Report of the

Subcommittee on Newborn HIV Screening

of the

New York State AIDS Advisory Council

February 10, 1994

PUBLIC TESTIMONY PRESENTED TO THE NEW YORK STATE AIDS ADVISORY COUNCIL
NEWBORN SCREENING SUBCOMMITTEE
ON
MONDAY - NOVEMBER 8, 1993

Submitted by: Wilma Montañez
Project Coordinator
Latina Roundtable on Health and Reproductive Rights
November 8, 1993

Creating Barriers to Health Care for Latinas

On behalf of the Latina Roundtable on Health and Reproductive Rights (LRHRR), I wish to thank the Latino Commission on AIDS and the AIDS Advisory Council Subcommittee on Newborn Screening for the opportunity to address our concerns regarding newborn screening - and it's impact on the Latino community.

The LRHRR was formed in May, 1990. LRHRR is the **only Latina organization in New York City exclusively devoted to advocating for increased access to a full range of quality and affordable health services and reproductive options for Latinas.**

In New York City, Latinas represent over 30% of the cases among women with AIDS and, a disturbing 38% of the pediatric cases are among Latino children.

Adolescent and young adults constitute the fastest growing group of new AIDS cases in New York City. More alarming is that the proportion of AIDS cases among females is higher among those 13-21 (31.2%) as compared to adults 21 (14.7%) and over. Approximately 30% of adolescent AIDS cases are Latino youth.

In 1988, 15.5% of live births to NYC Latinas were characterized by late or no prenatal care contributing to an infant mortality rate of 11% among Latinos and 13% for Puerto Ricans. Similarly, in that same year, the rate of low birth weight, associated with infant lung and liver complications, brain damage and infant mortality,1 reached 9% among Latinos and 11% for Puerto Ricans, and compared to 6% for white women.

Latinas teens account for 19% of births to teen mothers in NYC. In general, several studies suggest that Latina teens are less likely to use contraception, for example, a 1988 study conducted by Alan Guttmacher Institute revealed that 46.1% of sexually active Latina teens

did not use any form of birth control. Additionally, pregnant teens are also at greater risk for maternal mortality (60% higher rate than for women over 20) and serious medical complications such as anemia, toxemia, cervical trauma and premature delivery.

Access to adequate, affordable and culturally and linguistically appropriate are abysmal for Latinas in New York City. The latest Health and Hospital Corporation Report documented the criminal waits for prenatal services, family planning services and the overall lack of women's health services available to poor women in the city.

Latina health advocates and community leaders are concerned that any additional barrier, such as the "unblinding" of the **Newborn Screening** will further deter the most vulnerable of populations such as teens, substance users, and the undocumented from seeking reproductive health services, especially prenatal care. Furthermore, it is not clear as to how revealing the serostatus to a recently post partum mother will have a positive impact on her and the newborns well being. There is substantial evidence that disclosure of serostatus in the absence of the appropriate counseling and adequate resources such as health (including mental health), housing, drug treatment and familial support services has minimal impact on the necessary positive behavioral changes. In fact, the results are usually overwhelmingly devastating for the person involved and their significant others.

Over 300,000 low-income women and teenagers across the state use family planning Clinics. Approximately 40% of family planning patients are from ethnic minority groups. Fewer than 0.5% of all those who use these services have private insurance. Additionally, 20% of patients are 17 and under, making the family planning clinic network the state's single largest provider of primary preventive health services for teenagers as well as low-income women.

The constant surveillance of poor women and the constant lack of regard for their reproductive rights will, as it already has, continue to create unsurmountable barriers to health care. Already poor women who depend on subsidized reproductive health services such as family planning and prenatal care have had to submit themselves to extensive HIV screening and/or testing perhaps when they were not fully prepared to do so. The reasons for this are closely linked with the present funding streams. Monies have been eliminated from family planning and they have been placed in HIV. Community based family planning clinics, which coincidentally also are the largest providers of prenatal care in many of our communities, have had to juggle poor women's rights to privacy and limit choices in order to survive these harsh financial times.

Family planning clinics are the principal source of referrals to prenatal care services for poor women and teens in New York City. If women anticipate that they must submit to HIV screening without their consent, we fear they will not seek out appropriate health services. and therefore their already limited options will be further eroded.

If we want to sincerely make an impact on prevention of HIV and improve Latinas lives, we must closely examine these proposed policies to ensure that we are not working against our own efforts.

Latina Roundtable on Health and Reproductive Rights
140 West 22nd Street - Suite 301
New York, New York 10011
212 - 206-1090 FAX 212 - 206-8093

11-8-95 Mount Sinai Hospital Director, Pediatric HIV clinic

INCIDENCE OF SIX DISEASES INCLUDED IN NEWBORN SCREENING

Maple-syrup urine disease	1 in 175,000
Homocystinuria	1 in 100,000
Tyrosinemia	>1 in 300,000
Galactosemia	1 in 60,000
Phenylketonuria	1 in 14,000
Hypothryoidism	1 in 4,000

This is in contrast to:
INCIDENCE IN INFANTS BORN IN NEW YORK CITY OF:

Perinatal exposure to HIV	12.5 in 1,000
HIV infection	2 in 1,000

The number of HIV-exposed children who are born each year in New York City is estimated to be 1800 and the number of HIV-infected children to be 350.

Early diagnosis of HIV infection allows for the early institution of preventive measures such as use of trimethoprim-sulfamethoxazole to prevent Pneumocystis carinii pneumonia, a life-threatening infection affecting young infants in the majority of cases, childhood immunizations appropriate for HIV-exposed and infected children, antiretroviral therapy, nutritional support, etc. Children who present with an AIDS-defining condition, which is often the case, cannot benefit from these preventive measures.

Unblinding of newborn screening must be accompanied by education of health care professionals, available resources to treat children and families who many times learn of their diagnosis of HIV infection when the child is diagnosed, availability of laboratory tests to differentiate HIV exposure and HIV infection.

Along with unblinding of newborn screening, a concerted effort must be made to prevent the spread of HIV to the population and educate HIV-infected women about the risks of perinatal transmission.

Continued secrecy cannot prevent the spread of HIV infection.

NEW YORK CITY GAY AND LESBIAN ANTI-VIOLENCE PROJECT
647 Hudson Street
New York, New York 10014
Office Telephone: (212) 807-6761
Fax: (212) 807-1044

November 4, 1993

Dr. Robert Haggerty
Dr. Carolyn Britton
c/o NYS DOH AIDS Institute
5 Penn Plaza Room 407
New York, New York 10001

PUBLIC TESTIMONY
NEW YORK STATE AIDS ADVISORY COUNCIL
NEWBORN SCREENING SUBCOMMITTEE

Dear Drs. Haggerty and Britton:

On behalf of the New York City Gay and Lesbian Anti-Violence Project (AVP), I offer this testimony on newborn screening for HIV antibodies. AVP strongly believes that such screening must remain blinded, and that de facto mandatory HIV antibody testing of women giving birth in public hospitals is dangerous to women. AVP supports increased funding for public health initiatives designed to reach women and infants at risk, including routine, quality, non-coercive HIV counseling and education services for every pregnant woman seeking prenatal and birthing services.

AVP operates the country's only program to focus on HIV and violence. Since 1990, the HIV-Related Violence Program - largely funded by the AIDS Institute - has trained service providers to recognize and respond to HIV-related violence, published and distributed outreach materials, and provided direct counseling and advocacy services to over 400 survivors of HIV-related violence. These survivors include gay men and lesbians as well as heterosexual men and women; they are of every class background, ethnic and racial origin, and level of disability. Some are HIV-positive; some are merely assumed to be HIV-positive. All have been targeted for criminal victimization - harassment, bias assault, domestic violence, abuse by service providers, discrimination - because of their real or perceived HIV status.

A common thread uniting survivors of HIV-related violence is that many cite breaches of confidentiality and irresponsible service provision as the origin of their suffering. A health care worker discloses a patient's status to his friends; word spreads in the community that she is positive; suddenly she is harassed day and night by neighbors and landlords, graffiti marks her door, she feels afraid to leave home. An abusive lover learns that his partner is positive; he blames the partner for being infected and possibly infecting him, and accuses her of taking drugs and sleeping around; the partner is beaten, denied access to medical care, thrown out of the house. It is winter,

she has nowhere to go, no money, and goes into a city shelter where tuberculosis threatens her health. This is neither drama nor exaggeration. It the reality my clients face.

One heartbreaking story that came through my office was that of Miranda Rodriguez (I have changed her name to protect her). Miranda, who is HIV-positive, has three children, the youngest of whom - Cara - is also positive. The family lived in a shelter for a short while, because Miranda's boyfriend had become physically abusive. The last time she called the police to take him away, he screamed - in full earshot of her neighbors and police - "You want to be rid of me, you HIV-infected bitch? You'll never find anyone else with the shit you've got." After staying in the shelter, Miranda and her child became clients of the Division of AIDS Services, got medical treatment, were placed in permanent scattered-site housing in the neighborhood and got themselves together. One day months later, a DAS worker showed up at the shelter, somehow unaware that DAS had placed the family in housing or that Cara was being tracked at a nearby hospital. He asked to speak to "Ms. Rodriguez." He was taken to see another woman named Rodriguez who lived in the shelter, and he asked her where her baby was. She replied that she didn't speak English, at which point he recruited another resident to translate. He said, "Please tell Ms. Rodriguez that I am sorry, but her daughter Cara has AIDS." The translator replied, "Oh my God, you're talking to the wrong Ms. Rodriguez, you must mean Miranda and her daughter Cara! They have AIDS?" Shelter residents began a harassment campaign against Miranda, accusing her of infecting them and all their children, and threatening to kill her. She was confronted on the street and train. She received threatening phone calls. She nearly had a nervous breakdown and was afraid to send her children to school. The stress caused her T-cell count to plummet, and she developed several opportunistic infections.

I tell this story because I will hear many more like it should newborn screening be unblinded. The potential for widespread confidentiality violations, many with violent consequences, are enormous should such a policy be adopted. Many of my clients recall horror stories of being told their HIV status in hallways, by nurses, with no counseling and with many people listening. Many of these people, on top of adjusting to the severe shock of having devastating HIV information delivered in a callous and irresponsible manner, then suffered harassment, discrimination, and other forms of abuse.

In addition to abuse by strangers, persons living with HIV infection are at extreme risk for domestic violence, from lovers, spouses and family members. A full third of my caseload is made up by HIV-positive gay men, lesbians and straight women who have suffered domestic violence. Women, both heterosexual and lesbian, will have this risk further exacerbated by any policy which impedes their right to choose or reject both HIV testing and disclosure of the results. HIV-positive women who disclose their status to partners are often blamed for their own infection, the possible infection of the partner, and possible infection of a child. Such blame is often used to justify domestic violence, which in addition to causing physical injury can cause immune suppression, nervous disorders, severe depression, self-destructive behavior, and isolation from medical and emotional support services.

If newborn screening is unblinded, fathers of antibody-positive infants will learn the mothers' HIV status. These positive mothers will therefore be placed at extreme risk for domestic violence

at a time when they are undergoing shock, depression, and stress, even as they recover from the physical trauma of giving birth. What about fathers who are no longer involved with the mothers? Will they be found and informed? What about lesbian mothers, who are already at risk for homophobic harassment from ex-husbands and boyfriends? What about battered lesbians who learn their HIV status in the hospital after giving birth, and who are fearful to inform their lovers? Who will be sensitive to their needs?

Unblinding newborn screening will be a disaster for public health. The sheer number of women giving birth in public hospitals, combined with the lack of funding and training for these hospitals, guarantees widespread chaos and violations of the State HIV confidentiality law. The proposed Federal Health Insurance plan is projected to place further pressure on administrative resources in city-run hospitals. Women will be given incorrect test results, they will be given test results with no counseling or explanation, and they will be given test results in the presence of other people, some of whom will then abuse, harass or assault them. This abuse will have severe and immediate effects on the health of its victims, obliterating any health gains made by supposed "early intervention." Battered women, both heterosexual and lesbian, will avoid prenatal and birthing services in order to avoid disclosure to their partners; they and their children will be forced underground. The horror stories will be back in full force.

There are alternatives to unblinding newborn screening that will make progress in identification and care of women and infants with HIV. For example, any prenatal provider currently receiving PCAP funding must provide HIV counseling to all women receiving services. However, there are no monies built into PCAP to provide this counseling, which is often left up to the OB/GYN practitioner. That practitioner is in all likelihood overburdened, has very little time with any one patient, and lacks sufficient training to provide quality pre-test counseling. It is simply not possible for that practitioner to do a risk assessment, discuss perinatal transmission, develop an individual prevention plan, assess for risk of violence, or perform any of the interventions that make a quality HIV counseling session. A woman at risk who does not receive such a counseling session is unlikely to consent to HIV testing, as none of her concerns, fears, or problems have been addressed. The women who tend to agree to testing after little or no counseling are those who believe themselves to be at low or no risk; therefore, the program misses exactly those women it intends to reach. PCAP should provide funding for hiring and training of professional HIV counselors, establish and fund a mandatory fixed, low HIV counselor-to-PCAP patient ratio, and station these counselors in prenatal units so that women need not make extra appointments. This proactive program would ensure that many more women at risk and their infants would be identified and hooked into services.

New York State needs to put its resources into intensive, personalized, quality counseling and education services for all women, both heterosexual and lesbian, especially those who are considering parenting. New York State needs not to bend to inflammatory rhetoric which claims that newborn testing will save women and babies. Unblinded newborn screening will force women and babies underground, and will invite widespread violence against women with HIV.

Respectfully submitted,

Terry A. Maroney
HIV-Related Violence Program Coordinator

LIAAC
Long Island Association for AIDS Care, Inc.

"Serving Nassau & Suffolk, because HIV/AIDS doesn't stop at the city border"

Executive Director/CEO: GAIL BAROUH, PH.D. • *Board Chair:* DAVID R. JAMPOL, Esq.

Official Statement
New York State AIDS Advisory Council
Newborn Screening Subcommittee
Public Hearing
Monday, November 8, 1993

Good morning, my name is Jeffrey Reynolds. I am the Advocacy and Communications Coordinator for the Long Island Association for AIDS Care, otherwise known as LIAAC.

Incorporated in 1986, LIAAC is Long Island's oldest and most comprehensive AIDS service provider. As you may know, Long Island continues to lead the nation in suburban AIDS cases and 35% of LIAAC's client base are women, a proportion significantly higher than the national average.

As an agency, we vehemently oppose legislation that would unblind New York's newborn seroprevalence study. Reasons for that opposition are numerous and include the wide spectrum of medical, legal, fiscal and practical issues involved with what amounts to nothing more than an expensive, ineffective program designed to accomplish mandatory testing of pregnant women by proxy and with no guaranteed linkage to services.

I'm sure most, if not all, of those issues have been brought before you and discussed by this already-knowledgeable panel, so I'd like to focus a bit on the projected impact this plan on suburban Long Island. Of course, we all know Long Island as a picture-perfect example of white picket fence middle class mainstream America. Although Amy and Joey have tarnished that image a bit, most Long Islanders are content to believe that social problems stop at the midtown tunnel and belong here in Manhattan. Drugs, crime, prostitution, alcohol, poverty, homelessness teenage pregnancy?

HOTLINE 516/385-AIDS • *BUSINESS* 516/385-2451 • *FAX* 516/385-2496
PO BOX 2859 • HUNTINGTON STATION, NY 11746-0685

"Not here," declare Nassau and Suffolk County residents.

Long Island, though it leads the nation in suburban AIDS cases, still remains to a great extent, locked in a world of intolerant ignorance. In the last year, we've noticed an increasing number of news accounts about young women, many teenagers, who carry children to term and abandon them in alleys, dumpsters or hotel rooms. I'd be hard - pressed to detail all the reasons for this in the next few minutes, however, the role of the stigma associated with an unwanted pregnancy in suburbia coupled with the glaring lack of medical and social support services in undeniable. Now tell mom that delivering a baby in a medically safe environment automatically comes with a mandatory HIV test. I think Long Island's sense of suburban intolerance has fueled both the abandonment of newborns and most certainly the AIDS epidemic. Unblinding the newborn seroprevalence study will inextricably link the two together and more mothers will head underground for fear of being stigmatized in their suburban communities.

There is widespread agreement among women with HIV, community advocates, pediatricians, obstetricians and gynecologists, the CDC, the State Department of Health and local health departments and professional organizations such as the American Academy of Pediatrics and the National Pediatric HIV Resource Center that women should be routinely offered voluntary HIV-antibody testing and counseling before they become pregnant and/or certainly during the prenatal period as a routine component of care. Though I'm sure that you're all familiar with the numerous reasons why this is beneficial, health care providers in many areas of the state, and especially on Long Island, have ignored those repeated calls and still fail to mention HIV .

If ob/gyn physicians and other health care providers do not see women as being at risk, why in a community so content to bask in comfortable denial, would women ever see themselves as being at risk? The short answer is they wouldn't and they don't.

Perhaps physicians should be required under state law, as is done in state-funded PCAP and family-planning clinics, to offer all women voluntary HIV counseling and testing as a component of prenatal care or in a next-best scenario during post-partum care. Under New York's Maternal and Child Health Laws, physicians to be in attendance at a delivery are required to inform the mother of drugs to be used during delivery and those drugs'

possible effects on both the mother and child. Federal Law now requires that pharmacies offer drug counseling to those receiving prescriptions. Though there is not a direct parallel, a good case can be made that HIV - related information is just as important as drug information.

New York State's confidentiality law has served our public health goals quite well, and so, all such counseling and testing must be done under the strict guidelines of Article 27F.

Physicians would then note in the patient's record that universal HIV counseling was conducted and that testing was offered.

Undoubtedly, many physicians will oppose this as an undue burden. In fact, one Long Island physician told me that he "wouldn't have the time" to counsel all his pregnant women patients about HIV and that this would be an undue burden.

While mandatory measures are not always desirable or advantageous, it's clear that something more has to be done to stem the tide of the epidemic among women and children. Why, however, should we let health care providers off the hook and rather than mandating that they do their jobs properly, penalize women with mandatory invasions of privacy that will only drive them further away from the health care delivery system?

We know that when women are offered voluntary HIV counseling and testing, they most often accept it. At Harlem Hospital, they've achieved a 95% acceptance rate. While a number that high may raise some questions about the possibility of coercive counseling, it also highlights the efficacy of voluntary, universal measures.

In addition to the physician mandate, LIAAC also supports expansion of the State's Ob/Gyn Initiative, increased funding for the Anonymous Test Sites, increased emphasis on community-based outreach, expansion of primary care and all the other things that will enhance the health of women, both pregnant and not.

I thank the subcommittee for the opportunity to present our views on this very important topic. You are in the unenviable position of wading through some tough medical, legal, ethical and social dilemmas that pre-date AIDS, but which now need to be fully explored and finally resolved. We know that this body will proceed cautiously knowing that the lives of New York's women and children are at stake.

I welcome any comments or questions.

New Born Screening issues:

It is the opinion of Long Island Minority AIDS Coalition, that the unblinding of the newborn seroprevalence test results in nothing more than the mandatory testing of women.

Such mandatory testing tells us little about the true HIV status of an infant. The net result will be the further stigmatization of Black women who continue to be the only group for whom the rate of HIV - positive births continue to increase. Any advantage that will be gained by the identification of a hand full of individuals will be greatly outweighed by the gross violation of the mother's right to counseling and her right to decide the course of her health status. Additionally, the belief that merely informing mothers, identified through this method of detection of the possibility that their infant is HIV positive will automatically lead them to seek treatment is an ideal situation which would probably only hold true in a utopian society. Many people who actively seek testing do not follow through with treatment until it is absolutely necessary. The law of averages are against us here.

It is the contention of the Long Island Minority AIDS Coalition that all pregnant women and all women contemplating pregnancy should be counseled as to the risk behaviors associated with HIV, the potential risks of HIV positive mothers transmitting HIV to infants including the risks associated with breast feeding and the availability of testing. A vast majority of women would be reached though these interventions. In the cases where these scenario cannot be played out, LIMAC strongly supports expanded, aggressive voluntary HIV testing programs like the program implemented at Harlem Hospital, which has a 95 percent success rate in obtaining informed consent for HIV testing. We are in good company in our belief neither the CDC, the American Academy of Pediatrics nor the Institute of Medicine endorse mandatory screening.

In addition, according to the information presented at this subcommittee's first meeting, an acceptable testing program would cost approximately an additional 0.145 million dollars with a net effect of identifying 6 additional HIV positive persons 5 of whom would be mothers, in a given 1 year period. It is obviously more cost effective to prevent new cases of infection than it is to identify these new cases. As advocates for the minority populations of Long Island, it is our contention that prevention efforts targeting high risk

populations, would be a more viable and logical alternative to mandatory screening, given the scarcity of resources.

(18)

AIDS ADVISORY COUNCIL
SUBCOMMITTEE ON NEWBORN SCREENING

TESTIMONY OF
DEBRA FRASER-HOWZE
EXECUTIVE DIRECTOR/CEO
BLACK LEADERSHIP COMMISSION ON AIDS

NOVEMBER 8, 1993

My name is Debra Fraser-Howze and I am the Executive Director & Chief Executive Officer of the Black Leadership Commission on AIDS--the oldest and longest surviving public policy, advocacy, research and community development agency focused solely on communities of African descent. The agency's chief mission is to organize Black leadership across this city, state and nation on HIV/AIDS related issues.

