdotal evidence from pediatricians suggests that ~~TMP/SMX~~ has fewer side effects in infants than in adults.

Many infants who do not die of PCP develop encephalopathy and other diseases that seriously compromise their quality of life. ~~HIV-infected infants are at risk for serious bacterial~~ infections, interstitial pneumonia, gastrointestinal disorders,

and neuro-developmental impairment. Knowing an infant's HIV status would enable pediatricians to monitor children carefully for early symptoms of these diseases and for a change in levels of CD4+ cells that would indicate susceptibility to infections. It would allow more rapid diagnosis and treatment for these infections and the administration of AZT, DDI, or other treatment regimens that may improve the quality or length of life, such as the use of intravenous immunoglobulin (IVIG) to boost the immune system.

Clinical trials are underway in several states, including New York, to study the effects of AZT treatment in HIV-positive infants. This treatment is currently recommended in symptomatic HIV-infected children with severely depressed CD4+ cell counts. Currently, there is no antiretroviral therapy known to be efficacious in asymptomatic infants.

Another intervention recommended by the American Academy of Pediatrics and the CDC for children with HIV and those who are HIV antibody-positive at birth is a change in immunization ~~practices. Because there is a theoretical risk to~~ immunocompromised infants or their HIV-positive family members from live virus vaccine (since the virus can spread to family and other contacts), pediatricians change the schedule of ~~immunizations and use inactivated polio vaccine instead of live~~ virus for children who are antibody-positive or who are antibody-

negative but reside with antibody-positive family members.

In addition, influenza and pneumococcal vaccines are recommended in cases of HIV infection. Because HIV-infected children are at risk for severe chicken pox, they should receive zoster immune globulin within hours of exposure to this disease to prevent it or lessen its severity.

BENEFITS OF EARLY HIV IDENTIFICATION IN WOMEN

Whether pregnant or not, women can benefit from early knowledge of their HIV status. Monitoring of CD4 counts, appropriate treatment of opportunistic infections and HIV symptoms, antiviral therapy, participation in clinical trials of new drugs, family planning, and counseling to avoid infection of others are all most effective when initiated as soon as possible after seroconversion.

Women with HIV infection can benefit specifically from PCP prophylaxis and may benefit from AZT therapy and a range of preventive measures required by their immunosuppression, including immunization for hepatitis B and influenza, and testing and treatment for tuberculosis.

Their participation can be encouraged in clinical trials of new therapeutic drugs as well as drugs intended to prevent viral

transmission during pregnancy, including AZT in combination with other compounds, such as DDI, DDC, and hyperimmune globulin. Decreasing maternal viral load, increasing levels of neutralizing antibodies, hyperimmune globulin therapy, and cesarean section delivery have already been mentioned as emerging possibilities for prenatal and intrapartum management to avoid perinatal transmission. The decision not to breastfeed is also most effective when made prior to delivery.

Less tangible but nevertheless significant benefits of early knowledge of HIV serostatus include the opportunity for a mother, under New York State law, to designate a legal guardian for her child or children upon her death or incapacitation and to make other arrangements for family care, assets, and legal or medical services. The earliest possible detection of infection in a pregnant woman also presents her family with the opportunity to adjust to the possibility of infection in a newborn. A child with HIV infection requires vigilant care from family members as well as professionals to prevent opportunistic infections and provide the best possible conditions for growth and development. ~~In infected children, HIV-related disease is likely to be a~~ chronic condition until they succumb to their illness.

Further, the infected child's health and well being are ~~usually directly dependant on his or her mother's health and well~~ being. Early HIV identification in a pregnant woman improves the

quality and possibly the length of her life. It is also likely to improve the quality of care the HIV-infected child receives, both from the mother and from medical and social service personnel, who are trained to work most effectively with mother and child as a unit.

Finally, knowledge of her HIV status gives a woman the opportunity to prevent transmission to her partner and to make an informed decision regarding future pregnancies.

SERVICE DELIVERY FOR HIV-AFFECTED FAMILIES

Children and families who have been most affected by HIV tend to be among those who have traditionally had poor access to services. HIV infection is often added to the burdens of poverty, substance abuse, and social isolation. Women with HIV often function as heads of households, taking care of partners and children who are ill as well as those who are uninfected. Medical service needs are intense and frequent; visits are often long and require multiple providers in a single visit.

The HIV epidemic has shown the importance of "co-location" of comprehensive services to meet the complex medical and social needs of these families. Unfortunately, as nearly every provider at the Subcommittee's Public Hearing confirmed, programs providing services to affected families have encountered severe