The 65 members of the Commission consist of clergy, politicians, social policy, business and medical experts who have a daily outreach capacity to 2.5 million people of African descent across the state of New York. On behalf of this organization that has singlehandedly brought more than 750 Black churches to the HIV/AIDS epidemic from disparate philosophical issues to providers of service and has helped to access upward of $11 million for Black organizations working in AIDS, I am here today to discuss the "unblinding" of the HIV status of newborns and the effects this will have on us as a people and the current health care system. In all its good intentions, this system remains the most racist and benignly neglectful system in the universe.

In 1987, when it was formed, the Black Leadership Commission on AIDS {BLCA} began to ask questions regarding policies that were established in the early 1980s--to service a very different infected population. The primary question was: Do these policies and programs established for the White, gay male majority still stand to service the growing number of people of color who are increasing in numbers among those infected with HIV? Today, six years later, when AIDS has become the first disease to kill multiple generations of the same race of people, SIMULTANEOUSLY, across two continents, we can no longer passively examine AIDS policies. We must dissect them; turn them inside out; use our real experiences as the litmus test, and where we see the need for change and the allocation of dollars to effect this change, we **must** demand it!

The policies now in affect around newborns and their mothers must change, but they must change for the betterment of all and **not simply for the egos of some.** And it is in these days that common sensitivity, rationalized and illustrational behavior are most needed and the days I miss Dr. Nick Rango the most.

You are having discussions today about an issue that has two sides.

(1) Is it critically important to the health of the mother and child to know if a baby and mother are both HIV+?

(2) Is it not critical in standards of care for this information to be revealed?

But this, as most AIDS issues, is once again being fought out by the " AIDS community"

and its various factions that have little to do with this mother and child. Some are members of a Gay white male structure that has institutionalized an epidemic and must keep their financial and moral obligations to the groups for which they advocate--be damned the public health impact on people of color, particularly women and children. Some are white lesbians who never got a chance to play a meaningful role in the AIDS epidemic, so their white woman maternalism/paternalism says, "this is it!"

And then there are others of us--those that I hope are in this hearing now--who want to be rational, good thinking, caring, and professional providers of every sex, race or sexual orientation. These are those who care so much for the people this policy will affect that we will fight tooth and nail to get the right thing done.

The point here is no matter how good-natured, we are all still doing the wrong thing. We are here debating with each other, and little has been heard from the women and children who will really be impacted. So I share with you two perspectives.

In one of our more recent focus groups, a women named Sally sat in our board room and listened to us describe for her why, if she went to bed with a man who was HIV+ and the public health system knew she was at high risk by coming in contact with the virus, they would not tell her. It all boiled down to an issue of privacy and the avoidance of discrimination.

She looked at me and said, "Debra you mean if I am at risk for AIDS because somebody

I gave some to had it, you would not tell me so that I could get tested and if I am going to die, find someone to care for my five children because of privacy? When I go down to the welfare every six months with my life in a paper bag to get recertified for a check, I have no privacy! **If you do this to me what rights do you have to keep information from me that could help my babies."**

And Sally is right. So a system has to be designed in some way for Sally to get the information she wants, because she has a right to it, plain and simple!

But in the same vain Sally--a Black, single, welfare mother of 5--also knows the "the rush of white folks" to chew us up and spit us out because ***they are all in the Kool Aid and don't even know the flavor.***

That's what mandatory testing is for Sally - being all in the Kool Aid and not even knowing the flavor. If you want to be in the Kool Aid and know the flavor, then you should know that Sally cares as much for her babies as you care for yours.

If you have no babies, you can still be in the Kool Aid but not as a child advocate who does not take into account the importance of this mother to the survival of this child. And the most important thing to consider is the survival of this mother for the other children in the household and the survival of this mother for the communities I represent.

You will and must think about her, respect her and give her care within the context of the hippocratic oath that says: First do no harm! If you do not, we promise to organize a movement of the sisterhood in this state, like New Yorkers have never seen before, in opposition to the cruel and inhuman circumstances of telling a woman she has a fatal disease and that her child tested positive for the same virus that she has and may not make it. All of this will be happening while she is lying in the hospital trying to figure out how she will survive with this new life she created under great emotional and financial stress. She's resting her head on a pillow with no case, lying on sheets long ago stained, sharing a toilet with six profusely, bleeding women in a health care facility that won't even provide her paper slippers for the cold floor.

This is not a real health care system. This is torture, and if you seek to add torture to this clearly painful condition, which spells out that we are already at the bottom of the belly of the beast, then you have **no compassion**; you care not about the hippocratic oath, and you should get out of health care. We cannot fix hospitals with this issue, but this should provide an opportunity to start.

(19)

TESTIMONY TO THE SUBCOMMITTEE ON NEWBORN SCREENING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL ON NOVEMBER 8, 1993

CAROLA MARTE, M.D.
BETH ISRAEL MEDICAL CENTER

In the debate on parturient and newborn testing I believe that we all agree on the pivotal issue: access to care for the mothers and for their newborns. And access to care for the mothers carries with it also our concern for their other children and for future newborns.

The question is, what works? What will bring as many as possible of the infected children into care? Will unblinding the newborn study, or some other form of mandatory testing necessary? Or will voluntary testing, with targeted counselling to pregnant and parturient women, be more effective in achieving this goal? A goal, again, which we all agree is of utmost importance.

I base my recommendations, which are in favor of increased and improved voluntary counselling and against mandatory testing in any guise on the following information and experience.

We know that if testing -- testing with sufficient and appropriate counselling -- is offered, it is accepted by a large number, by most women. There are members of this panel who have developed highly successful counselling and testing programs for pregnant women. We also know that mandatory programs do drive away a certain number of persons -- what proportion in any given situation is not predictable -- drive them away from utilization of services. I am sure you have been given documentation of both these experiences by other speakers.

I will speak from my own particular experience. I am a physician who practices in and develops programs for substance users and former substance users who have <u>never</u> had medical care and who already carry a burden of distrust and suspicion about HIV and the medical system. In focus groups and individual interviews, stigmatization in the health care system is given as the primary reason for not seeking or for refusing HIV care, and distrust in the availability of acceptable HIV care is the reason for not being HIV tested. Many, especially from the African American community, also believe that, understood in the context of the Tuskegee syphilis study, HIV is a racist government plot.

My concern is that the women we would most like to reach will become most inaccessible once they have left the hospital as post-partums. I am also concerned that down the line the job of getting women into prenatal care in the event of future pregnancies will become even more difficult. At the same time, I know from my own experience in working with mothers of HIV infected children that most -- not all, but nearly all -- of these mothers, drug users or otherwise, are fanatical about taking care of their children. I

saw this first at Bellevue when I served as an internist in the pediatric Infectious Disease Clinic trying to draw the mothers into care for themselves. This was a formative experience for me. I see it now every day as I work directly with chemically dependent women.

I believe we must find the means to offer the women the care they really do want for their children. The problems with access to care for newborns, as for women and many others in our quirky health care system, is one of distrust and especially inadequate resources, not one of noncompliance. (A noncompliance which requires credence in a Reagenesque stereotype of a drugged out welfare mother. This is unfortunately a stereotype that our media are sometimes willing to purvey.)

Mandatory testing will simply delay and probably worsen the problems we are already having of providing adequate health care to HIV infected newborns (that is, better access to care than newborns under our current health care system routinely have). Mandatory testing will only push back the problem by one step because it does not get an infant to all his or her appointments nor maintain ongoing health care after that HIV test.

On the other hand, I also know of the extent of the problem from my experiences working with a methadone program. If voluntary counselling and testing is the best strategy, it needs to be where the women are. I had occasion to review the charts of women who were reported pregnant in one methadone clinic in the course of a year. In this particular period, all were cocaine (and polysubstance) users and none had prenatal care. Interviews and chart review in this clinic have told us that crack/polysubstance use, BCW interventions, psychiatric illness and lack of medical care are all far more frequent in HIV infected women. We therefore know from direct experience what our Health Department zip code maps tell us: namely, the confluence of poverty, unplanned pregnancies, HIV infection and chemical dependency in what epidemiologists refer to as a core population for an epidemic.

I can tell you that very little is being done to reach this population prior to the moment of childbirth. Our state and city HIV efforts do not include programs or special measures to identify, educate and offer counselling and testing to pregnant women in drug treatment centers. Why are we not offering HIV counselling and testing to every pregnant woman in drug treatment? Why is this service not funded and mandated, as it is for family planning centers? A large number of the unidentified HIV infected mothers we are discussing could be reached through drug treatment programs.

As much as has been done in this state to promote counselling and testing, including among pregnant women, it has not been nearly enough, and not always as efficient as it should be. Recently

gathered CDC data shows that 43% of HIV infected women receive an AIDS diagnosis only 2 months after being identified as HIV infected. Pure and simple we are not reaching the women in time, in time to help them, in time to help their newborns, in time to help all the children.

In a thoughtful editorial in the New England Journal in August 1992, Dr. Quinn reported the overall experience in Baltimore. Like that in New York State, it reflects increasing success as we have risen on the learning curve. However, their acceptance rates for HIV testing are 96% of hospital and 85% of STD clinic patients (a 20% increase in 2 years). [See attached reprint.] We need to study such experiences closely and learn from them.

Speaking more broadly, we also know that peer counselling and education are extremely effective. In fact, peer education and the media, especially television and radio talk shows, are so far the only demonstrably effective means of reaching into communities that are largely ignorant of the risk of HIV infection to women and children. And they can change that ignorance and the attitudes of distrust and fear that support it. We need to pay much more attention to these strategies before we blame the mothers and declare that unblinding the newborn results is the only or even the better solution to helping their children.

Lastly, but certainly not least, mandatory testing raises serious ethical concerns under any circumstances. Mandatory testing for special populations is untenable. And we can know with certainty that legislation will not settle the issue. Mandatory testing for pregnant women as a selected population will be assailed by women and by advocates everywhere and result in a lengthy and costly battle in the courts.

The role of professionals is to view the available data objectively in order to provide a rational and effective basis for public policy. It is our job to lead the policy makers and legislators away from succumbing to the current fashion of our litigious society in which the health and interests of mothers and children are believed to be adversarial, rather than the welfare of each being intimately bound to the other.

There is much work to be done in the HIV epidemic, and too few of us to do it. We are all exhausted, and I question the wisdom of spending our slender resources to join in a costly legislative and court battle when all of us in this room so clearly agree on the objective, and the evidence is there of how to accomplish it.

The New England Journal of Medicine

Owned and Published by the
Massachusetts Medical Society

SCREENING FOR HIV INFECTION — BENEFITS AND COSTS

Now in its second decade, the human immunodeficiency virus (HIV) epidemic continues to escalate relentlessly. Approximately 1 million people in the United States are infected with HIV, and nearly a quarter of a million have been given diagnoses of the acquired immunodeficiency syndrome (AIDS).[1] During the first eight years of the epidemic, 100,000 cases of AIDS were reported; another 100,000 were reported within the next two years.[2] AIDS has caused 150,000 deaths in the United States and is now ranked as one of the leading causes of premature death for both men and women in this country,[3] as well as in many others. The epidemic has penetrated many segments of our society. In particular, the incidence of new HIV infection and of AIDS continues to rise rapidly among women and minority groups in our inner cities, where financial resources and access to routine medical care are severely limited.

The early initiation of antiretroviral therapy for asymptomatic persons and of chemoprophylaxis to prevent opportunistic infections can delay the progression of HIV disease and increase survival. Yet there are substantial inequities in access to care for HIV infection. In Maryland[4] and San Francisco,[5] women and minority populations receive zidovudine significantly less often than men and non-Hispanic whites, resulting in marked differences in survival. Since it is likely that future therapeutic advances will involve even earlier treatment interventions, it is imperative that early access to care be provided to all HIV-infected persons to help reduce these differences in survival.

Unfortunately, one of the many tragedies of this disease is that most HIV-infected persons are unaware of their infection. Too often, such people learn of their serologic status only after an opportunistic infection or other serious HIV-related disease has developed. More than half of those with newly diagnosed HIV infection qualify for antiviral therapy at the time of their first serologic test for HIV, and a

PROSPECTIVE authors should consult "Information for Authors," which appears in the first issue of each month and may be obtained from the *Journal* Editorial Office (address below).

ARTICLES with original material are accepted for consideration with the understanding that, except for abstracts, no part of the data has been published, or will be submitted for publication elsewhere, before appearing here.

NOTICES should be sent at least 30 days before publication date.

THE *Journal* does not hold itself responsible for statements made by any contributor. Statements or opinions expressed in the *Journal* reflect the views of the author(s) and not the official policy of the Massachusetts Medical Society unless so stated.

ALTHOUGH all advertising material is expected to conform to ethical standards, acceptance does not imply endorsement by the *Journal*.

FOR information on subscriptions, permissions, reprints, and other services see the "Business Information for Readers" page preceding the Classified Advertising section.

EDITORIAL OFFICES: 10 Shattuck St., Boston, MA 02115-6094.
Telephone: (617) 734-9800. FAX: (617) 734-4457.
BUSINESS, SUBSCRIPTION OFFICES: 1440 Main St., Waltham, MA 02154-1649.

third of these also qualify for *Pneumocystis carinii* prophylaxis.[6] However, from estimates of the number of HIV-infected persons eligible for antiviral therapy[1] and from statistics on the current use of zidovudine, it appears that only 20 percent of eligible persons are receiving therapy. Testing on the basis of clinical suspicion or risky behavior has been insensitive, identifying only 30 to 40 percent of HIV-infected persons. At the Johns Hopkins Hospital, three fourths of the patients found to be HIV-positive on anonymous screening had unrecognized infection.[7] Because HIV infection is so often unrecognized, routine voluntary testing for HIV infection in medical clinics and hospitals, particularly in areas of endemic disease, is a rational approach to ensure that all HIV-infected persons receive adequate medical care and counseling. Routine voluntary testing means specifically offering HIV testing to all patients. This contrasts with routine testing, in which the test is performed unless there is a refusal, and with voluntary testing, in which patients must request the test. The necessary corollary to recommending routine voluntary screening is that financial resources for these activities must be increased. Future policies must reduce barriers impeding the coverage and treatment of all HIV-infected persons, not just those with AIDS.

There have been numerous articles, editorials, and commentaries in the *Journal* over the past five years debating the pros and cons of screening for HIV infection, and no simple recommendation will please everyone. On the one hand, it is in patients' interests to know their serologic status, so as to afford the opportunity for early intervention with antiretroviral therapy and for intensive counseling that might alter behavioral patterns and decrease transmission. On the other hand, HIV testing raises issues of confidentiality and discrimination, individual and social matters that must be addressed in any HIV-testing program. Physicians should work with legislators to forge antidiscriminatory laws that protect HIV-infected persons, and to provide additional funding for indigent populations that require better medical care.

To achieve the objective of identifying HIV-infected persons seeking medical care, Janssen and colleagues in this issue of the *Journal*[8] propose a national strategy for the HIV screening of patients at U.S. hospitals that would provide ready access to appropriate counseling, clinical referral, evaluation, and therapy. In a blinded serologic survey of patients at 20 hospitals in 15 U.S. cities, they found that hospital-specific HIV seroprevalence ranged from 0.2 percent to 14.2 percent and that nearly two thirds of seropositive persons presented with medical conditions other than symptomatic HIV infection or AIDS. Seroprevalence was consistently highest in men and women 25 to 44 years of age, with a rate of 40 percent in one hospital. Whereas infection rates were highest among those presenting with infectious or drug-related conditions, HIV infection was nevertheless widely distributed among those with a variety of presenting symptoms. Like previous investigators,[7,9] Janssen et al. found that nearly two thirds of HIV-positive patients presented with conditions apparently unrelated to HIV infection.

There are several aspects of the study that should be addressed. The hospitals studied were not randomly selected and were more likely than other U.S. hospitals to be in urban areas, to have teaching programs, and to have a large percentage of Medicaid patients. Despite these differences, the authors demonstrated that the AIDS-diagnosis rate was the only variable associated with HIV seroprevalence. The authors suggest that HIV testing of patients 15 to 54 years old in U.S. hospitals with an AIDS-diagnosis rate of 1 or more per 1000 discharges per year would identify 68 percent of all HIV-positive patients admitted with conditions other than AIDS. The authors appropriately caution that the predicted numbers of HIV-positive patients with unsuspected infection may be too high, since it could not be ascertained whether some of the HIV-infected persons were already known by their doctors to be infected. Nevertheless, these figures are remarkably similar to those from studies performed in other selected hospitals.[7,9] Although individual hospitals may wish to validate the association between HIV seroprevalence and the number of AIDS cases per 1000 discharges, the strategy offered by Janssen and colleagues provides a new formula for HIV screening that would be more effective than routine HIV testing of all hospital patients. The latter would entail screening five times as many people (25 million), with only a 20 percent increase in the identification of HIV-positive patients over the strategy suggested by Janssen et al.

Opponents of this strategy will suggest that screening targeted only to people who acknowledge high-risk behavior would be more cost effective. However, as shown in previous studies, many HIV-infected persons report in pretest counseling that they do not engage in high-risk behavior, and more than half of HIV infections may be missed.[10] Other opponents may suggest that the screening of hospitalized patients is designed primarily to prevent transmission of HIV from patients to health care workers.[11] The intent of screening for HIV should only be to identify persons with early HIV infection, so that they can receive appropriate counseling and therapy. Universal precautions remain the only policy for protecting health care workers from HIV transmission. In a recent study at the Johns Hopkins Hospital, my colleagues and I showed that routine screening for HIV alone would fail to identify over 80 percent of patients who pose a risk of transmitting other viruses, such as hepatitis B and hepatitis C viruses, to health care providers.[12]

Public acceptance of this policy will depend largely on how it is presented. Previous polls have demonstrated that 76 percent of those polled are in favor of routine voluntary testing. In a recent study at the Johns Hopkins Hospital, 96 percent of 351 patients admitted to a medical service, excluding the AIDS

inpatient service, agreed to HIV testing, and 15 percent of these were found to be seropositive (Munday L, Janis E: personal communication). Even in sexually transmitted disease clinics in Baltimore, 85 percent of patients now consent to testing, a 20 percent increase over the past two years (Baltimore City Health Department: unpublished data). It is evident that compliance with a screening program can be markedly enhanced with proper education and pretest counseling.

What are the obligations of the hospital? With routine voluntary screening it is the hospital's responsibility to protect confidentiality. There will be a need for additional counselors; facilities for comprehensive HIV evaluation, including appropriate laboratory support; and treatment services and referrals for those found to be infected with HIV. What must be avoided is a laissez-faire attitude toward counseling and testing, or the development of policies in which HIV testing is a requirement for admission or for invasive procedures. If HIV-antibody testing is to be offered routinely, appropriate consent procedures must be followed, and opportunities for education, counseling on risky behavior, and access to care must be provided. Since the assurance of confidentiality is an important factor in any testing policy, this transition would be eased substantially if appropriate federal antidiscrimination legislation were enforced and legal safeguards maintained.[13]

The goal of promoting widespread voluntary HIV testing that is based in the health care system is to inform all persons infected with HIV about their condition. This is a disease of great public health importance, and screening in the hospital setting has clear benefits, particularly in the light of the recent outbreaks of multidrug-resistant tuberculosis among hospitalized HIV-positive persons.[14] Identifying those who are HIV-positive early in their disease affords them the opportunity for reliable tuberculin skin testing and for the provision of antituberculous prophylaxis. This provides benefit to the patient, to the health care provider, and to other patients. With these benefits, however, there will be costs. Many facilities are already under stress, with increasing numbers of HIV-infected persons, a short supply of qualified counselors, and inadequate financial resources. A call for more screening must be accompanied by more resources to meet in full the challenge of caring for newly identified infected patients. Providing access to early treatment means enhancing ambulatory care systems, particularly in the inner cities, where the dearth of resources has limited the availability of high-quality health care.

Weiss and Thier[15] stated that the question "Why test?" must be fully addressed in any policy of HIV screening. Access to early therapy and prophylactic regimens, as well as repeated counseling to reduce further transmission, clearly benefits the patient and society. Increased voluntary testing in health care facilities appears to be the most rational approach to achieve these objectives. With all the improvements in survival and quality of life for HIV-infected persons, it is imperative that patients be given the opportunity to be routinely counseled and tested for HIV. In the end, the patient benefits, the medical profession benefits, and society benefits, but it must be recognized that this benefit is not without certain costs. More financial resources at the local, state, and national levels will be needed and must be made more readily available if we are to meet this obligation.

National Institute of Allergy
and Infectious Diseases
Bethesda, MD 20892 THOMAS C. QUINN, M.D., M.Sc.

REFERENCES

1. HIV prevalence estimates and AIDS case projections for the United States: report based upon a workshop. MMWR Morb Mortal Wkly Rep 1990;39 (RR-16):1-31.
2. The second 100,000 cases of acquired immunodeficiency syndrome — United States, June 1981–December 1991. MMWR Morb Mortal Wkly Rep 1992;41:28-9.
3. Mortality attributable to HIV infection/AIDS — United States, 1981–1990. MMWR Morb Mortal Wkly Rep 1991;40:41-4.
4. Moore RD, Hidalgo J, Sugland BW, Chaisson RE. Zidovudine and the natural history of the acquired immunodeficiency syndrome. N Engl J Med 1991;324:1412-6.
5. Lemp GF, Hirozawa AM, Cohen JB, Derish PA, McKinney KC, Hernandez SR. Survival for women and men with AIDS. J Infect Dis 1992;166:74-9.
6. Hutchinson CM, Wilson C, Reichart CA, Marsiglia VC, Zenilman JM, Hook EW III. CD4 lymphocyte concentrations in patients with newly identified HIV infection attending STD clinics: potential impact on publicly funded health care resources. JAMA 1991;266:253-6.
7. Kelen GD, DiGiovanna T, Bisson L, Kalainov D, Sivertson KT, Quinn TC. Human immunodeficiency virus infection in emergency department patients: epidemiology, clinical presentations, and risk to health care workers: the Johns Hopkins experience. JAMA 1989;262:516-22.
8. Janssen RS, St Louis ME, Satten GA, et al. HIV infection among patients in U.S. acute care hospitals — strategies for the counseling and testing of hospital patients. N Engl J Med 1992;327:445-52.
9. Lombardo JM, Kloser PC, Pawel BR, Trost RC, Kapila R, St Louis ME. Anonymous human immunodeficiency virus surveillance and clinically directed testing in a Newark, NJ, hospital. Arch Intern Med 1991;151:965-8.
10. Castro KG, Lifson AR, White CR, et al. Investigations of AIDS patients with no previously identified risk factors. JAMA 1988;259:1338-42.
11. Brennan TA. Transmission of the human immunodeficiency virus in the health care setting — time for action. N Engl J Med 1991;324:1504-9.
12. Kelen GD, Green GB, Purcell RH, et al. Hepatitis B and hepatitis C in emergency department patients. N Engl J Med 1992;326:1399-404.
13. Angell M. A dual approach to the AIDS epidemic. N Engl J Med 1991;324:1498-500.
14. Edlin BR, Tokars JI, Grieco MH, et al. An outbreak of multidrug-resistant tuberculosis among hospitalized patients with the acquired immunodeficiency syndrome. N Engl J Med 1992;326:1514-21.
15. Weiss R, Thier SO. HIV testing is the answer — what's the question? N Engl J Med 1988;319:1010-2.

HEPATITIS A VACCINE

THE first effective control measures for the prevention of enterically transmitted viral hepatitis resulted from research conducted during World War II. In 1945, Neefe et al.[1] demonstrated that infectious virus could be transmitted by contaminated drinking water, that treatment of the water by filtration and chlorination made it safe to drink, and that gamma globulin derived from convalescent-phase serum from patients with hepatitis could protect adults from clinical hepatitis.[2] Except for refinements in methods of preparing food and water and the establishment of standards for the preparation and use of immune globulin, there

(20)

TASK FORCE ON WOMEN & AIDS

NOVEMBER 8, 1993

Dr. Rogers, Dr. Britton, Dr. Haggerty, Members of the Council Sub-Committee:

Thank you for the opportunity to present testimony before you today.

My name is Elizabeth B. Cooper. I am an attorney in the Gibbons Fellowship in Public Interest and Constitutional Law at the law firm of Crummy, Del Deo, Dolan, Griffinger & Vecchione and I am here today on behalf of the New York Task Force on Women & AIDS. The Task Force is a coalition of physicians, nurses, social workers, psychologists, researchers, administrators, lawyers and advocates. We work with HIV-infected and affected women in health centers, city and voluntary hospitals, jails, methadone clinics and the streets. We have joined together in an effort to create a comprehensive approach to the needs of women in the HIV epidemic. Our commitment is to the provision of culturally appropriate, accessible health and social services that foster women's abilities to manage their health care needs.

The Task Force strongly opposes any effort to "unblind" the newborn seroprevalence study or any other plan to mandate HIV screening of newborns, pregnant women, or parturient women.

While we admire, and in fact, strongly support the principle that HIV-infected newborns must be provided with health care, mandating HIV testing will only undermine this goal by chasing women of childbearing years away from the health care system. Mandatory testing programs will not accomplish the goal cited by many of its supporters: they will not facilitate entry into care for newborns with HIV infection.

If the seroprevalence study is unblinded, the State will, in effect, be instituting a mandatory HIV-testing program for delivering women. Our extensive experience throughout the eleven years of the AIDS epidemic establishes that mandatory testing programs serve only to discourage people from seeking

HIV-related care and services, and health care generally.[1] Mandatory programs will rightly be viewed as selective and repressive by women and therefore counterproductive to the goal of increasing their use of health care services for their children and themselves.[2]

Through the imposition of a mandatory testing program, the State will have interposed itself between the mother and her child with the message that the State is a better caretaker

---

1 Consider, for example, the sharp decline in marriages in the State of Illinois after it mandated HIV testing as a pre-requisite to obtaining a marriage license in that State. Telephone conference with Aimee Berenson, Legislative Council, AIDS Action Council, Washington, D.C., November 1993, reporting citations in Areen, Family Law: Cases and Materials, 3d Ed., 1992, including: Wilkerson, "Pre-nuptual AIDS Screening Taxes Illinois Health System," New York Times, January 26, 1988, at A1, col. 1; Taylor, "Illinois Law Offers A Futile Exercise in Combatting AIDS, Chicago Tribune, September 8, 1989, at C27; Endstad, "AIDS Test Has 40,000 Fleeing State to Wed," Chicago Tribune, January 4, 1989, at C1. This legislation ultimately was repealed. Ill. Public Act 86-881, September 1989. Further consider the data that disproportionately high testing rates occur at anonymous test cites located over the border from states with mandatory HIV-name-reporting. AIDS Action Foundation, "Should HIV Test Results Be Reportable: A Discussion of Key Policy Questions," March 1993.

2 Mandatory testing programs will create incentives to women to give birth at home (and avoid the health care setting, the locus of the mandatory testing program), thereby creating even greater risks to the health of the mother and her newborn. Moreover, as women avoid the health care setting, the efficacy of the newborn serosurvey will be undermined.

than the mother. This mode of State intervention is unacceptable, particularly as it sets the stage for broader intrusions of the government into the lives of women and their children.

Concern over such intrusions -- particularly the removal of children to foster care -- historically has worked to discourage women from seeking services that might otherwise be beneficial to them or their families. As such, implementation of a mandatory testing program would create a further barrier to health care and would have a significant negative impact on children, first and foremost, as well as on their mothers.

Women also will rightly fear that if they are HIV-positive, the State will criminalize their choosing to have a child, or, that if their children are truly HIV-infected, they may be prosecuted for transmission of HIV (in much the same way that women have been charged with violating drug statutes when their children are born with drug metabolites). Such fears are not unrealistic.

Consider, for example, the prosecution of a young woman in North Carolina. C.M. is an African-American woman in

her early twenties. It is alleged that she has actively used drugs and has been a prostitute for many years. C.M. has been dependent on government assistance for most of the last many years and, as a result, has sought health care services at the county clinic. C.M. had two successful pregnancies before her third child died shortly after birth. It is alleged that the third child had tested positive for the presence of HIV antibodies and that when C.M. was tested shortly thereafter, she also tested positive.

County officials claim that they gave repeated warnings to C.M. that whenever she was to have sexual intercourse, she had to reveal that she was carrying infectious agent and she had to use a condom. County officials further assert that despite repeated warnings, C.M. generally did not comply with their public health order. There is some evidence, however, that C.M. functions at a level slightly above a classification of mentally retarded.

In early 1992, C.M. told a county health nurse that she thought she might be pregnant. When C.M.'s pregnancy test came back positive, the county sought and obtained a warrant for her arrest. C.M. was prosecuted for failure to follow public health warnings; the evidence against her consisted of

statements of the county health officers and the fact that she had gotten pregnant. C.M. was sentenced to two years in jail.[3]

We call upon you to acknowledge that mandatory testing for parturient women is unacceptable, prejudicial and demeaning to women. Because testing newborns reveals the serostatus of their mothers, mandatory programs would selectively remove the right of informed consent for HIV-antibody screening of delivering women. It is unconscionable for informed consent --- a value so highly regarded in other areas -- to be dispensed with only for women who have just given birth. Moreover, when care for newborns alone replaces care for both mother and child, a woman's role becomes exclusively that of carrier and deliverer of the newborn. The role of health care in the woman's own life simply does not seem to be a priority for those who seek to impose a mandatory testing scheme. Quite

---

3 E.B. Cooper, "When Being Ill is Illegal: Women and the Criminalization of HIV," HEALTH/PAC Bulletin, Winter 1992, at 10, and citations therein. Convictions under any other misdemeanor generally result in serving 15 to 30 days. C.M.'s statements that she became pregnant when a condom broke were ignored. In addition, prior to trial, C.M. obtained an abortion and a tubal ligation; she has indicated that she took these actions, at least in part, to appease public health officials. Id.

plainly, mandated testing is unacceptable and, in all likelihood, illegal.

Implementation of mandatory, unblinded perinatal HIV-testing will be contested as a violation of women's constitutional rights to privacy, to equal protection, and against unwarranted search and seizure; a challenge also will lie in the laws that require proper counseling and specific, written, informed consent prior to testing and laws that protect the rights of persons with disabilities. The State will need to defend its position that only parturient women as a class are exempted from the principles contained in that law. While the State's interest in assisting newborns is high, the State will not be able to establish that a mandated testing program will allow the State to attain this goal; nor will the State be able to show that this program is the constitutionally-mandated "least restrictive alternative" available to meet the State's otherwise laudable goal. As such, an approach that incorporates mandatory testing will not sustain this legal challenge.

Moreover, transforming blood samples taken for blinded serosurvey research into blood samples used for diagnostic purposes, linked to the identity of an individual patient, is

likely to violate State statutes (see, e.g., N.Y. Public Health Law § 2780, et seq. (McKinney's Supp. 1993); N.Y. Public Health Law § 2441, et seq. (McKinney's 1985); 45 C.F.R. §46.101, et seq. (1993)) and certainly contravenes ethical standards regarding the conduct of research.

To the extent this proposal also allows disclosure of test results to the newborns' father, this program further would be a gross violation of parturient women's constitutional right to equal protection, statutory right to confidentiality, and, perhaps most disturbing, will place hundreds, if not thousands, of women at risk for domestic violence. As increasingly has been noted by researchers, the disclosure of a woman's positive HIV status to her partner subjects the women to potential violence from her partner.[4]

Moreover, it would be particularly suspect for the government to consider instituting as its first mandatory testing program one that will burden primarily low-income women

---

4 R.L. North and K.H. Rothenberg, "Partner Notification And The Threat of Domestic Violence Against Women With HIV Infection," 329 New Eng. J. Med. 1194 (October 14, 1993); Telephone Conference with Sally Zierler, Dr.P.H., Associate Professor of Medical Science, Deptartment of Community Health, Brown University, November 1993.

and women of color and one that will further distance these women from health care institutions. This discriminatory approach to HIV-testing policy cannot be condoned. Instead, we all must focus on the most effective means of getting both child and parent appropriate health care. We must ask: "How do we ensure access to care and early intervention for children and their mothers -- in the context of HIV and generally?" In this light, unblinding the newborn seroprevalence study is neither practical nor ethical.

Experience has shown that when offers of HIV-testing are linked to the actual provision of services, individuals consent to being tested; this is as true for pregnant and delivering women as it is for all others. Those of us working in high-prevalence areas further have found that when health care services are truly available, patients do understand the importance of HIV testing and accept such testing for themselves and their children.

For these many reasons, we encourage the State to further enhance its programs that focus on increasing access to care and case management for both mother and newborn. Specifically, we recommend that the State survey those programs that effectively provide HIV counseling and testing options and

facilitate access to appropriate care and services. Winning elements of these systems should then be replicated in facilities throughout the State. The best approach to preserve life and to improve its quality is the provision of counseling and care services to all. A voluntary program, building from successful elements of existing models of care, is our best place to start.

* * *

The Task Force would like to comment on one other aspect of the prospect of unblinding the seroprevalence study. Recently, we have heard discussion of an alternative, so-called "voluntary" program, that while not before the Sub-Committee, is nevertheless an appropriate subject for testimony. This program would provide parturient women the option of learning the results of the "blinded" serosurvey test after the test has been conducted.

The Task Force has long held the position that such a program is not a viable "compromise," but is, in fact, a

back-door means of unblinding the seroprevalence survey.[5] For the reasons stated above, and for the additional reasons set forth below, such a proposal is not a viable alternative.

First, such a program would violate established federal and state constitutional standards regarding consent to the "search and seizure" inherent in the drawing of blood and its processing in laboratory analysis. Because the serosurvey currently is conducted as an anonymous, or unlinked study, a mother need not provide consent to the taking of the blood sample and its processing. However, once we enter the realm of non-consensual blood testing, the protections of the Fourth and Fourteenth Amendments to the Federal Constitution come into play. If the State takes blood for one purpose, i.e., the

---

5 The Task Force opposed this approach to testing the first time it was proposed in 1989. Due in large part to the advocacy of diverse communities the first time this "after-the-fact" disclosure proposal was suggested, the State's seroprevalence study was constructed in such a way that it cannot be unblinded. Therefore, not only has this proposal already been rejected by the State, its adoption would require the State to re-visit and re-construct the entire structure of how the seroprevalence tests are run and processed.

conducting of an anonymous serosurvey, but then wishes to use it for another, i.e., the linking of results with identified individuals, we argue that the State must obtain the woman's consent prior to the blood's being drawn; otherwise, the State will be violating her constitutional rights to be protected against unconsented to search and seizure. Indeed, such taking and processing of blood would be a stark intrusion on these vital constitutional rights.

Second, even if "counseling" is provided with the unblinding option, this approach is likely to violate the strong mandate for pre-test and post-test counseling contained in the State's Confidentiality Law and broadly recognized as being a critical aspect of facilitating both a seropositive person's entry into healthcare and prevention efforts. Abrogation of counseling responsiblities, or the adoption of unduly directive counseling techniques (which, one might argue is inherent in this approach), would not comply with the letter or spirit of our State's law, a law developed with the considered expertise of those providing psychological and physical care for people with HIV/AIDS.

In this context, it further is likely that a plethora of legal challenges will be generated as to whether full,

voluntary, informed consent has been provided; it is possible that the volume of such challenges would undermine the functioning of this type of testing program. Moreover, and most important in terms of those advertising the efficacy of this approach, by insufficiently accounting for the woman's needs, entry into care for both mother and child will not be facilitated. Fundamentally, this approach precludes the type of pre-test and post-test counseling that has been securely safeguarded by the State in virtually every other context.

Third, such a program likely will be experienced and perceived by parturient women as a form of mandatory testing. Therefore, the concerns outlined above regarding parturient women's alienation from the healthcare system do not disappear under this proposal. Regardless of whether one considers such perceptions (or experiences) to be reasonable, the impact will be such that women and their newborns will not receive the kind of care and services they need and deserve.

Finally, if the Sub-Committee were to seriously consider such a proposal, it would have an obligation to the people of the State of New York to hold hearings on this issue. Indeed, its adoption is not a minor matter, or a mere compromise that protects the interests of women and their

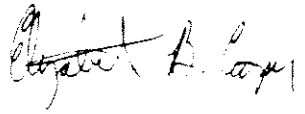
newborns; rather, it is a matter of significant concern -- and severe ramification -- to the women and children of the State of New York. They deserve the opportunity to have their voices heard on such a proposal.

* * *

Unblinding the seroprevalence study, or otherwise mandating the testing of pregnant or parturient women or their newborns, would send the clear message that New York State is more concerned with mandating testing than with mandating -- or even facilitating -- access to care. Neither the children nor the women of this State can afford for you to make such a choice.

Moreover, it would be a truly fatal mistake to institute any program that creates additional disincentives to accessing pre-natal and post-natal health care. Those who will lose the most in those circumstances are those on whose behalf advocates of unblinding profess to wish to protect: the children. As a society, we cannot afford to make this mistake.

For the Task Force on Women and AIDS



Elizabeth Cooper, J.D.
Gibbons Fellowship in Public Interest and Constitutional Law; Crummy, Del Deo, Dolan, Griffinger & Vecchione

Anitra Pivnick, Ph.D.
Montefiore Medical Center

Donna Futterman, M.D.
Montefiore Medical Center

Sally Guttmacher, Ph.D.
New York University

Tracie Gardner
Gay Men's Health Crisis

Jayne Berrier, M.A.
Medic Aware, Inc.

Cynthia Schneider, J.D.
Lauren Shapiro, J.D.
Tanya Hernandez, J.D.
Brooklyn Legal Services, Corp. B

Kathryn Anastos, M.D.
Bronx-Lebanon Medical Center

Carola Marte, M.D.
Beth-Israel Medical Center

Yvonne Chambers
Susanna Yurick
Women and AIDS Resource Network

Alma Gomez, J.D.
ACLU AIDS Project

S. Helen Daniels, M.S.W.
Upper Manhattan Task Force on AIDS

Audrey Jacobson, M.D.
Montefiore Medical Center

Vicki Peters
Mt. Sinai Hospital
Public Hearing • November 8, 1993

Transcription 21

The incidence of four diseases included in newborn screening are for: tyrosine anemia greater than 1 in 3,000; galactosemia 1 in 60,000; phenylketonuria 1 in 14,000; hyperthyroidism 1 in 4,000. This is in contrast to the incidence in infants born in New York City of perinatal exposure to HIV which is 12.5 per 1000 -- HIV infection 2 per 1000. The number of HIV exposed children who are born each year in New York City is estimated to be 1,800 and the number of HIV infected children to be 350.

Early diagnosis of HIV infection allows for the early institution of preventive measures such as the use of [bactrim] to prevent PCP, which is a life-threatening infection affecting young infants in the majority of cases, childhood immunizations appropriate for HIV exposed and infected children, antiretroviral therapy, nutritional support, etc. Children who present with an AIDS-defining condition, which is often the case, cannot benefit from these preventive measures. Unblinding of newborn screening must be accompanied by education of health care professionals, available resources to treat children and families who many times learn of their diagnosis of HIV infection when the child is diagnosed, availability of laboratory tests to differentiate HIV exposure and HIV infection. And along with unblinding of newborn screening a concerted effort must be made to prevent the spread of HIV infection to the population and to educate HIV infected women about the risks of perinatal transmission. And continued secrecy cannot prevent the spread of HIV infection.

Phyllis Sharpe
Woman Living with HIV
Public Hearing • November 8, 1993

Transcription (22)

My name is Phyllis Sharpe. I'm HIV positive and so is my little girl. I disagree with this testing the babies immediately after birth. The mothers should be asked, should be counseled before and during the pregnancy -- with this I do agree because me and my little girl's living with AIDS. I would have liked to known during the pregnancy but the lifestyle I was living, I didn't even have time to take care of myself. But I know that had they presented that to me after giving birth, it wouldn't have helped my mental status any. And I don't think that it would help any other mother that just gave birth, because basically being a mother of six I know all mothers, regardless to what lifestyle you living, care about your baby.

I really believe counseling and other agencies should be in place to get this information available to the mother that's carrying the child. If she wasn't present, like myself -- I just never went to prenatal care, I just went in to have a baby -- I should be counseled by someone like myself -- maybe another woman living with HIV with a baby to let me know its not as bad as it seems but it's the right thing to do to get the proper care for the baby, also to have it tested to see. Or maybe a mother who gave birth who didn't know she was HIV positive.

Recently one of my daughters, 27 years old, had a nervous breakdown during her pregnancy. Now if this was to occur upon her giving birth to the baby -- which she loved but had a little problem -- it would have just sent her totally out of her mind -- just to come and tell you that your baby's HIV positive. I think it's unhumane, unless a person that you actually feel doesn't have any senses to make judgement for themselves, that's the only time I see that this would be appropriate, otherwise I think it's totally wrong, even though that information should be known to the mother. Because like I said, my little girl is HIV positive, and I didn't find out until she was 18 months old. Gee, many a day I sit and I wonder, if only I had known earlier, even though she's in good health. But all that 18 months that information was unknown to me because I didn't know the proper channels to go through. That's what I'm saying, that would really make a mother as a very devastating thing to hear that yourself or much less your child is HIV positive. People just get diagnosed go through denial. Can you imagine what it is for a mother to find out that her baby is HIV positive? Just abruptly like that?

Basically that's all I have to say. I think it's wrong.

Patricia Benoit
Executive Director
Haitian Women's Program
Public Hearing • November 8, 1993

Transcription 23

We're a small community-based organization that provides HIV/AIDS prevention education to the Haitian community, and we're also providing support services to HIV infected women and women with AIDS in the community. I'd like to paint sort of a general global picture of our community, because as you all know HIV infected women do not live in a vacuum -- they live in a community, they're part of that community and are influenced by other members of the community and like other members of the community we feel that it is vital that they have access to information, to education about medical issues.

As you all know, our community has been subjected to special treatment. The special treatment started when the federal government decided that just because of who we are, not because of anything that we do, we were at high risk for contracting AIDS. Now, that's an incredible prevention message to send out to the community -- means that since I can't do anything about who I am, I might as well not do anything, right, because I can't change where I'm from. Luckily, the community reacted against that message and realized that it was just a question of scapegoating and political targeting. But because of that message we've had to pay a price and the price is collective denial of HIV and AIDS.

Now, that collective denial has been reinforced by another special treatment that we recently received. As you all know, 140 HIV plus refugees and their families were detained in Guantanamo by the federal government simply because of their seropositive status. They were admitted, they were screened as to their legitimacy for political asylum -- they were allowed to enter the country to request political asylum but they were denied entry because of their status. This is another message sent out to the community and we hear it every day: if you're Haitian, if you're HIV plus, bad things will happen to you, your human rights will be violated.

Now I want to talk about something else. As you can imagine, this special treatment really complicates the effort of an organization like ours and other organizations to provide information in the community; it adds an extra barrier. Another barrier to getting adequate information is the fact that many people in our community have not had the luck of having access to educational institutions and medical institutions in Haiti, so that when they come here they have had no experience with these institutions. Many people have never even seen a doctor, they've seen an herbalist, but they've not seen a mainstream doctor. And because of that they need education about basic medical services and they also need education, obviously, about a specific disease like AIDS.

Contrary to the general belief that I hear out there, I hear this over and over in conferences, that we are "beyond" getting information out there -- everybody knows everything about

AIDS, we have to get into behavior. That is not true. It simply is not true for our community. Many people are still not informed about the disease, because of their low literacy levels, because of their lack of fluency in English, they're not informed. Now, what does this mean? If we're talking about HIV infected women and their children and we're talking about testing, obviously before you're going to get tested you need information about the test. Of course, we believe that testing must mean access to services. To get access to services you need information; you need to have information in order to make an informed choice about these services and if you are a seropositive woman you need information about making an informed choice about whether to get pregnant or not, obviously. And this also means that these women need enhanced access to services by linkages done by people who can continue the process of education, people who can do it in a culturally-specific manner and in a language-specific manner -- not French, Creole. I still here today doctors who talk about giving services to Haitian patients in French. Everyone in Haiti speaks Creole. Some people speak French -- if you had the luck of going through the educational system you speak French, but everybody speaks Creole.

I want to also again put further emphasis on the need for education. We're a small CBO -- we're the only CBO who gets funding from the AIDS Institute to do prevention and now we're doing support services. And in case of the HIV positive women its also important, because as you all know, these women go back home. They see their friends and their family. And if the general impression in the community is "you're being scapegoated," or if there's mistrust in the community, which their is, concerning authorities, concerning doctors because of that Guantanamo treatment, and because of the stigmatization, this is then reinforced in the outside world so that what can happen if the approach is focused on the woman is that the woman will go to a hospital and might receive wonderful care and support services from Creole-speaking staff, she will then go back into her community and her boyfriend or her mother and her father and her Grandmother will negate the information she's received. We see instances, for example, of seropositive women who go in and out of believing their status and in and out of believing the status of their children -- when the child is well they no longer believe that the child is infected, then the child is sick and they believe that the child is sick. So you can imagine the repercussions of this in terms of self-protection and protection of the community at large.

I also just wanted to say one thing about anonymous testing. Obviously, we're not in the special medical environment where there's follow-up for the child and follow-up for the mother. And there has to be follow-up for the mother, not just the child. We've had instance of mothers being taken to a clinic in the Bronx and services were offered for the child but not for the mother -- you know, transportation services were offered for the child and not for the mother, which is a problem. We firmly believe that for the community at large and for the potentially seropositive mother there needs to be anonymous testing because of the fear and distrust of authorities and because of the fact that we have all learned in the community that very bad things can happen to you when you are seropositive and Haitian and it takes a lot of work and a lot of support to convince people to accept care. Thank you.

Lenora Sobers
Women and AIDS Resource Network
Public Hearing • November 8, 1993

Transcription 24

I'm here basically to share some of the experiences that we have at WARN as it relates to this issue. First let me tell you about Women and AIDS Resource Network. We have been around between 8 and 9 years. The organization was created to support women who are HIV positive and their families as well as women who are affected. Our mission is to empower women and serve them with dignity -- to look at creating quality of life in dealing with HIV and AIDS.

We serve a variety of women from ethnic backgrounds, however, most of the women that we serve are women of color from very disproportionate socioeconomical background. Oftentimes, these women have nowhere to go, no one to talk to, and are very afraid and scared of reaching out to the larger establishments. We provide these women with supportive services, case management, individual services, group services, advocacy, referral services, and other special projects. We encourage these women, as I said before, to deal with the issue as it comes to educating them to understand what it is to live with HIV positive.

We feel that the unblinding of the seroprevalence test would be very harmful to these women, particularly because we work hard for them to understand or to help them be educated on what it is to be HIV positive and all the stigma that that encompasses in terms of being positive and living in this society. Oftentimes these women have children, they're unprepared in sharing or disclosing this information. They have partners who they're terribly afraid to share when they're positive. As a result, what we're experiencing at WARN is women coming in saying that they do not know how to share with their partners that they're positive. Who do they turn to? Where do they go to get this kind of support?

What we find that if this law is passed it will create lot of disruptive home environment for women and their families, in particular the children. We have a lot of the partners who are possibly positive but also do not want to take responsibility for being positive or even sharing this information with their partners. We also feel that it will further disintegrate their units as well as it breaks down the individual and their self-esteem.

At WARN we also receive a number of calls, where women are often -- as a matter of fact people but particularly women, because that's who we serve -- just asking all sorts of questions as it relates to HIV and AIDS and we find that we want to be able to give them as much as possible the best and vital information as it relates to what it is to be tested. As it is right now, they're being tested and they don't really know and we would like to encourage them to find ways that they can trust the establishment. Oftentimes they do not trust going to the medical establishment. And we want to be able to continue to provide the service where they can come and feel comfortable and they can feel trusted.

Ruth Bezares
Mothers of Children with AIDS
Public Hearing • November 8, 1993

Transcription 25

[Missing the first part of testimony.]

...are at risk of being removed from a person's right. It also negates a woman's right to a decision that is inherent and her only right, not someone else's. From a more personal perspective, if I were in a childbearing age, my right to consent and confidentiality does not belong to anyone else. It rests solely as my right and my responsibility.

Sally Guttmacher
Chairperson of the Medical Care Section
American Public Health Association
Public Hearing • November 8, 1993

Transcription (26)

The American Public Health Association has in its policy decisions gone on record in several instances in opposition to mandatory HIV testing, and that's what I want to discuss now. If the seroprevalence study is unblinded the state will in effect be instituting a mandatory HIV testing program for women who are giving birth. And as I mentioned the APHA, the American Public Health Association, is on record in opposition to mandatory testing for HIV.

Mandatory testing programs serve only to discourage people from seeking HIV-related care and services and health care generally. Mandatory programs will rightly be viewed as selective and repressive by women and therefore counterproductive to the goal of increasing the use of health care services for their children and for themselves.

Furthermore, because testing newborns reveals the serostatus of their mothers, mandatory programs would remove the right of informed consent selectively for HIV antibody screening of delivering women. It would be unconscionable and prejudicial if informed consent, a value so highly regarded in other areas, was dispensed with only for women who have just given birth. And the American Public Health Association has again, in many of its policy statements, supported informed consent for all individuals involved in the health care delivery system.

Implementation of mandatory, unblinded, perinatal HIV testing will also be contested as a violation of laws that require proper counseling and specific written informed consent prior to testing. The state would need to defend its position that only delivering women, as a class, are exempted from the principles contained in that law. Such a discriminatory approach to HIV testing policy should not be condoned. Moreover, it will be particularly suspect for the government to consider instituting, as its first mandatory testing program, one that will burden primarily low income women and women of color and one that will further distance these women from health care.

Experience has shown that when offers of HIV testing are linked to the actual provision of services, individuals consent to being tested. This is as true for pregnant delivering women as it is for all others. Those of us who have worked in high prevalence areas have found that when health care services are truly available, patients understand the importance of HIV testing and accept such testing for themselves and their children. Therefore, it would be a mistake to institute any program that creates additional disincentives to accessing prenatal and postnatal health care, particularly for women who we have found need such services and have sometimes been reluctant to come into the health care system.

(28)

Statement

Five years ago it was difficult to argue that the need to know a newborn's HIV status superseded a woman's right to privacy. We had little to offer the seropositive child other than a better health care system and a modified immunization schedule. The situation today is very different.

PCP is the primary cause of death in HIV-infected children less than one year of age; the disease often occurs in four to six month olds. It has recently become clear that PCP prophylaxis is safe, effective, and, essentially life-saving. For this therapy to be most effective the HIV status of the baby must be known as early as possible. The situation is analogous to PKU and thyroid screening; the sooner therapy is initiated, the better the outcome.

Women at risk for HIV/AIDS are among the most difficult to engage in ongoing medical care. Hence, many programs use the post-partum period to offer at-risk women HIV counseling and testing. At Bronx-Lebanon Hospital we have had a voluntary post-partum counseling and testing program (part of the Ob initiative) in place for over four years. Unfortunately, our experience has been that this system is costly, labor-intensive and extremely porous. Although most women consent to be tested (96%), few return for post-partum counseling and test results. We feel that this is primarily a consequence of their dysfunctional life styles, for when we help facilitate their return (eg, providing a carfare allowance or transportation) many keep their appointments. Moreover, our experience on the inpatient service demonstrates that mothers, when faced with a health care problem in their babies, will invariably allow us to do HIV testing in spite of the implications regarding their own HIV seropositivity.

In our desire to protect the rights of HIV-infected women we cannot overlook the rights of their HIV-infected children. Conversely, in our desire to offer potentially life-saving therapies to these children we should not ignore the rights of their mothers. If mandatory testing becomes a reality, then we must make sure that we can protect the privacy of both the mother and child and protect them from discriminatory practices. Clearly, however, it is time to revisit the mandatory testing issue and do what is right for both mother and child.

William B. Caspe, M.D.
Project Director
Bronx Pediatric AIDS Consortium

Director of Pediatrics
Bronx-Lebanon Hospital Center

Professor of Pediatrics and
Assistant Dean
Albert Einstein College of Medicine

NASW New York City Chapter
National Association of Social Workers

545 EIGHTH AVENUE • NEW YORK, N.Y. 10018-4381 • TEL: (212) 947-3030 • FAX: (212) 947-3311

(29)

TO: Members of the Assembly Health Committee

RE: A.6747

DATE: June 15, 1993

The New York City Chapter of the National Association of Social Workers' AIDS Task Force opposes A.6747, which would amend the public health law to allow for the unblinding of the NY State Department of Health's newborn serosurvey. Over many years, these newborn serosurveys have aggregated-anonymous HIV test results for every infant born in New York State in order to understand the epidemiology of HIV disease among women giving birth in New York State.

Serosurveys are an important public health tool for understanding trends in any health issue. It is used as a tool for developing a public health strategy; it is not the public health strategy. It is not designed to identify individuals. The procedures do not include individual informed consent or any knowledge that HIV testing is occurring.

Unblinding of the serosurvey would violate New York State's HIV Confidentiality Law which requires that specific consent be given by the individual before HIV testing occurs. It also requires that specific HIV related information be communicated before testing. These standards are included in NASW's Recommendations for "Social Work Practice for People Affected by HIV Infection." (See attachment)

The unblinding of the serosurvey would be a retrospective changing of the rules which would directly affecting a population which is disproportionately poor and of color, who have been, historically, most vulnerable to infringements on their civil rights. It would be unfortunate for this group to have history show that, once again, the public health establishment cannot be trusted to play by its own rules and

that, once again, the rules are not being equitably applied to all affected groups.

We are sure you are aware that HIV testing of newborns is one way of identifying the mother's HIV status; it cannot determine whether the newborn is truly infected. Studies show that anywhere from fifty to seventy percent of newborns who test positive for HIV antibodies will not be HIV infected. Since NY State Law required (and still requires) prior consent of adults before HIV testing when these blinded serosurveys were conducted, it is hard to justify retrospectively changing these rules. And, behavioral studies do not suggest that knowledge of ones HIV status is an incentive for preventing future pregnancies.

In summary, we encourage the New York State Health Committee to make funding available to assure access to a continuum of HIV care for families affected by HIV and the continued development of public education initiatives. We hope you will not enact A.6747.

Thank you.

Sincerely,

Patrick Moriarty
Susan Rosenthal

Mr. Patrick Moriarty, ACSW
Ms. Susan Rosenthal, ACSW

Co-Chairs
AIDS Task Force

30

NOW NYC
The Founding Chapter, 1967

The Subcommittee on Newborn Screening of the NYS AIDS Advisory Council

November 5, 1993

TESTIMONY
by Diane Welsh
President, NOW-NYC

The proposed bill to "unblind" the HIV testing of newborns not only will do little to increase the quality of care for HIV positive women and their children, but also brings into question some serious issues for women. It is not a simple matter of the mother's versus the child's rights; it is a question of the right to privacy.

If this bill is passed, a woman's autonomy would be usurped because the medical community would decide when and if she will be tested for HIV. A woman's right to choose what medical procedures will be performed on her body will be altogether denied. The bill reflects the erosion of a woman's fundamental right to control over her body; at the same time, the measure highlights the state's increasing encroachment on the private lives of women. Indeed, the bill can be seen as part of a general backlash against women's rights.

The bill proposes to disclose a woman's HIV status to the father of their child, destroying her right to privacy, and revoking her option to tell only close relatives. If the bill is seeking to protect the father from infection by the mother, it assumes that the mother and father retain a sexual relationship after the conception of the child. It also implies irresponsible sexual behavior on the part of the woman, suggesting that she was willfully trying to infect the father. Additionally, disclosure could also create a

potentially harmful domestic situation for a mother and child, such as physical violence or other harm.

There is a serious potential for discrimination if a woman's HIV status becomes part of her hospital records. A woman applying for public assistance, housing, or employment may be denied government services on the basis of her hospital records. Furthermore, the welfare of the child could be wrongfully jeopardized. Under the proposed bill, all children born to HIV positive mothers would be labelled as HIV positive; however, 80% of newborns who test positive in the first few days of life will later test negative. Studies have shown that HIV positive infants are given less care in neonatal clinics; therefore, the babies would be subjected to unnecessary suffering.

The bill does not have any influence on preventing transmission of the HIV virus, especially among newborns. HIV testing after birth is too late to prevent perinatal transmission, for most babies are born with the disease. Moreover, breast feeding, cited by the bill's proponents as a major danger is not as widespread as believed, particularly among high-risk women. If the proponents of the bill were truly concerned with the health of newborns, and their HIV status, the bill would surely include mandatory testing for the fathers as well as mothers. While we don't support mandatory testing under any circumstances, we would like to point out the gender discrepancy. We vehemently oppose a bill that places responsibility for the HIV status of a newborn on the woman alone.

Finally, mandatory testing is not recommended by the Center for Disease Control(CDC), the American Academy of Pediatrics or the Institute for Medecine. Mandatory testing will only will flood the systems of support without enlarging or improving them. We at NOW-NYC would like to see public policy that supports education and counseling, provides readily available HIV testing, and most importantly, advocates care for women and children who are HIV positive. NOW will strongly join in the effort to amend any law which denies only women the right to informed consent.

WRITTEN STATEMENT OF

RONALD S. JOHNSON
Citywide Coordinator for AIDS Policy
Office of the Mayor, City of New York

ON THE QUESTION OF WHAT POLICY SHOULD NEW YORK STATE EMPLOY IN ATTEMPTING TO MAXIMIZE ACCESS TO HEALTH CARE SERVICES BY HIV-INFECTED WOMEN AND THEIR CHILDREN AND PREVENT THE TRANSMISSION OF HIV FROM INFECTED MOTHERS TO THEIR CHILDREN

NEW YORK STATE AIDS ADVISORY COUNCIL
NEWBORN SCREENING SUBCOMMITTEE

The Office of the Mayor/AIDS Policy Coordination strongly recommends that to maximize access to health care services by HIV-infected women and their children and to prevent the transmission of HIV from infected mothers to their children, New York State policy should be to promote voluntary counseling and HIV antibody testing of women prior to their becoming pregnant or during their pregnancy and prior to giving birth. Efforts to promote voluntary counseling and testing should especially target areas that have a high prevalence of reported AIDS cases and projected incidence of HIV infection. NYS policy should also be to insure access to health care, especially HIV-specific primary care, for all women who test positive for HIV and their children. To this end, the AIDS Policy Coordination office is opposed to any legislative effort to "unblind" the NYS Department of Health's seroprevalence survey of newborn infants.

To implement the policy of promoting voluntary counseling and HIV antibody testing, State and local public health officials should continue and expand current programs that provide such voluntary counseling and testing. New York State, and especially New York City, already has an extensive network of programs that provide voluntary counseling and testing. Efforts should be made to develop new programs in underserved areas, including rural areas that may not have a current program that offers such services.

Experience has already shown the efficacy of this approach. At least 50% of HIV-infected mothers are already identified as a result of prenatal care provided by Federal and State funded programs that offer voluntary counseling and testing. If voluntary counseling and testing provided by private doctors and at anonymous counseling and testing sites are included, then the proportion of HIV-positive women who know their HIV status prior to giving birth rises to 70%.

Once a women learns that she is HIV-positive, it is essential that she have access to primary care. This is even more critical if a women is tested during a pregnancy. State and local officials must expand the availability of health care services for women and their children, especially in areas that have a fragile (or virtually

non-existent) health care infrastructure. There is sufficient documentation that shows that those areas that have a weak health care delivery system also have a high incidence of reported AIDS cases and HIV infection.

A policy that serves to increase the number of women who know their HIV status before or during a pregnancy would maximize prevention of HIV transmission from an infected mother to her newborn infant. Studies have shown that approximately 50% of mother-to-child transmission occurs during delivery. With the prior knowledge that the mother is HIV-positive, procedures can be taken that would reduce the risk of transmission during delivery. Efforts to identify HIV-positive mothers after they have given birth are too late to prevent perinatal transmission. HIV transmission as a result of breast-feeding is a negligible risk factor in the United States. Current policies and procedures in New York State that caution HIV-positive women and women at risk not to breast-feed their newborn infants is sufficient given the degree of actual risk.

The Office of the Mayor\AIDS Policy Coordination believes that there are compelling reasons for a public health policy to increase the number of women who know that they are HIV-positive. This policy goal is best accomplished through aggressive efforts that promote counseling, informed consent, and voluntary HIV antibody testing. Any effort that directly or indirectly involves mandatory testing of women giving birth would be counter-productive to the public health goal. This public health policy must also be linked with policies that expand access to primary health care for women and their children. The AIDS Policy Coordination office commends the New York State AIDS Advisory Council for establishing a subcommittee to review this issue and to make recommendations to the Department of Health and to the Legislature.

ACT UP
AIDS Coalition To Unleash Power

135 W. 29th Street, #10, New York, NY 10001 Tel 212 564-AIDS FAX 212 989-1797

18 November 1993

Eileen Tynan
New York State Department of Health
AIDS Institute
5 Penn Plaza
New York, NY 10001

Dear Ms. Tynan:

ACT-UP/New York strongly opposes A6747, the newborn infant "un-blinding" bill put forth by Assemblymember Mayersohn.

Testing is not treatment. Surveillance does not provide services. All too often, AIDS advocates confront legislators for whom "doing something" about AIDS lies in testing for HIV persons belonging to unpopular or vulnerable groups and recording the names of the seropositive for potential disclosure to third parties, without regard to whether infected individuals receive proper attention. Such measures work against the welfare of persons with HIV disease; it is well demonstrated that HIV reporting deters persons, particularly those who believe in the likelihood of their own infection, from getting medical care.

Ms. Mayersohn's bill would allow physicians to inform the father and mother of a newborn infant of the result of the HIV antibody test now conducted blindly on all newborns under a New York State Department of Health surveillance study. It would gut the requirement of informed consent before the administration of an identified HIV test contained in the landmark AIDS Confidentiality Law of 1988.

HIV antibody tests on infants yield the HIV status of their mothers. Not until a baby is eighteen months old will HIV antibody screening detect the infant's own status. Only about twenty to thirty percent of children born to HIV-positive mothers are actually infected. A6747 would therefore institute mandatory HIV antibody testing for all childbearing mothers. New York would gain the dubious distinction of having the largest compulsory HIV testing program of any state.

Proponents of Assemblymember Mayersohn's legislation argue that the "unblinding" of the HIV tests would enable infants who may be infected to get prophylaxis and other treatments recommended by many physicians. However, A6747 contains not one word about providing treatment for newborns with HIV disease.

Discrimination against persons with HIV in medical settings has been documented by federal and state anti-bias agencies. A survey of medical personnel at neonatal intensive care units, where many mothers and infants with HIV end up, showed that an alarming percentage of medical personnel would deny certain treatments to babies--and mothers--whom they knew or suspected to be HIV-infected. Levin, et al., "Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS," JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 12 June 1991, pp. 2976 et seq. Assembly-member Mayersohn's scheme would result in the withholding of care to infants in need.

A6747's supporters state that mothers forced to know their sero-status could abstain from breastfeeding their infants, thereby lessening the chance of infecting their baby. Some health experts feel that HIV may, in exceptional instances, be transmitted through breast milk. As HIV tests do not reflect nearly all in-fections, any warning against breastfeeding should apply to all women at risk for HIV. There is no good reason for the government's intervention in the private decision of whether to breastfeed an infant.

Ms. Mayersohn's comments to the AIDS Advisory Council's Sub-committee on Newborn and Pre-Natal HIV Testing teems with references to infants' care and "infants' rights." The Queens legislator expends few words,however, on treating the mothers of these children, as if these women do not deserve care. "[W]hen providing care and services to newborns becomes more important than caring for both mother and child, one must conclude that the institution has reduced its vision of the newborn solely to that of carrier and deliverer of the newborn." Cooper, "When Being Ill Is Illegal: Women and the Criminalization of HIV," HEALTH/PAC BULLETIN, Vol. 22, No. 4, Winter 1992, p. 13.

Many women avoid HIV screening because they fear the revelation of a positive test result to their male sexual partners. The obligatory disclosure of their newborn's HIV status, and therefore their own serostatus, to the father of the infant would expose some women to violence from men who may blame them as the "vector" or "vessel" of infection. A6747 would inhibit women from getting

important pre-natal and neo-natal care.

New York State directs pre- and post-test counseling for HIV screening. Such counseling is required to ensure that the subject understands the nature of the test, the rights of individuals who test positive, and the treatments available to the infected. Persons tested without proper counseling or who, like the Haitian refugees at the Guantanamo concentration camp, are mandatorily tested, will often not believe a positive result. By forcing childbearing women to be screened for HIV without any counseling, Assemblymember Mayersohn's bill would prevent many of these individuals from making the best choices for themselves and their families.

Pregnant women or women considering pregnancy (or men thinking of fathering a child) can get tested for HIV voluntarily, and, if seropositive, make informed decisions about their treatment, and their child's. The Centers for Disease Control and Prenvention (CDC), the New York State Department of Health, the American Medical Association, and all other reputable health authorities oppose compulsory HIV screening without informed consent as ineffective in limiting the spread of HIV and facilitating access to care. Assemblymember Mayersohn's claim that her proposal would furnish medical assistance to seropositive infants is a cruel joke to those who know how difficult it is for poor persons, especially those stigmatized by HIV, to find adequate medical attention in our overburdened health care system. ACT-UP urges the Department of Health to recommend against passage of this destructive bill.

Very truly yours,

Michael K. Swirsky
Testing and Disclosure Issues
Working Group

Planned Parenthood Association of the Mohawk Valley does not support "unblinding" the NYS newborn HIV serosurvey. The survey should be used as a statistical tool to assist with projecting the numbers of childbearing women infected with HIV, as well as, the potential numbers of children infected. Currently, women who are counseled and choose to be tested for HIV, will receive their test results. Women who do not choose to be tested, should not be forced to be tested or receive results from a test they did not consent to. Testing persons for a disease without their consent will be the inevitable result from unblinding this serosurvey.

To maximize access to health care services by HIV infected women and their children:

1. Urge all clinics, physicians, hospitals and other health care providers to educate all of their patients about the risk of HIV transmission and to offer to conduct the HIV test on site.

2. Health care providers should have bi-lingual staff available to discuss HIV and to do HIV counseling & testing.

3. Continue to educate the community (medical, social service, mental health, general population) about women's risk of infection dealing with behavior or activities which may put a woman at risk of infection.

4. Provide medical services in a manner that has a family focus. eg. making appointments convenient for a woman and her children; minimizing the amount of time spent in a waiting room; offering childcare on site; assisting with transportation. Women who need hospitalization or whose child needs hospitalization, also need assistance with short-term childcare.

5. Offer counseling services to women with HIV infection and their familes. Services for children with HIV infections should also be available. Services should be readily available and integrated into already established counseling agencies/programs. Professionals should be trained and knowledgable in HIV infection/AIDS.

6. Increase the number of medical providers who treat women and children so that waiting time for appointments are minimal.

7. Increase the number of drug treatment services geared for women.

To improve upon existing prevention strategie:

1. Offer HIV counseling and testing at times and places easily accessible to women in all communities taking care to protect their privacy and confidentiality. Establish testing sites or programs in rural locations. Testing sites should not be limited to traditional health care settings.

2. Expand current outreach efforts, bringing educational and testing programs to women in their own communities. Develop more community-based peer education models for women of all ages.

3. Keep the recommended HIV/AIDS curriculum updated and make available to all school personnel throughout New York.

4. Rather than relying on spermicides or barrier methods to prevent transmission, promote the development of an anti-viral method for women and men. Acknowledge that women are not always able to negotiate safer sex practices with their partners and that current methods of risk reduction do not work all the time.

5. Develop and maintain accessible (information, location, cost, multi-cultural, women with physical disabilities) family planning services to women with HIV who may not want to become pregnant.

(34)

NYU Medical Center

550 First Avenue, New York, N.Y. 10016
Cable Address: NYUMEDIC

Department of Pediatrics
(212) 263-6425 FAX: (212) 263-8172

Wade P. Parks, Ph.D., M.D.
Pat and E. John Rosenwald Professor and Chairman

NOV - 5

October 27, 1993

Dr. Robert Haggerty
Dr. Carolyn Britton
Chairs, Subcommittee on Newborn Testing
New York State AIDS Advisory Council
5 Penn Plaza, Room 407
New York, NY 10001

Dear Drs. Haggerty and Britton,

One basic fact that should guide public HIV-1 policy is that HIV-1 is largely a sexually-transmitted disease (STD). From a pediatricians' point of view, pediatric AIDS is almost exclusively the perinatal infection of an infant delivered to an HIV-1 infected mother. It is often stated that our screening for other STD's such as syphilis and Hepatitis B must be wrong if our current screening policies for HIV-1 are correct. However, the availability of prophylactic and therapeutic interventions for these and other non-HIV-1 infection detected by newborn screening have resulted in institutionalization of screening in practice and law. The most common rejoinder to this enlightened cry for change in current HIV-1 screening policy is that HIV-1 is life-threatening and that we cannot do very much for infected patients. The rejoinders usually go on to raise the omnipresent issues of confidentiality as a shield behind which we continue our present policies of "don't ask, don't tell". However in the context of health care, this point of view fails to account for the contract between patient and provider to mutually discover risk factors and disease processes that are amenable to modification in order to preserve the health and well being of the client.

Case finding has been and continues to be the cornerstone of management of those infectious diseases that are not vaccine preventable. To be sure HIV-1 case finding strategies should be available to all classes of men, women and children. Case finding is especially important among sexually active women in order to be able to make informed decisions about conception and management of pregnancy. However, this need does not obviate the necessity for identification of newborn infants who would benefit from prospective HIV-1 specific management. As a pediatrician, it is especially difficult to accept that our greatest tool, prevention, is not being maximally used in the AIDS effort. Almost every pediatric AIDS case today comes from an

obstetrical situation. Until our profession and/or the public says enough, pediatric AIDS will continue because we do not screen anyone! We anonymously screen populations such as newborns, but I shudder to think what history will say of the HIV-1 positive results that go unlinked, unidentified and untreated.

Testing all pregnant women in "high-risk" settings may seem excessive to some, but is possible. It is not the answer, but it is the first step to the ultimate answer. Screening newborns is a more preliminary step and poses positive and negative aspects. We would favor a multi-targeted approach to screening but regard early testing in pregnancy and newborn testing (of any group where the HIV-1 seroprevalence is $\geq$ 0.5%) as the most appropriate populations to impact perinatal HIV and management of infants at risk for HIV-1.

Until we know the extent of HIV-1 infection in women, until we understand factors associated with HIV-1 infection in women in our communities, the most effective, least expensive interventions will not be possible. Medical science will not produce a deus ex machina that delivers us from this "evil"! What is emergently needed is individual responsibility, education and accountability. Our health care system may not be perfect, but it would be much more effective if allowed to manage HIV-1 on an individual patient basis and on a local community basis. HIV-1 testing as a routine (not special) consensual part of medical care is an essential step in mainstreaming HIV related care. Until better drugs, better vaccines, and other interventions are available, education based on risk assessments and knowledge of HIV infection is the most responsible action we can take as physicians and as a member of our community.

Fear of too many things has prevented screening of high risk populations such as the women who delivery their babies at Bellevue Hospital Center and other Health and Hospital Corporation Hospitals. These patients deserve better care because in fact, they are the unwitting and often unknown carriers of HIV-1. Case finding will make all our policies consistent and will focus on individuals and their risk factors at smaller and more manageable levels -- the hospital(s) and the individual doctor-patient relationship.

Your re-consideration of this long overdue matter is greatly appreciated. I am confident that sooner (hopefully) or later that mainstreamed HIV-1 screening will be commonplace and we can begin to manage HIV-1 infection in the context of our strengths -- community, science and medicine and not our weaknesses -- ignorance, fear and isolation. Thank you.

Sincerely,

Wade P. Parks, Ph.D., M.D.
Chairman
Department of Pediatrics

MEMORANDUM

TO: Ms. Eileen Tynan, Director of Policy
N.Y.S. Department of Health
AIDS Institute
5 Penn Plaza, Room 407
New York, NY 10001

FROM: Alma Gomez, AIDS Project, ACLU

DATE: November 18, 1993

RE: Testimony Submitted to the AIDS Advisory Council's Subcommittee on HIV Screening of Newborns

---

We are submitting testimony on behalf of Alma Gomez, Esq., of the American Civil Liberties Union's AIDS Project; Nina Perales, of the Puerto Rican Legal Defense and Education Fund; and Nitza Escalera, Esq., on an individual basis, to express our strong sentiment against mandatory, unblinded HIV testing of newborns.

TESTIMONY SUBMITTED TO THE AIDS ADVISORY COUNCIL'S SUBCOMMITTEE ON HIV SCREENING OF NEWBORNS

BY: Alma Gomez, J.D.
American Civil Liberties Union
AIDS Project

Nina Perales, Esq.
Puerto Rican Legal Defense
and Education Fund

Nitza Escalera, Esq.*

November 18, 1993

* Submitted on an individual basis; Member, the Latina Roundtable on Health and Reproductive Rights and Boardmember, the Hispanic AIDS Forum.

We appreciate the opportunity to submit this testimony to the Subcommittee on HIV Screening of Newborns regarding the legal and medical questions raised by the mandatory unblinding of newborns' HIV test results. We jointly submit this statement to address the impact that such mandatory HIV testing of newborns will have on the legal rights of women and their children. We strongly oppose any plan to mandate HIV testing of newborns.

Two levels of analysis will be used to examine the impact of unblinding newborns' HIV test results. First, we will examine the scientific and medical background of this proposed policy. Second, we will consider the legal questions posed by mandatory unblinding of HIV test results in newborns.

SCIENTIFIC AND MEDICAL BACKGROUND

The scientific and medical background to this issue provides no guarantee - - and, indeed, little hope - - that mandatory unblinded testing will bring about health gains that could not be achieved through voluntary testing programs. There is no widely available diagnostic tool to detect active infection accurately at the time of birth. The test used now cannot identify perfectly which infants are truly HIV-infected; it only identifies which children carry their mothers' HIV antibodies. In a recent study evaluating the effectiveness of various HIV diagnostic tests for infants, researchers concluded that polymerase chain reaction

analysis or PCR analysis, apparently the most sensitive diagnostic tool available, could diagnose, with a two- to three-day turnaround time, only forty-two percent of those HIV-infected infants tested during the period from birth to one week after birth. This same test can detect HIV infection in newborns with one hundred percent accuracy not earlier than two months after birth.[1] Furthermore, this test is not widely available and is costly to use. Thus, the technology currently available is unable to establish with certainty which newborns are in need of treatment - - what it does do with accuracy is identify women with HIV disease.

Regrettably, even accurate forced testing would not ensure that HIV-infected infants will benefit from treatment options. The effective treatment of children requires the cooperation of mothers. Mandatory testing may frighten women away from the health care system both during and after pregnancy and as a consequence, some HIV-infected children will neither be identified nor treated. Parents of HIV-infected infants, like parents of all other children with a chronic disease, must commit themselves to the child's course of treatment by keeping doctor's appointments, administering medications and carefully monitoring the child's condition. Therefore, forcing mandatory testing -- instead of offering the test voluntarily together with counseling

---

[1] J. Conroy, Ph.D., "Paper on Early Identification of HIV Infection in Infants - Evaluation of Diagnostic Methods." (Oct. 19, 1993) (published through the Wadsworth Center for Laboratories and Research).

to parents -- will not ensure the welfare of HIV-infected newborns.

Moreover, medical staff sometimes harbor negative attitudes that are either communicated overtly or subtly to persons that are HIV-infected. For example, one study, which was conducted to investigate attitudes surrounding treatment of HIV infants at six neonatal intensive care units in New York City, found that physicians are less likely to treat HIV-positive infants aggressively because of their belief that the newborn will not really benefit from treatment.[2] These researchers concluded that perceived HIV status may influence treatment decision-making for critically ill infants, including infants not actually HIV infected. Therefore, knowledge of an infant's HIV status will not necessarily lead to better treatment of newborns with HIV. Medical personnel would still need to shift their attitudes and beliefs regarding who can benefit from treatment.

In addition to erroneously arguing that forced newborn testing is the best way to achieve proper health care for HIV-infected newborns, proponents argue that it will prevent transmission from mother to infant through breast-feeding. The need for mandatory HIV testing to protect newborns against the risk of infection through breast-feeding is highly unclear. Although the World Health Organization (WHO) and The Center for Disease Control (CDC) recommend that HIV infected mothers not

---

[2] Levin, Driscoll & Fleischman, "Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS," 265 JAMA 2976 (1991).

breast-feed their children, there is no proof to sustain this recommendation.[3] Furthermore, members of the at-risk population most affected by unblinded HIV tests have been described as rarely breast-feeding their children and educational alternatives have proven effective in counseling mothers about the dangers of HIV transmission from breast milk.

LEGAL RIGHTS AFFECTED BY MANDATORY HIV TESTING

Thus, the scientific foundation for mandatory HIV testing of newborns is highly uncertain. When the important legal rights at stake are examined, it is clear that such mandatory testing of newborns should not proceed. The proposed testing scheme violates New York State laws governing informed consent and confidentiality of HIV tests. Additionally, it violates federal and state constitutional rights. Because mandatory HIV testing of newborns is an unnecessary infringement of fundamental rights, the use of less restrictive alternatives is required.

The most troubling concern is the fact that testing a newborn for HIV is de facto testing of the mother. Under New York Public Health Law section 2781, no person can perform an HIV test without first obtaining the written informed consent of the subject of the test. If an individual lacks the capacity to consent, permission to test must be obtained from a

---

[3] The CDC AIDS Clearinghouse had no information or statistics on transmission by breast-feeding and a representative of La Leche League, Intl. has stated, in a recent telephone conversation, that there are virtually no reported cases of transmission by human milk.

person authorized to give consent. Mandatory HIV testing of newborns violates this state informed consent requirement, both for the mother and for the infant.

In addition, the unblinding of HIV tests of newborns violates the right of the mother and newborn to pre-test counseling. State law provides that, before an HIV test, the person to be tested or person authorized to give consent to the test should be provided with information about HIV disease, information about discrimination problems that disclosure of the test result can cause as well as legal information to prevent such discrimination, and risk prevention information.[4] At the time the test results are communicated, counseling or referrals to social or legal services must be provided.[5] New York Public Health Law section 2782 further prohibits any person who obtains confidential HIV-related information in the course of providing any health service from disclosing such information without the consent of the protected individual.

The New York legislature has stated that all the guarantees established in the "HIV and AIDS-related Information" statute are intended to "encourage the expansion of voluntary confidential testing. . . so that individuals may come forward, learn their health status, make decisions regarding appropriate treatment, and change behavior that puts them and others at risk of infection." The current proposal conflicts directly with the

---

[4] See New York Public Health Law section 2781(3).

[5] See New York Public Health Law section 2781(5).

specifics and spirit of New York's exemplary HIV testing statute.

Furthermore, mandatory HIV testing of an infant and therefore of the mother, without the informed consent of the mother, implicates several constitutional rights. These include:

- Equal Protection Under the Law: Under the proposed scheme, only women who have given birth and their infants are singled out from the general population that is entitled to give written informed consent and receive counseling before testing. Government action that discriminates against women can only be sustained if the party seeking to uphold the policy demonstrates by an exceedingly persuasive justification that the classification serves an important governmental objective and that the discriminatory means employed is substantially related to accomplishing those goals.
- Right to Privacy: By forcing women and their infants to be tested, the state invades their right to privacy. Intimate medical information can only be demanded by the government if its action is justified by a compelling state interest.
- Right Against An Unreasonable Search and Seizure: By imposing an unwanted medical test, the state unreasonably intrudes upon the mother's and the infant's rights to refuse such intrusions absent some overriding government justification.
- Right of a Mother to Direct Her Infant's Medical Care:

HIV testing of the newborn will be done without the mother's consent. By superseding the mother's consent to testing, the newborn is subjected to involuntary medical care. The New York State Court of Appeals has said that "great deference must be accorded a parent's choice as to the mode of medical treatment to be undertaken and the physician selected to administer the same."[6]

Additionally, HIV-infected mothers will unfairly be placed at increased risk of being reported to New York State's registry of child abuse and maltreatment for medical child neglect. Unblinded testing and the state's paternalistic approach to controlling the care of infants could lead to a permanent break in the constitutionally protected parent/child relationship. The threat of this risk to parents, especially to the low-income women, single head of households, and teenage mothers most at risk for HIV infection, is not a speculative one. Parents, in other instances, have been wrongly accused of medical neglect and reported to the state's registry for child abuse and maltreatment.[7] The risk is especially grave given the hysteria

---

[6] In the Matter of Hofbauer, 419 N.Y.S.2d 936, 940 (Ct.of Appeals, 1979).

[7] See In Matter of Hofbauer, 419 N.Y.S.2d 936 (Ct. of Appeals, 1979) (Parent wrongly charged with medical neglect for choosing nutritional or metabolic therapy as opposed to radiation) and Weber v. Stony Brook Hosp., 467 N.Y.S.2d 685 (A.D. 2nd Dept. 1983) (Parent wrongly charged with medical neglect for choosing the conservative treatment of antibiotic therapy over surgery for an infant with multiple serious disorders.)

that surrounds HIV and the lack of proven treatments for HIV-infected infants.

Before the state can restrict these constitutional rights, it must demonstrate that the restrictions are narrowly tailored to achieve a compelling state interest - - a very vigorous burden. Where such fundamental rights are at stake, moreover, the state has to serve its interest through the least restrictive alternatives available.

A preferable alternative to mandatory testing is the use of voluntary counseling, testing, and treatment programs. Supporters of mandatory HIV testing of newborns argue that the best interests of HIV-infected newborns will only be served if their mothers are neither counseled nor consulted about an HIV test. This is an outrageous and empirically insupportable assumption, especially in light of the current number of women who agree after counseling to the testing of their infants.

It is unfortunate that the proponents of mandatory HIV testing of newborns have chosen to portray HIV-infected mothers as inconsiderate and selfish, unable to make decisions in the best interests of their babies. These same persons would not dare advocate the impromptu inspection of every citizen's home to observe whether the children are well cared for, yet they argue that bypassing the knowledge and consent of an HIV-infected mother is the only way to ensure her infant's health.

Studies on access to health care have shown that when testing is linked to the provision of actual services,

individuals consent to treatment. Voluntary programs, such as those located at Harlem Hospital or Bronx-Lebanon Hospital, have been effective in educating pregnant women about HIV and the need for HIV testing and early treatment of HIV-infected infants. Unfortunately, no effort has yet been made to replicate these successful voluntary health care programs throughout the state. Building on the best models of health care for women at risk for HIV would be extremely productive -- both in distribution of resources and in outreach and continuing treatment. These efforts would assure that the medical needs of newborns are met both efficiently and with the cooperation of the parents - - a key factor in the treatment of chronic illnesses in children. Therefore, to comply with the constitutional imperative of the least restrictive alternative and to truly advance the health of New York state residents, we urge the state to focus its efforts on strengthening and expanding existing voluntary counseling, testing and treatment programs for pregnant women and mothers of newborns.

In addition, family planning and inpatient medical care settings, in which the majority of women are not pregnant, would be effective settings for HIV testing since presumably women could benefit from HIV education and counseling and incorporate this information into reproductive decisions. Finally, AIDS training must become a standard part of medical education and continuing medical education so that physicians can provide

supportive counseling to at-risk mothers and can treat aggressively HIV-infected children.

family planning advocates of new york state, inc.

NEW YORK STATE AIDS ADVISORY COUNCIL
PUBLIC HEARING ON NEWBORN SCREENING
NOVEMBER 1993

I am submitting this testimony to offer Family Planning Advocates' perspective to your deliberations on what policy should New York State employ in attempting to maximize access to health care services by HIV-infected women and their children and prevent the transmission of HIV from infected mothers to their children. I will concentrate on your issue D., prevention, and touch lightly on testing and service delivery issues.

First, I commend you for acknowledging the rapidly increasing threat of HIV infection to women and children. As you know, this past summer the Centers for Disease Control named women and children as the two most rapidly growing populations suffering from HIV/AIDS. The high rate of HIV infection among adolescents brings a new urgency to the issues involved in *school health education*. Aggressive strategies to curtail the high rate of unprotected sexual activity among school age youth are essential to reducing this mounting health plague.

We must intensify our efforts to reach young people *earlier*, before they become sexually active, with the preventive education they need to make responsible decisions and take appropriate steps to protect their health and well-being. The Board of Regents has already taken a major step in the right direction with the AIDS education mandate, but the time has come to re-examine its provisions and give serious consideration to placing the program within a broader context as many states have done. Surely a comprehensive health education program K-12, such as the Education Department's Family Life Education Program, which also focuses on educating parents, would serve as an appropriate context within which issues of AIDS could be best addressed. Updating the AIDS curriculum to bring it into the 1990's is a very necessary step to reach success, and I urge your assistance in trying to get the Board of Regents to move more quickly and responsibly on this life and death matter.

The Family Life Education Program has proven to be successful in helping young people build self-esteem, a sense of responsibility, respect for others and decision-making skills which they must possess if they are to avoid the misinformation and risk-taking behavior which leads to HIV

17 Elk Street • Albany, New York 12207-1002 (518) 436-8408 / FAX (518) 436-0004

infection. An evaluation of family life education in California found that 70% of the parents reported that the family life program had improved their communication with their children, and we know that youth whose parents are involved in their children's sex education demonstrate more respectful and responsible sexual attitudes and behaviors, such as postponing first intercourse, having fewer partners, and using contraception more consistently, all necessary steps to reducing the risk of HIV infection in young people.

Severe access barriers prevent thousands of school-age children in New York State from getting health care counseling and services. We must expand our *school-based health clinic program* which provides not only health screenings for children, comprehensive health and nutritional services, but reproductive health care for at-risk adolescents. School-based clinics have proven to be a cost-effective model for delivering comprehensive primary health care services and it is critical that we all join together to advocate for their expansion.

Family planning clinics, which are mandated to make available HIV counseling and testing for all its patients, also are in the front-line for *preventing* the deadly infection. By providing outreach, education, counseling and testing to adolescents and women prior to pregnancy and early in pregnancy, women will be able to make informed decisions regarding pregnancy and parenting so as to safeguard their babies' health. Unfortunately, our clinics have received no increase in funding for HIV testing and counseling since 1989, although the number of testing and counseling sessions have increased dramatically throughout the state. (see enclosed graph)

Additionally, it is well known that being infected with a sexually transmissible disease greatly increases a woman's chances of acquiring HIV. STDs have reached epidemic proportions in New York State, and much of the growth is among females under age 25. The most pervasive are Chlamydia and human papilloma virus (HPV), which can lead to pelvic inflammatory disease, infertility and life threatening ectopic pregnancy, as well as, significantly increased risks of cervical cancer and HIV infection. But, this has been obscured because attention has been focused on syphilis, where, for the first time ever, the incidence in women has outpaced that of men. In each case, *poor women and those from ethnic minorities suffer most,* with higher rates of disease, and later stage diagnosis.

Access to affordable early screening services must be guaranteed for *all* women of reproductive age: a goal that has become increasingly remote as family planning agencies — which are the state's largest network of preventive and primary care services for low-income women and adolescents — have been forced to retrench, creating waits of up to six weeks in some

areas for clinic appointments – essentially, turning away the most vulnerable high-risk patients who have nowhere else to go for confidential reproductive care.

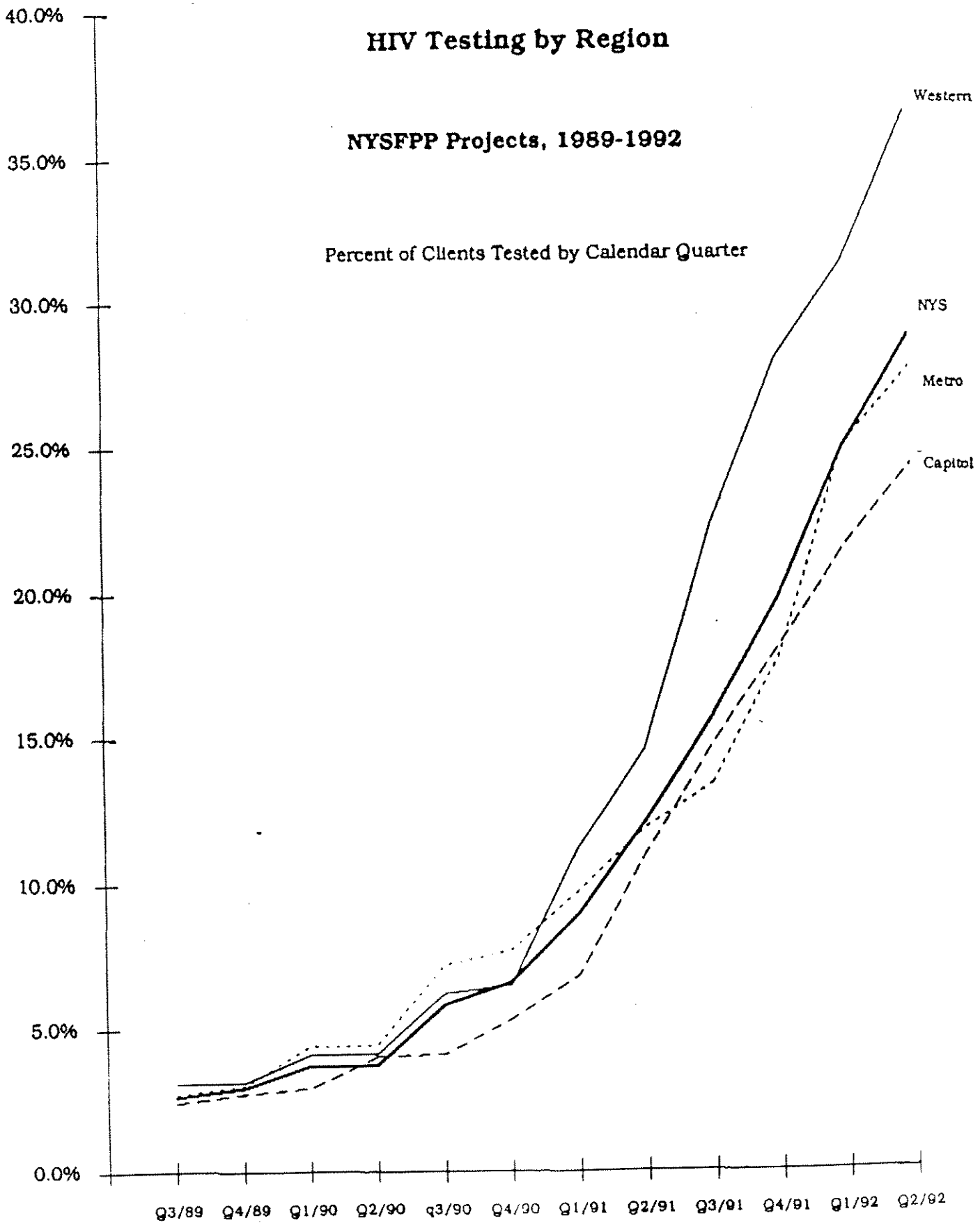
Because of the floundering economy, high unemployment, and lack of insurance, ever greater numbers have come to rely on these clinics. In fact, these family planning clinics now screen *more low-income women of childbearing age* for cancer, hypertension, diabetes, anemia, STDs, HIV infection, cervical and breast disease and, even heart, lung and thyroid abnormalities than *all* other facilities combined. Many clinics also provide case management for HIV positive women. Yet except for a modest increase this year, funding for these clinics remained static for several years, reducing their ability to serve promptly and well all who need it.

Surely these aforementioned prevention programs, along with enhancing our efforts to counsel all pregnant women on the importance of HIV testing as early as possible in the pregnancy, are more humane and more effective in safeguarding the health of newborns than is mandating notification of parents of infants who test positive for HIV. This policy, although superficially appealing, has several serious drawbacks. Chief among them is forcing women who did not wish to be tested, to be told of their HIV status, contradicting all current policy, regulations, and law, and stigmatizing infants as being HIV-positive when the majority are not. Both arguments might be discounted if there were any viable treatment for infants born with the virus. But currently there is no way to detect which infants truly are HIV positive, and there is no treatment available for those who are.

Responsible legislation would mandate high quality sex education and AIDS prevention programs in the schools, expand school health clinics and assure that they provide a full range of health care services, enhance HIV counseling programs for pregnant women, strengthen family planning clinics so they can provide more services to their at-risk patients, and expand the resources and support services necessary to improve care for those mothers and children who are infected.

We thank you for inviting us to submit testimony in this critical area.

Ruth Sabo,
Director of Governmental Relations


HIV Testing by Region
NYSFPP Projects, 1989-1992
Percent of Clients Tested by Calendar Quarter
40.0%
35.0%
30.0%
25.0%
20.0%
15.0%
10.0%
5.0%
0.0%
Western
NYS
Metro
Capitol
Q3/89
Q4/89
Q1/90
Q2/90
q3/90
Q4/90
Q1/91
Q2/91
Q3/91
Q4/91
Q1/92
Q2/92

(37)

Nassau County HIV Commission
Presentation to New York State AIDS Advisory Council
Newborn Screening Subcommittee

Public Hearing - Monday, November 8, 1993

In attempting to address the question of "what policy New York State should employ in attempting to maximize access to health care services by HIV-infected women and their children, and prevent the transmission of HIV from infected mothers to their children," the Nassau County HIV Commission feels that while great efforts must be made to inform women of their HIV status and the potential that their newborn could be HIV positive, there is an equally urgent need to educate women about HIV infection prevention before they have concieved a child, indeed, to provide education to those women who are not considering having a child. To that end, the Nassau County HIV Commission strongly suggests the following steps be taken:

An amendment to the public health law (that section relating to Maternal and Child Health) to mandate that obstetricians and gynecologists provide information about HIV infection and the availability of testing to all their patients, and requiring that confirmation that HIV counseling and testing (if accepted) be noted in the patient's record. It would then become a standard of care which would be incorporated into all OB/GYN practices. This would be preferable to newborn testing because it would identify HIV positive women prior to conception, allowing them the opportunity to consider whether they wish to become pregnant. Additionally, those women who do not choose testing would benefit from the education delivered in the pre-test counseling session.

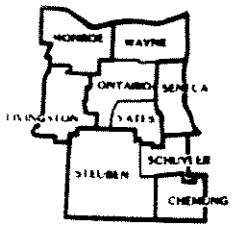
The Nassau County HIV Commission appreciates this opportunity to make their views known to the New York State AIDS Advisory Council.

Sincerely,

Ralph A. Nappi
Chair
Nassau County HIV Commission

Doris Guidi, Ed.D.
Vice Chair
Nassau County HIV Commission

RAN:DG:pg



ROCHESTER AREA TASK FORCE on AIDS, INC.

MEMORANDUM

TO: Jonathan Moreno

FROM: Kelli McMahon

RE: Written Comments Regarding Unblinding the Newborn Seroprevalance Study

DATE: November 12, 1993

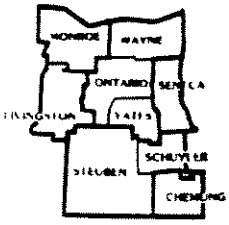
Attached you will find written comments prepared by the Women's Health Care Initiative Committee (WHCI) of the Rochester Region HIV Care Network.

Please call me at 716-461-3520 if you have any questions.

KEM\kp
attachment

NOV 19 '93

Finger Lakes Health Systems Agency
145 College Avenue, Rochester, New York 14607
(716) 461-3520 FAX (716) 461-0997



ROCHESTER AREA TASK FORCE on AIDS, INC.

Opening Statement

The issue of the proposed legislation to unblind the newborn seroprevalance screening has been thoughtfully considered by the Women's Health Care Initiative (WHCI) Committee of the Rochester Region's HIV Care Network. The committee is comprised of a wide range of health care providers and professionals, volunteers and researchers all working with women affected by HIV. Unfortunately, no one from the Network was able to attend the November 8 public hearing. The following summarizes the concerns raised by the committee. We urge you to take these concerns into account as you proceed with your deliberations. They represent the realities of the lives of HIV+ women across the state.

CENTRAL QUESTION: WHAT POLICY SHOULD NEW YORK STATE EMPLOY IN ATTEMPTING TO MAXIMIZE ACCESS TO HEALTH CARE SERVICES BY HIV INFECTED WOMEN AND THEIR CHILDREN AND PREVENT THE TRANSMISSION OF HIV FROM INFECTED MOTHERS TO THEIR CHILDREN?

RESPONSE: Abolish newborn seroprevalance studies altogether and replace with aggressive, comprehensive prenatal care, including outreach, education, HIV counseling and testing and health care services. The NYS Health Department has gathered this data for six years; we have an accurate picture of affected populations. ANY policy must be sensitive to the already fragile medical, legal, economic, and social environment of women impacted by HIV. Equally, respect for the natural mother and child unit and the reciprocity of their needs and concerns must be recognized.

RELEVANT ISSUES:

WHCI THEME: Mandatory testing will not produce the desired result, unless the desire is to develop a list of infected women. Services needed by the women and their infants so identified are not readily available. Furthermore, the legal, social and economic protections are not in place and will not be in the foreseeable future. These are universal and disturbing concerns expressed by the committee. They shape our thinking on the following issues.

Finger Lakes Health Systems Agency
145 College Avenue, Rochester, New York 14607
(716) 461-3520 FAX (716) 461-0997

A. **Testing Issues:** Mandatory testing is rightly perceived as a threat by vulnerable women. HIV counseling and testing should be routinely offered to women, whether in a public or private setting, because ALL women are at risk for infection. The NYSDOH should intensify and widen its efforts to require health care providers, including physicians, to routinely offer testing to all women.

B. **Service Delivery Issues:** HIV+ women often deal with fragmented and inhumane care. The emphasis on infant identification and care further erodes the viability of the family by concentrating resources on the infant thus validating the perception of mother as vectors. Parental tracing is only necessary when the service delivery system is viewed as punitive. If the mothers needs are not adequately addressed, we cannot successfully access and treat her infant.

C. **Medical Issues:** In order to be effective and humane, we recommend family centered HIV care, which is culturally, geographically and physically accessible. This model must include more cultural, language and gender sensitivity than currently exists. Medical care cannot be delivered in a vacuum unresponsive to these realities. Medical outcomes and quality of life are significantly shaped by the socioeconomic factors that already cripple many of these families lives.

D. **Prevention Issues:** There are many prevention issues, but none of them are affected by newborn screening, either blinded or unblinded. Redirect staff and resources currently in place for the newborn study to prevention, education and outreach efforts for all women.

E. **Legal Issues:** First, it must be noted that discrimination is a legal issue, as well as a social issue. Unblinding, with no protection and services securely in place, will undermine confidentiality, privacy, equal protection and the right to obtain and refuse treatment. The welfare of children is better served by prevention than detection of infection after it occurs.

F. **Social Issues:** Unblinding will serve to exacerbate the harmful impact of social inequalities on women vulnerable to HIV infection. In no way will unblinding these results lessen the burden of poverty, discrimination, violence and racism, that diminish the lives of affected families. These social forces are the matrix that creates and molds the negative experience of women and their children in all life areas, including medical care, access to needed services, employment, education and vulnerability to HIV infection. Nor will unblinding improve already overburdened services directed specifically to children. The impact on those children left parentless by HIV may be further fragmentation of the planning for their long term placement and care as mothers become more a focus for blame than support. It has been our experience that what harms the mother, will harm the child, no matter how separately the mother and infant/child are treated.

G. **Economic Issues:** The cost of abolishing this screening and reorganizing the funds and personnel, could never be greater than the costs incurred by the neglect of prepregnancy, prenatal and postpartum outreach, education, non-threatening testing and accessible care. Establishing a further epidemiological portrait is not defensible in the face of untreated suffering that creates enormous human and fiscal costs. Substandard care is equally expensive in its fragmentation, duplication of services, late intervention and the creation of excessive management structures. Attention to the actual needs of the persons and families affected by HIV, as they exist in each community, will be humane and more cost effective in the long run.

H. **Ethical Issues:** It can be destructive as well as traumatic for a woman to learn her HIV+ diagnosis through diagnosis of her infant. Channeling scant resources to after-the-fact diagnosis is unethical. There are currently no protections in place for women who are diagnosed HIV+. To expose women to potential discrimination, domestic violence and a host of other difficulties as a result of such a precipitous diagnosis is equally unethical. Our primary concerns about ethical issues stem from these problems. The NYSDOH AIDS Institute has been aggressive in assuring that professional, compassionate pre and post test counseling be available to all people who choose to be tested. Positive test results are shared in a supportive and responsible manner. We see unblinding the newborn surveys as diametrically opposed to this stance. We expect that whatever policy is implemented by NYS, this compassionate consideration will be given to women and their families.

I. **Practical Considerations:** All of the above comments <u>are</u> the practical considerations that shape the lives of HIV+ women and their families. These resources are better spent in outreach, intervention and other supportive programs.

G. **Economic Issues:** The cost of abolishing this screening and reorganizing the funds and personnel, could never be greater than the costs incurred by the neglect of prepregnancy, prenatal and postpartum outreach, education, non-threatening testing and accessible care. Establishing a further epidemiological portrait is not defensible in the face of untreated suffering that creates enormous human and fiscal costs. Substandard care is equally expensive in its fragmentation, duplication of services, late intervention and the creation of excessive management structures. Attention to the actual needs of the persons and families affected by HIV, as they exist in each community, will be humane and more cost effective in the long run.

H. **Ethical Issues:** It can be destructive as well as traumatic for a woman to learn her HIV+ diagnosis through diagnosis of her infant. Channeling scant resources to after-the-fact diagnosis is unethical. There are currently no protections in place for women who are diagnosed HIV+. To expose women to potential discrimination, domestic violence and a host of other difficulties as a result of such a precipitous diagnosis is equally unethical. Our primary concerns about ethical issues stem from these problems. The NYSDOH AIDS Institute has been aggressive in assuring that professional, compassionate pre and post test counseling be available to all people who choose to be tested. Positive test results are shared in a supportive and responsible manner. We see unblinding the newborn surveys as diametrically opposed to this stance. We expect that whatever policy is implemented by NYS, this compassionate consideration will be given to women and their families.

I. **Practical Considerations:** All of the above comments <u>are</u> the practical considerations that shape the lives of HIV+ women and their families. These resources are better spent in outreach, intervention and other supportive programs.

TESTIMONY: NYS AIDS ADVISORY COUNCIL
Newborn Screening Subcommittee
David M. Abramson, MPH
Staff Associate
Columbia School of Public Health
(212) 305-5656

As one of the field directors of a recent Columbia University evaluation of New York State HIV counseling and testing services at Family Planning Programs and Prenatal Care programs I had an opportunity to speak with administrators and HIV counselors at numerous agencies across tne state. Additionally, I have analyzed the responses to an open-ended questionnaire answered by 346 women, specifically regarding their perceived barriers to taking an HIV test.

The overriding concern expressed by these women was fear.

Fear of knowing their results, fear of the effects of disclosure that might result in loss of housing, jobs, or children. One could extrapolate from these women's answers a general fear of learning a result when they are not prepared to handle it.

Clearly the proposed policy of unblinding the newborn screening study would force women to hear the results of an HIV test when they would not be prepared to handle it. The postpartum period can be one of great precariousness for the mother -- addressing issues of caring for a child, making sure the home environment is stable, attending to the constant needs of a newborn, dealing with newfound emotional problems that might arise in a primary relationship. All of these possibilities counsel against forcing a mother to hear HIV test results immediately after giving birth. This is especially true since there is no immediate and proven treatment to offer the mother or the child.

Furthermore, the benefits of the voluntary testing program have not been maximized. Anecdotal evidence suggests that the greater a program's emphasis on HIV counseling and testing, the greater the client's willingness to accept counseling and testing.

Surely there will be a percentage of women who resist being tested, and this may include those at the greatest risk. One of the findings in our evaluation of Counseling and Testing services was that women at PCAPs who considered themselves at the highest risk were the least likely to take the HIV test. These are women, it can be argued, with the greatest reason -- a

pregnancy -- to be tested. And if they are reluctant to take the test in the relatively unpressured setting of a PCAP, they might be even more unwilling to take the test when it is mandated at a hospital. The repercussion could be an increase in the number of unattended homebirths, travel to other states to deliver a baby, or quite possibly abortions. These are women who need to be reached, especially if they constitute a high-risk population, and the mandatory test may not be the best avenue. The voluntary program allows for the building of trust between clients and counselors, over time.

In conclusion, I would urge the AIDS Advisory Council to redouble the voluntary effort rather than mandating an HIV test for postpartum women.

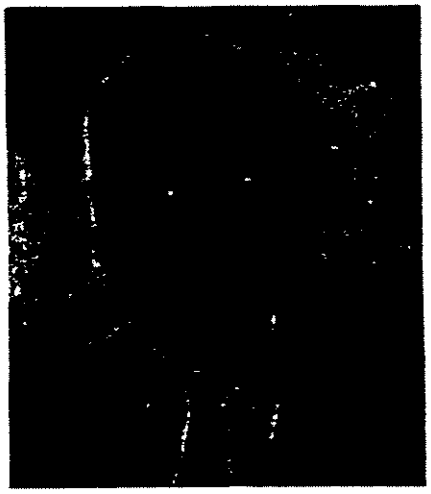
VIEWPOINT

40

A Plea For Mandatory Prenatal HIV Testing

Marvin Thalenberg*

I AM THE HEALTH COMMISSIONER in a small suburban county, a bedroom community of New York City. Our county shares many of the city's problems, including AIDS. We are therefore concerned with AIDS education, prevention, and treatment. We perform about 800 antibody tests a year for infection with the human immunodeficiency virus (HIV), and we have an active counseling program. In addition to an HIV clinic, we have a flourishing prenatal and maternity clinic, which delivers about 700 babies a year, 25 percent of all the babies born in our county.



Marvin Thalenberg is the Commissioner of Health for Rockland County, N.Y.

This is my plea for routine, mandatory prenatal HIV testing.

As New York state law provides, we perform seroprevalence studies of HIV infection on umbilical-cord blood for all babies born in Rockland County. But because of confidentiality laws, the identity of these babies is not revealed. Therefore, although I know that of the 15,557 cord blood tests performed in our county from November 1987 to March 1992, 60 were HIV-positive, I do not know who the infected women are. And until the seriously ill children are brought to our hospitals—as 30 have been so far this year—I do not know who the HIV-positive babies are.

Rockland County is not unique. In New York state as a whole, 943,418 cord-blood specimens were tested between November 1987 and March 1992, and 6,217 were positive for HIV. But again, doctors and health officials don't know who the infected women are. And in many cases, the women themselves do not know that they are infected.

The avowed purpose of the confidentiality requirement in the New York state law[1] is praiseworthy. In the language of the legislation, "The legislature recognizes that maximum confidentiality protection for information related to HIV infection and AIDS is an essential public health measure....By providing additional protection of the confidentiality of HIV-related information, the legislature intends to encourage the expansion of voluntary confidential testing for the human immunodeficiency virus so that individuals may come forward, make decisions regarding appropriate treatment, and change the behavior that puts them and others at risk of infection."

But the effect of this well-meaning law is to have 6,217 women in New York state—with approximately 1,500 infected babies, at a mother-to-infant transmission rate of around 25 to 35 percent—unreached and unreachable. Withholding the information that mothers, and some infants, have a fatal infection not only violates public health principles but is, in my view, unconscionable.

There is no provision in New York state law for mandating HIV testing without confidentiality or anonymity—except, remarkably, for an individual "proposed for insurance coverage."[1] A curious side effect of the insurance exclusion is that women at low risk for HIV infection often have to take several HIV tests for various kinds of insurance, and are therefore much more likely to be tested than are high-risk women.

In April, our early-care social worker told me of a 12-month-old baby she had just placed in foster care. The infant had been hospitalized three times with pneumonia. The pediatrician was sure that the baby had AIDS, but he was unable to get the mother's consent for an HIV test. Nor was he able to determine the mother's HIV status. He therefore went to a local judge, and the judge ordered testing of the baby even though he was not clear that he had the authority. The child was HIV-positive.

It is difficult to test a child for HIV without the mother's consent because the mother's HIV status also becomes known if the child is seropositive, and the law is not clear whether this is a breach of the mother's confidentiality status. What is clear to me is that the ability of a physician to treat a sick child is severely compromised if the mother's HIV status is unknowable. Confidentiality does not help HIV-infected infants, who ordinarily die before they are 3 years old.

The prevalence of AIDS in women increased by 34 percent nationwide from 1989 to 1990, compared with a 21 percent increase in men[2]. AIDS is now the fifth leading cause of death in women of childbearing age. Seventy percent of HIV-infected women are black or Hispanic, and 33 percent now become infected from heterosexual activity rather than intravenous (IV) drug use[3]. Many women learn that they are infected in one of two ways—through the illness of a sexual partner or the illness of their babies. Illness may not become apparent in a partner for up to 10 years. The baby may not become ill for a year. And because the transmission rate from the mother is 25 to 35 percent in most studies, most children of infected mothers do not develop AIDS. Therefore, some infected mothers may not learn of their HIV status for years. Mandatory prenatal testing would permit earlier diagnosis and treatment.

There are many other reasons, however, why it is vital for a pregnant woman to know her HIV status.

Women are less likely than men to be diagnosed early in the course of HIV infection. The early studies were mostly on gay men. Physicians readily recognize Kaposi's sarcoma—which is rarely seen in women—as a sign of AIDS. But they are less likely to think of HIV when confronted with such conditions as protracted herpes simplex infection, refractory vaginal candidiasis, aggressive cervical disease,

continued on page 30

*County of Rockland, Department of Health, Sanitorium Road, Pomona, NY 10970. Responses intended for publication should be addressed to Advice and Dissent, THE JOURNAL OF NIH RESEARCH, 2101 L Street N.W., Suite 207, Washington, DC 20037.

continued from page 26

severe pelvic inflammatory disease, and intractable genital ulcers, all of which can signal HIV infection in women[4].

Some studies show that women have a shorter time from diagnosis to death than do men and that *Pneumocystis carinii* infection is more often fatal in women. Yet, women in high-risk groups are likely to have poor access to health-care providers because high risk and poverty go together.

When an HIV-positive woman becomes pregnant, she needs counseling, education, and support to prepare her for her own illness, to alert her to signs of illness in her baby, and to ensure that she understands the necessity of bringing the baby back for testing over a period of months. This support must start during the relatively calm time of pregnancy; it cannot wait until the woman is in the delivery room[5]. An HIV-positive woman is also at increased risk of cervical cancer and should have a Pap smear every six months. The prenatal time may be the only opportunity to get her into gynecological care that she can continue postpartum.

Furthermore, repeated exposure to the virus by intercourse or IV drug use during the pregnancy may increase the chance of transmission of HIV to the fetus[6]. The woman can only be counseled if her status is known[6].

In addition, of course, if the woman knows her HIV status early enough, she has the choice of continuing or terminating her pregnancy.

Pregnancy itself mildly suppresses the immune system to blunt response to the fetus, but there is generally no evidence of extra risk to the pregnancy or to the neonate if an HIV-positive woman is asymptomatic. However, risk increases as the infection progresses to AIDS. The HIV-positive patient must be watched more closely, with more nonstress testing and visits to detect growth retardation of the fetus[6].

At birth and afterward, there is more chance of hemorrhage because of the HIV effect on platelets. Postpartum, there is also extra risk of infection—endometritis, puerperal febrile illness, and genital urinary-tract infections—especially if the woman's immune status is compromised[7].

An HIV-positive mother also must be taught self-care to avoid infecting her infant. She must learn to use bleach and water to neutralize blood spills, and infection control by avoiding tampons and douching[8]. She must be trained in washing and protecting abrasions and wounds.

In addition, there is clear evidence that breastfeeding increases HIV transmission from an infected mother to her infant. It is patently unfair to an uninfected infant that our ignorance of the mother's disease should compromise his or her life[9].

Even babies who are seronegative can show traces of HIV-like illness, including parotitis, lymphadenopathy, and inverted T lymphocyte ratios. Ignorance of the mother's seropositive status makes diagnosis very difficult[10].

Medical personnel, too, need to know the HIV status of the woman. They should know for their own safety. They may be at risk from needle stick, from puncture wounds, and from splash exposure to mucous membranes. Although medical personnel are trained to follow the universal precaution rules set by the Centers for Disease Control, universal precautions are not a sure safeguard against those risks[11].

They should know for the baby's safety, too. When a pregnant woman is HIV-positive, there is an increased risk of transmission to the fetus from common invasive procedures such as internal scalp monitoring, vaginal exams after rupturing of membranes, and vacuum extraction. If the mother's HIV status is known, her physicians can make better-informed decisions about these procedures[12].

Voluntary testing is not enough in the face of an increasing and disastrous plague. It has failed so far.

AIDS is now the leading cause of death in New York state among black and Hispanic children between one and four years of age, and the prevalence of AIDS in children is increasing nationwide. If a mother is known to be HIV-positive, her infant can be tested and—if infected—can be brought into treatment more quickly, increasing the chances of delaying the course of the disease[13]. An uninfected child of an infected mother may test positive for antibodies for up to 15 months because of the mother's antibodies, making diagnosis difficult. However, newer techniques may make diagnosis possible as early as three months after birth[15]. And treatment with zidovudine (AZT) can begin as early as 3 months of age. The clinical, immunological, and virological improvements are similar to those reported in adults[14].

Furthermore passive immunity by administration of neutralizing HIV antibodies is being studied as a means of preventing mother-to-infant transmission of HIV. If this is successful, maintaining confidentiality would be achieved at the expense of some infant lives[15].

Voluntary testing is not enough in the face of an increasing and disastrous plague. It has failed so far[16]. And to be successful, it must be universal. Prenatal testing is a special case, because it involves two lives instead of one. My own informal soundings of physicians and nurses involved in obstetrics and pediatrics show that they enthusiastically support prenatal testing. When asked about the 6,217 positive, confidential cord blood tests in New York state, the overwhelming opinion of those I have spoken with was, "It's lunacy."

I understand that a plea for mandatory HIV testing in pregnant women can be seen as sexist and discriminatory. The circumstances of pregnancy, however, are unique. Because infection is transmitted heterosexually in about 30 percent of women, many are asymptomatic and unaware of the possibility of being infected. HIV infection puts extra stress on mother and baby. There is always a surgical procedure involved in childbirth, which involves caregivers. And most common and rare at the same time, there is another life to take care of.

References

1. New York State Public Health Law Article 27-f, section 2782.
2. Centers for Disease Control. *MMWR* **39**, (47), 1 (1990)
3. M. Oxtoby, "Perinatally acquired HIV infection," *Pediatr. Infect. Dis. J.* **9**, 609 (1990).
4. M. Tinkle, M. Amaya, and O. Tamayo, "HIV disease and pregnancy, part 1" *J. Obstet. Gynecol. Neonat. Nurs.* **21**, 86 (1992).
5. Y. Acosta, C. Goodwin, M.D. Amaya, M. Tinkle, E. Acosta, and I. Jaquez, "HIV disease and pregnancy." Part 2, Antepartum and intrapartum care. *J. Obstet. Gynecol. Neonat. Nurs.* **21**, 97 (1992).
6. H. Minkoff and D.E. Hovitz, "HIV in women," *AIDS Clin. Care* **3**, 33 (1991)
7. N. Bastin, O. Tamayo, M. Tinkle, M.A. Amaya, L. Trejo, and C. Herrera, "HIV disease and pregnancy. Part 3. Postpartum care of the HIV positive woman and her newborn," J. Obstet. Gynecol. Neonat. Nurs. **21**, 105 (1992).
8. M. Allen, "Primary care of women infected with the human immunodeficiency virus," *Obstet. Gynecol. Clin. North Am.* **17**, 557 (1990)
9. P. Van de Perre, A. Simonon, P. Msellati, D.-G. Hitimana, D. Vaira, A. Bazubagira et al., "Postnatal transmission of human immunodeficiency virus type 1 from mother to infant," *N. Engl. J. Med.* **325**, 593 (1991).
10. M. Mayers, K. Daverny, E. Schoenbaum, A. Feingold, P. Selwyn, V. Robertson et al., "A prospective study of infants of human immunodeficiency virus seropositive and seronegative women with a history of intravenous drug use or of intravenous drug-using sex partners in the Bronx, New York City," *Pediatrics* **88**, 1248 (1991).
11. J. Tokars, D. Bell, D. Culver, R. Marcus, M. Mendelson, and E. Sloan et al., "Percutaneous injuries during surgical procedures," *JAMA* **267** 2899 (1992).
12. Task Force on Pediatric AIDS, "Guidelines for HIV infected children and their foster families," *Pediatrics* **89**, 681 (1992).
13. R. McKinney Jr., M. Maha, E. Connor, J. Feinberg, G. Scott, M. Wulfsohn et al., "A multicenter trial of oral zidovudine in children with advanced human immunodeficiency virus disease," *N. Engl. J. Med.* **324**, 1018 (1991).
14. M. Rogers, C.-Y. Ou, B. Kilbourne, and G. Schochetman, "Advances and problems in diagnosis of HIV infection in infants," *Pediatr. Infect. Dis. J.* **10**, 523 (1991).
15. L. Mofenson and D. Burns, "Passive immunization to prevent mother-infant transmission of HIV current issues and future directions," *Pediatr. Infect. Dis. J.* **10**, 456 (1991).
16. K. Kabrinski, W. Borkowsky, D. Bebonbroth, T. Moore, "Failure of voluntary testing for HIV to identify infected parturient women in a high risk population," *N. Engl. J. Med.* **318**, 185 (1988) (letter)

(41)

November 17, 1993

Ms. Sonja Noring
Medical Editor
AIDS Institute
5 Penn Plaza, Room 407
New York, NY 10001

Dear Ms. Noring:

WOMEN'S
HEALTH
EDUCATION
PROJECT

While I was unable to attend the hearing on November 8, I would like to submit the following testimony against mandatory HIV testing for infants. I would like to address how such a policy would affect pregnant and/or parenting women.

Firstly, the most obvious effect of imposing mandatory HIV testing on infants is that by doing so, mandatory testing will also have been imposed upon their mothers. Not only would this represent a gross disregard for personal privacy, it would violate a mother's confidentiality, guaranteed to her under Article 27F. In effect, **by imposing this mandatory testing, the State would be penalizing women, singling them out as a group whose privacy can be violated solely because of their ability to reproduce.**

Mandatory HIV testing for infants will affect most directly those women who already have a tenuous relationship with the system -- low-income women and women of color. For many of these women, their first contact with the health care system is when they become pregnant. Health care providers find it challenging enough to get women to seek prenatal care. If word were to get out on the street that having a baby means getting tested for HIV, it could drive pregnant women further away from getting crucial prenatal care, not to mention make them hesitant to go to the hospital when it comes time to give birth.

We have found, in our work in New York City shelters for homeless and battered women, a pervasive mistrust of anyone or any institution representing "the system." Mandatory HIV testing for infants will only intensify this mistrust. Undocumented residents will have even more to fear. Undocumented women know that contact with any governmental authority may ultimately result in deportation. Why should she take the chance? Added to this is the fear of

2271 Second Avenue
New York
New York
10035

persecution and/or discrimination in one's home country -- or in the U.S. -- because of one's HIV status.

To make matters worse, the proposal before this committee does not stop at notifying only the State and health providers of a newborn's HIV status (and therefore his or her mother's status). The proposal before this committee allows for foster caregivers and the infants' biological father to be notified as well. This is a problem for battered women. A woman who has been battered may choose, for reasons of personal safety, to withhold her HIV status from her current or estranged partner. By breaking this confidence, the State would put her in danger of further violence at the hands of an abusive partner.

Mandatory testing of infants, and by extension their mothers, sets an ugly precedent and opens the door for further violations of reproductive freedom. Already, court-mandated contraception has come to pass in this country. By forcing HIV testing on women, the state is allowing an intrusive penalty which may be capitalized upon, taken one or two steps further, and used for purposes this committee never intended. Will women someday be pressured to abort an HIV-positive fetus? Will women be accused of in-utero child abuse by infecting her child with the HIV virus? These questions are not so far-fetched.

Harlem Hospital has a program, under the direction of Dr. Janet Mitchell, which serves high-risk pregnant intravenous drug users. Dr. Mitchell manages to get more than 90% of her clients to voluntarily submit to an HIV test. If this is possible, why not study and replicate her methods rather than trampling on the privacy and rights of women?

Sincerely,

Shannon Cain
Executive Director

Appendix F

Current Procedure for Newborn Congenital Disease Screening and the HIV Newborn Seroprevalence Survey in New York State

THE NEWBORN HIV SEROPREVALENCE SURVEY IN NEW YORK STATE

The Newborn HIV Seroprevalence Survey in New York State is part of a nationwide program of blinded testing for the presence of HIV antibodies in newborns. Newborn HIV seroprevalence surveys are conducted in 43 states and territories. Administered by state departments of health, they are funded by the Centers for Disease Control and Prevention, the states, in some cases, by the National Institute of Child Health and Human Development.

Since reported AIDS cases give no indication of the prevalence of HIV infection in the population at large or in selected populations or geographic areas, the surveys are a method, among others in New York State, to assess the extent of HIV infection in a given population. Newborns carry their mother's HIV antibodies at birth, without necessarily being infected themselves, and thus are a measure of HIV seroprevalence and epidemiological trends in childbearing women. New York uses the data to make decisions about program allocation and funding for HIV prevention and treatment services for women.

The Survey is an epidemiological study, not a public health screening program. Tests are not linked to individual mothers or newborns, are not done in conjunction with counseling and treatment services, and do not produce results quickly enough for clinical application.

Blinded testing of all newborns for the presence of maternal HIV antibodies began in New York State in November 1987. As of September 1993, the Department of Health had tested 1.6 million newborns (96 percent of those born since the start of the survey).

<u>Screening for Congenital Diseases in New York State</u>

New York screens for seven congenital diseases. Hospitals tell parents that blood has been drawn to screen for congenital disorders and that some blood may be used for other purposes (HIV is not mentioned as it is not part of newborn screening). Blood is taken by heelstick a day or two after birth. Parents may refuse congenital screening for religious reasons, in which case the blood sample from their infant is destroyed. Fewer than ten parents per year refuse screening.

In the event of congenital disease, the attending physician of record, the hospital, and the appropriate specialty care center (the regional center for a specific disease) are notified. Parents are contacted by these authorities to bring the child in for evaluation and diagnosis.

There is no reliable estimate of what it costs to contact a parent in the case of a positive newborn test for any of the seven congenital diseases. The cost and success in contacting parents varies widely by hospital, by geographic location, and by disease.

Current HIV Seroprevalence Testing Protocol and Cost

Because the newborn seroprevalence survey is not a screening program, HIV testing is done on the portion of blood remaining after screening for congenital diseases is completed. The only information accompanying the HIV sample is age of mother, race, zip code, hospital, month of birth, and birth weight. These samples are not linked to the portion of the blood sample tested for congenital diseases.

No notification is or can be made currently for a positive HIV sample.

The HIV lab receives the samples from the congenital screening lab two or more weeks after birth. Because specimens are tested in batches to minimize cost and positive tests must be confirmed by retesting the sample, HIV results are available in 1 to 2 weeks. Overall, HIV results currently take 15 to 30 days from birth.

For about 4 percent of samples there is either insufficient blood remaining after congenital screening to test for HIV or the sample was never received. About 75 percent of requests for a second sample are successful.

Laboratory costs for the seroprevalence survey in New York State are currently about $3 million per year.
raises for personnel.

Appendix G

Types of HIV Tests

HIV TESTING TECHNOLOGY

Standard Antibody Tests

There is no test for AIDS, which is a diagnosis made according to clinical criteria established by the federal Centers for Disease Control and Prevention (CDC). However, standardized tests for HIV infection can detect HIV antibodies once they have reached adequate levels. (Antibodies are protein molecules produced by white blood cells to counteract invasion by infectious agents.)

Antibody tests

The first test used to screen people for antibodies to HIV is an **ELISA** (enzyme-linked immunoassay). A positive ELISA test is followed by a **HIV Western Blot** assay.

Currently in New York State, Elisa testing is done in certain commercial labs; all Western Blot testing is done by the Wadsworth Center for Laboratories and Research of the New York State Department of Health.

ELISA tests may produce false negatives (due to insufficient antibody in the blood, which is common in the early stages of infection) and occasional false positives. Suspected test inaccuracies, or ELISA and Western Blot results that are discrepant, require repeat testing.

All children born to mothers with HIV infection test positive on the ELISA test either because they are actually infected (15-25 percent of the time) or they carry maternal HIV antibodies. Specialized lab tests are necessary in order to more accurately identify newborns who are HIV infected.

Non-Standard Tests

Viral Isolation

Co-culture consists of incubating white blood cells from an HIV-exposed individual with susceptible cells from a non-infected person under optimal conditions for HIV growth within a culture. The lab then tests for the presence of HIV in the previously uninfected cells.

Viral Components

PCR (Polymerase Chain Reaction) testing looks for viral nucleic acid in the white blood cells of HIV-exposed persons. PCR involves the amplification of HIV genes (increasing them to detectable levels) in a DNA sample. The test involves 32 cycles of amplification with a theoretical doubling of the HIV gene copy in each cycle.

Antigen tests look for viral proteins which can precede the appearance of HIV antibodies in the blood. Antigen is present primarily early in HIV infection and in the very late stages of AIDS when the immune system has been destroyed. One problem, therefore, is insensitivity in known infected people, both adults and infants.

The test uses an antibody to trap HIV proteins; in children, their own antibodies or their maternal antibodies can bind to the antigen and obscure it from immunological detection. A new methodology tries to free the antigen from antibodies to make it more detectable. This involves pretreatment of the sample with acid. Both acid associated and free acid antigen tests have some problems that currently prevent widespread use for HIV detection in infants.

In 1991, Wadsworth began a pilot HIV testing program to find the best and fastest test for HIV in infants. To date, the project includes 245 at risk infants who were enrolled at one week of age. Among known HIV infected infants, about 40 percent tested PCR-positive in the first week of life; 75 percent tested PCR-positive between 1 and 3 weeks; almost 100 percent tested PCR-positive by 1 to 3 months of age. (Only two specimens did not test PCR positive in the 1 to 3 month age range).

PCR's ability to find only 40 percent positive in the first week of life may not be due to limitations of the testing method. It may be that the only children identified in the first week of life are those infected in utero and that others are infected postnatally.

Wadsworth Laboratory has chosen not to use co-cultures as an early diagnostic procedure because of a turnaround time of 7 to 28 days. PCR turnaround takes only 2 days.

Test:	Difficulty	Cost	Turnaround
PCR	Complex	$175	2 days
Co-culture	Complex	$200-400	7-28 days
Antigen	Moderate	$40-100	2 days
ICD-Antigen	Moderate	$40-100	2 days

Currently, none of the non-standard tests described above are routinely available, although some institutions have access to them (especially PCR) through various research projects. PCR testing is helpful in determining which infants with HIV antibodies are actually infected. Based on existing research, if an infant is PCR positive, it is almost certain that the infant has the virus. However, it still takes several months to definitively rule out HIV infection in those infants who have maternal antibodies but not the virus.

Appendix H

Continuum of Services for HIV-Infected Families

CONTINUUM OF SERVICES FOR WOMEN AND CHILDREN

PREVENTION/EDUCATION

Woman

- Outreach
- Risk Reduction
- Parenting
- Managing HIV Disease (for self/child/family)
- Peer Education
- Community Norms Modification
- Violence Prevention
- GED & Vocational Training
- Long - Term Behavior Modification (Skills Building)

Child

- HIV Prevention Educaiton (age appropriate)
- Preschool Programs
- Special Education Services (specialized education services and access to school - based health services)

HEALTH SERVICES

Woman

- HIV Counseling & Testing
- HIV Primary Care
- Women's Health Care (GYN, Family Planning, Prenatal Care)
- General Health & Specialty Care
- STD Clinics
- TB Care
- Dental Care
- Clinical Trials
- Acute Care

Child

- HIV Counseling & Testing
- HIV Primary Care
- General Pediatric Care
- Subspecialty Care
- TB Care
- Dental Care
- Clinical Trials
- Developmental Services (Early Intervention)

CONCRETE SUPPORTIVE SERVICES

Woman

- Case Management
- Transportation
- Family Support
- Escort Services
- Homemaker Aides
- Home Visits
- Clothing and Furniture

Child

- Cash Fund for incidentals such as toys, diapers, etc
- Medical Transport of children on oxygen or those requiring suction

FINANCIAL/INSURANCE ASSISTANCE

Woman

- Medicaid
- ADAP
- ADAP Plus
- AFDC
- SSI/Medicare
- HEAP Assistance
- Interpretation of Private Insurance Benefits
- Employment Referrals

Child

- Medicaid
- ADAP
- ADAP Plus
- SSI
- Child/Teen Health Plan
- Child Health Insurance Program

SHELTER/HOUSING

Woman

Assistance With:

- Emergency Shelter
- Obtaining Tier II Transitional Housing
- Obtaining and Keeping Permanent Housing
- Helping Client with Housing Repair Issues
- Supportive Housing

Child

MENTAL HEALTH SERVICES

Woman

- Individual Counseling
- Group Counseling
- Peer Support
- Day Treatment
- Crisis Intervention (24 hour)
- Psychotherapy
- Family Therapy
- Bereavement Counseling
- Buddy Support
- Building Self Esteem
- Recreation Activities

Child

- Child Life Programs
- Play Therapy
- Counseling (for older children as needed)
- Recreation Activities

DRUG TREATMENT SERVICES

Woman

- Harm Reduction Counseling
- Needle Exchange
- Detoxification
- Residential Treatment Program
  - - Drug free
  - - MMTP
- Outpatient Treatment Programs
  - - Drug free
  - - MMTP
- Outpatient Individual Counseling
- Acupuncture

Child

- (Drug Treatment programs should address special needs of the children of women in treatment)

CHILD CARE SERVICES

Woman

- Interim Day Care
- Babysitting
- Medical Respite

Child

- Interim Day Care (regular or specialized if child has needs that require medical oversight and developmental services)
- Babysitting
- Medical Respite

LONG TERM CARE

Woman

- Home Health Services
- Day Treatment
- Nursing Facility Care (HRF & SNF levels of care)
- Hospice

Child

- Home Health Services
- Nursing Facility Care (HRF & SNF levels of care)
- Hospice

NUTRITION SERVICES

Woman

- Assistance in Accessing
- Food Pantry
- Congregate Meals
- Home Delivered Meals
- Nutrition Counseling
- Emergency Cash Assistance for Food
- WIC
- Food Stamps
- Special Diets
- Nutritional Supplements (i.e. Ensure)

Child

- Formula
- School Meals
- Special Diets
- Nutritional Supplements (i.e. Ensure)

LEGAL SERVICES

Woman

- Related to Immigration Status
- Outstanding Criminal Record
- Landlord/Tenant Conflict Resolution
- Child Custody
- Permanency Planning
- Living Will
- Power of Attorney
- Wills
- Disclosure of HIV status
- Discrimination

Child

- Foster Care
- Protective service issues
- Custody Issues

Appendix I

Cost Projections for Enhanced HIV Counseling, Testing, and Treatment Services for Pregnant and Postpartum Women and HIV Positive Infants

Cost Projections
HIV Counseling and Testing for Pregnant and Postpartum Women
and
Comprehensive Health and Related Services
for HIV+ Infants and Mothers

Cost projections in this document were assembled by staff of the AIDS Institute of the New York State Department of Health at the request of the New York State AIDS Advisory Council's Subcommittee on Newborn Screening. Cost estimates and program designs below were formulated to implement a policy of mandatory HIV counseling with encouraged voluntary testing and expanded treatment services for pregnant and postpartum women, with the understanding that this initiative may be expanded to include other groups. Five million in new funds has recently been allocated for HIV counseling, testing, and treatment services for women and children in hospital reimbursement legislation.

SUMMARY
First Year implementation - **$7,716,000 in new funds** (estimated)
Annualized cost - **$9,046,000** (estimated)

Includes:
$4,360,000 (first year) for expanded counseling and testing for pregnant and postpartum women. Program components:

- a comprehensive public and provider education initiative
- enhancements to existing core grants in the postpartum units of high newborn seroprevalence hospitals
- new grants at currently unfunded high seroprevalence postpartum and prenatal care sites
- a statewide community follow-up strategy for infected pregnant and postpartum women
- increased funds for test-related lab costs
- a system for data collection and analysis to assess program impact
- staff to do contract management and technical assistance

$3,356,000 (first year) to enhance comprehensive health and related services for HIV seropositive infants and their mothers. This program will award core grants to geographically targeted hospitals, community-based providers, and/or consortia. Program components:

<u>Primary Care</u>

- comprehensive examinations
- routine monitoring, including CD4 testing
- PCR testing for infants
- pentamidine administration
- IVIG Administration for children
- developmental assessments for children
- preventive care for children (immunizations)
- acute care visits
- GYN care visits
- colposcopy visits

<u>Related Essential Services</u>

- family-centered case management
- counseling/crisis intervention
- nutrition counseling
- substance abuse counseling
- transportation assistance
- child care assistance

PROGRAM ASSUMPTIONS

Program designs and budgets are based on the following assumptions. Changes will lead to substantial modifications in cost estimates.

1) Mandatory HIV counseling with voluntary testing strongly encouraged will be the new standard of care established by statute for all pregnant and postpartum women in New York State. Public health law and, if necessary, hospital code will be revised to accomplish this and to provide for appropriate maintenance of records and reporting of data.

2) Commercial health insurance carriers will be required to cover the cost of prenatal/postpartum HIV counseling (pre- and post-test) and HIV testing for pregnant women who use private physicians.

3) Medicaid will continue to provide enhanced rates for pre- and post-test HIV counseling and testing in participating facilities. Co-payments for these services will be eliminated. The inpatient Medicaid HIV pre-test counseling rate will be extended to hospitals that do not have grant-funded counseling programs.

4) Core grants to providers will be elected as the most effective way to provide stable administrative support, a base for program development, and funding for non-reimbursable services. High seroprevalence and underserved areas will be specifically targeted for contracts and core grants.

5) Recognizing that the earliest knowledge of HIV status yields the greatest benefit, new and existing programs will emphasize provision of HIV counseling and testing prior to conception and as early as possible in the prenatal period, seeking to focus and strengthen efforts particularly in family planning and prenatal care settings. The obstetrical setting would serve as the "fail-safe" point for mandatory counseling and offer of testing to women who have not previously been seen by health care providers.

6) Harlem Hospital Center's highly effective program featuring intensive, interdisciplinary coordination of HIV counseling, testing, clinical care, and follow-up will be adopted as the standard to emulate throughout the State. Funding would ideally link prenatal, obstetric, pediatric, and primary care providers and would attempt to elicit the level of institutional commitment illustrated by the "Harlem Model" from all providers of care to pregnant and postpartum women.

7) HIV health care programs will be designed to offer comprehensive, family-centered services so that mothers and children can receive HIV care in the same setting.

Report of the

Subcommittee on Newborn HIV Screening

of the

New York State AIDS Advisory Council

APPENDICES

February 10, 1994

Appendix A

Members of the Subcommittee on Newborn Screening

NEW YORK STATE AIDS ADVISORY COUNCIL

SUBCOMMITTEE ON NEWBORN SCREENING

Robert J. Haggerty, MD
Professor Emeritus
Department of Pediatrics
University of Rochester Medical Center

==========

Carolyn Britton, MD
Associate Professor of
Clinical Neurology
Columbia Presbyterian Hospital

==========

Machelle Allen, M.D.
Assistant Professor
Dept. of Obstetrics &
Gynecology
NYU School of Medicine

==========

Petra Berrios

==========

Authur Cooper, MD
Associate Professor &
Chief, Pediatric Surgical Critical Care
Harlem Hospital Center

==========

Louis Cooper, MD
Director, Department of Pediatrics
St. Luke's-Roosevelt Hospital

==========

Nancy Neveloff Dubler, Esq.
Director, Division of Bioethics
Epidemiology & Social Medicine
Montefiore Medical Center

==========

Ana Dumois, Ph.D
Executive Director
Community Family Planning Council

==========

Msgr. Charles Fahey
Senior Associate
Third Age Center
Fordham University

==========

Judith Figueroa
Program Manager
Program for Children & Families
St. Luke's-Roosevelt Hospital

Alan Fleischman, MD
Director, Division of Neonatology
Albert Einstein College of Medicine

==========

Terry Hamilton
Director, HELP/AYUD
Settlement Health & Medical Services, Inc.

==========

Margaret Heagarty, MD
Chief, Department of Pediatrics
Harlem Hospital Center

==========

Keith Krasinski, MD
Associate Professor of Pediatrics
Department of Pediatrics
New York University Medical Center

==========

Hermann Mendez, MD
Project Director
Brooklyn Pediatric AIDS Network
SUNY Health Sciences Center at Brooklyn

==========

Janet Mitchell, MD
Chief of Perinatalogy
Harlem Hospital Center

==========

Lorraine Montenegro
Executive Director
United Bronx Parents, Inc.

==========

Nancy Montgomery, RN
Coordinator, AIDS Program
Nassau County Medical Center

==========

Sandra Palleja, MD
Director, Infectious Disease Clinic
St. Vincent's Medical Center

==========

Mark Rapoport, MD, MPH
Commissioner
Westchester County Health Department

==========

Allan Rosenfield, MD
Dean
Columbia University School of Public Health

Nancy Wade, MD
Assistant Professor of Pediatrics
Director, Maternal Child Program
Albany Medical Center

Marie Williams

Jonathan D. Moreno, Ph.D., Exec. Secretary
Professor of Pediatrics & Medicine
Division of Humanities
SUNY,Health Sciences Center-Brooklyn

Appendix B

Dates and Locations of Subcommittee Meetings

Newborn HIV Screening Subcommittee
Schedule of Meetings

September 15, 1993 • 9:00-12:00, 5 Penn Plaza

October 19, 1993 • 4:30-9:30, 5 Penn Plaza

Public Hearings: November 8, 1993 • 9:00-4:30, 5 Penn Plaza

November 9, 1993 • 9:00-12:00, Bar Association of the City of New York, 42 W. 44th

November 30, 1993 • 9:00-12:00, 5 Penn Plaza

Additional Meeting:
December 13, 1993 • 9:00-12:00, 5 Penn Plaza

Appendix C

List of Presenters at Subcommittee Meetings

List of Presenters at Subcommittee Meetings

Elaine Abrams, M.D.
Harlem Hospital Center

Victoria Alexander, M.D.
Community Family Planning Council

Kathryn Anastos, M.D.
Bronx-Lebanon Medical Center

Stephen Arpadi, M.D.
St. Luke's Roosevelt

Mary Applegate, M.D.
Division of Family Health
New York State Department of Health

Susan Champion, M.D.
Harlem Hospital Center

James Conroy, Ph.D.
Wadsworth Laboratory
New York State Department of Health

Maria Favuzzi
Director, Pediatric AIDS Unit
Child Welfare Administration

Cheryl Healton, Dr.PH.
Columbia University School of Public Health

Hannah Nelson
Bronx Municipal Hospital Center

Lloyd F. Novick, M.D., M.P.H.
Director, Office of Public Health
New York State Department of Health

Michael Rampolla
AIDS Institute

Martha Rogers, M.D.
Chief, Epidemiology, HIV/AIDS Branch
National Center for Infectious Diseases
Centers for Disease Control and Prevention

Lawrence Sturman, M.D., Ph.D.
Director, Wadsworth Laboratory
New York State Department of Health

Appendix D & Appendix E

Public Hearing Testimony
&
Additional Written Statements

STATE OF NEW YORK
AIDS ADVISORY COUNCIL

CORNING TOWER • THE GOVERNOR NELSON A. ROCKEFELLER EMPIRE STATE PLAZA • ALBANY, N.Y. 12237 • (518) 473-7238

DAVID E. ROGERS, M.D.
Chairperson

November 29, 1993

TO: MEMBERS OF THE SUBCOMMITTEE ON NEWBORN SCREENING

As you know, an all-day public hearing on newborn screening was held on Monday, November 8, 1993.

Twenty-six people offered oral testimony, including two mothers with HIV and HIV infected children, representatives from many community based organizations, especially in communities of color, and groups representing the interests of children, women, and medical and public health professionals.

The great majority of statements were against mandatory newborn testing with parental notification. Many supported more aggressive systems of voluntary counseling and testing and greater access to HIV treatment and support services.

Many speakers submitted written testimony as well as oral. The written testimony of scheduled speakers, together with transcriptions of the oral testimony of speakers who did not provide manuscripts, is enclosed here in manuscripts numbered 1 through 26.

Others with an interest in this topic did not speak at the public hearing but did submit written statements. These manuscripts are numbered 28 through 42 and are enclosed here.

Following is a list for your reference of those submitting written and/or oral testimony and their affiliations and manuscript numbers. Numbers do not reflect the order in which speakers testified or manuscripts were received.

PUBLIC HEARING ON NEWBORN SCREENING - Nov. 8, 1993

MANUSCRIPTS OR TRANSCRIBED ORAL TESTIMONY OF SPEAKERS

1	Colin Crawford	Association to Benefit Children
2	Dr. Donna Futterman	Adolescent AIDS - Montefiore
3	Marguerita Rosa	NYS Commission on Human Rights
4	Diana Correa	Latino Commission on AIDS
5	William Viscovich	Counsel for Nettie Mayersohn
6	Theresa McGovern	HIV Law Project
7	Stephan Koblick	Community Family Planning Council
8	Eleanor Mitchell	Woman living with HIV
9	Dr. Wendy Chavkin	Columbia University, Center for Population and Family Health
10	Karin Timour	NY AIDS Coalition
11	Tracie Gardner	Gay Men's Health Crisis
12	Miguelina Maldonado	Hispanic AIDS Forum
13	Dr. Aaron Meislin	Medical Society of State of New York
14	Wilma Montanez	Latina Roundtable on Health and Reproductive Rights
15	Terry Maroney	Gay and Lesbian Anti-Violence Project
16	Jeffrey Reynolds	Long Island Association for AIDS Care
17	Dr. David Williams	Long Island Minority AIDS Coalition
18	Debra Fraser-Howze	Black Leadership Commission on AIDS
19	Dr. Carola Marte	Beth Israel Medical Center
20	Elizabeth Cooper	Task Force Women and AIDS
21	Dr. Vicki Peters	Mt. Sinai Hospital
22	Phyllis Sharpe	Woman living with HIV
23	Patricia Benoit	Haitian Women's Program
24	Lenora Sobers	Women and AIDS Resource Network
25	Ruth Bezares	Mothers of Children with AIDS
26	Dr. Sally Guttmacher	American Public Health Association

SUBMISSIONS OF WRITTEN TESTIMONY ONLY

28	Dr. William Caspe	Bronx Pediatric AIDS Consortium
29	Patrick Moriarty Susan Rosenthal	National Association of Social Workers
30	Diane Welsh	National Organization for Women
31	Ronald Johnson	Office of the Mayor, New York City
32	Michael Swirsky	ACT UP
33		Planned Parenthood Association of the Mohawk Valley
34	Dr. Wade Parks	New York University Medical Center
35	Alma Gomez Nina Perales Nitza Escalera	American Civil Liberties Union; Puerto Rican Legal Defense and Education Fund
36	Ruth Sabo	Family Planning Advocates of New York State
37	Ralph Nappi Dr. Doris Guidi	Nassau County HIV Commission
38	Kelli McMahon	Rochester Region HIV Care Network
39	David Abramson	Columbia University, School of Public Health
40	Dr. Marvin Thalenberg	Rockland County Department of Health (journal article)
41	Shannon Cain	Women's Health Education Project
42	Cheryl Lackman	Bronx Perinatal Consortium

(1)

TESTIMONY BEFORE

NEW YORK STATE AIDS ADVISORY COUNCIL

NEWBORN SCREENING COMMITTEE

BY

COLIN CRAWFORD

FOR

ASSOCIATION TO BENEFIT CHILDREN

NOVEMBER 8, 1993

Ladies and Gentlemen:

Good morning. I am Colin Crawford, and I am appearing on behalf of Association to Benefit Children (ABC), a not-for-profit organization serving homeless, poor and handicapped children and their families in New York City. I am also on the faculty at Brooklyn Law School.

ABC is delighted that you are revisiting the important and difficult issue of pediatric HIV and AIDS testing, treatment and care. For over a year, ABC has been working strenuously, through lobbying, meetings with government officials and various public advocacy groups and others, to articulate its belief that, in light of advances in medical treatment for pediatric AIDS, there is no longer any justification for universal blinding of newborn

HIV test results.

About one year ago, at the request of Gretchen Buchenholz, ABC's Executive Director, I began contacting private and public entities concerned with this issue. One of my first calls was to the AIDS Institute. When I articulated ABC's concern, the staff member with whom I spoke was shocked. "Oh no! Surely no one wants to revisit that issue," my respondent sighed. Revisit the issue we have, and, on behalf of ABC, I applaud the AIDS Institute for hosting hearings to review this political hot potato just one year after expressing reluctance to reconsider it.

Although ABC engages in advocacy (most notably in bringing the "boarder babies" lawsuits), its work is largely practical. ABC's interest in this issue arose in the course of administering its programs. Specifically, we confronted the issue in our role as both a day care/therapeutic nursery provider and as an organization that provides transitional, "Tier II" housing to previously homeless families -- many of whom are dealing with HIV. In case after case, ABC was seeing children, from newborns to pre-teens, who developed an AIDS-related opportunistic infection soon after they entered our care. In most, but happily not all cases, these children died in relatively short order, typically from complications associated with the deadly but treatable pediatric HIV killer, pneumocystis carinii pneumonia (PCP), a disease that,

as many of you know, affects hundreds of newborns in New York State each year -- 70% of whom will survive less than six months.

These tragically high numbers convinced ABC that the Commissioner of Health's policy of testing newborns for HIV but blinding the results constitutes a shameful neglect of his duties. Our conviction was confirmed in conversations with pediatric health care providers throughout New York City and across the state.

Because the lives of infants and children can and are being saved by early detection and treatment for pediatric HIV, there is, quite simply, no longer any reason that organizations like ours -- not to mention literally thousands of other parents and guardians each year who are responsible for children with HIV -- should be left to do too little too late merely because the government is unwilling to address the complexities of and allocate the funds necessary to test and treat for and educate people about pediatric HIV.

This is particularly true where the civil liberties concern typically raised by opponents of this issue, namely that compulsory testing robs the HIV-infected mother of the right to make choices about the health of her child (and, by implication, forces her to confront painful realities about her own health), is being rendered increasingly less compelling due to developments in HIV testing and treatment. To be exact, new tests, including the Polymerase

Chain Reaction test, are now widely available and their cost is increasingly reasonable. They are also more reliable than past tests and help identify the approximately 30% of infants born to HIV-infected mothers who will actually test HIV-positive themselves. This amounts to at least 500 infants born in New York State each year who actually carry HIV. (Although approximately 2,000 newborns annually will test positive for HIV at birth in New York, 1,500 will later "sero-convert". It is ABC's understanding that these new tests are less likely than previous tests to identify the sero-converters.) Moreover, because treatment for PCP is most effective if administered within an infant's first three months of life, it is ABC's view that we must recognize the civil liberties interests of these infants and children to live in good health into adolescence and perhaps beyond. It is worth emphasizing that the failure to test and treat results in high infant mortality if diseases like PCP are not avoided in the first three to six months of life.

Therefore, it is ABC's view that newborn HIV test results should be unblinded immediately. In conjunction with this essential and tragically-delayed step, ABC also believes that it is essential for the Departments of Health and Social Services to implement comprehensive counseling, treatment and education programs for infected infants, children, their mothers and fathers, or their guardians. Whenever possible, these programs should focus

on the health of the entire family, and not just that of the mother and child.

As a first step to implement these measures, ABC urges the Commissioners of Health and Social Services to implement unblinded tests, counseling and treatment programs for both all children in foster care and all those who have risk factors for HIV. As wards of the State, this is an action that can be effected with relative speed and efficiency (and may build upon efforts already underway by the New York City Child Welfare Administration which, although incomplete in ABC's view, are at least a step in the right direction.) However, ABC remains firmly committed to the view that the unblinding of foster care results be a first-step only, and not a compromise solution for a politically sensitive issue.

In closing, let me add a couple of observations about likely advantages of the position I have articulated here. In ABC's experience, when a mother learns that she and her child are HIV-positive, the result is not abandonment or neglect, as some scare-mongers may tell you. On the contrary, ABC has repeatedly observed the contrary result, namely that a positive test result causes a mother to focus on and bond with her child, and to concentrate on protecting both of their health and well-being. In addition, it is ABC's belief that these measures will help end the unnecessary fear and shame associated with HIV and AIDS, to help increase public awareness as to

the fact that although not yet curable, HIV is a treatable condition that, if managed properly, can allow someone -- infant, child or adult -- many happy, healthy years.

When I began, I mentioned that ABC has investigated possible options for changing the unconscionable policy of blinding newborn HIV results. One option we have seriously pursued is a lawsuit to force this issue to a head. To this end, we have prepared a complaint and identified possible plaintiffs. But ABC certainly hopes it does not have to come to this, recognizing that hearings like this one and legislation like that proposed last year by Assemblywoman Mayersohn and Senator Villella are less antagonistic methods for developing the proper approach to issues like pediatric HIV care.

I am offering into the record a copy of "A Preventable Crisis," a report on this subject issued by ABC in September. Thank you for your time and attention.

BROOKLYN LAW SCHOOL
250 JORALEMON STREET
BROOKLYN, NEW YORK 11201

COLIN CRAWFORD
INSTRUCTOR OF LAW

AREA CODE 718
780-7558
FAX NO. 718-624-6557

November 11, 1993

Carolyn Britton, M.D.
Associate Professor of Neurology
Director - Ambulatory Care
Columbia Presbyterian Hospital
710 West 168th Street - 2nd Floor
New York, New York 10032

Re: Request for Infant HIV Testing Under CWA Policy

Dear Dr. Britton:

You will recall that I testified on behalf of Association to Benefit Children (ABC) at the November 8, 1993 hearing of the Subcommittee on Newborn Screening. This is to follow-up your question to me concerning the required approvals for testing of children in foster care under the New York City Child Welfare Administration's (CWA) new policy.

I enclose copies of pages 7-11 and 17-27 of CWA's Bulletin No. 93-2 (dated September 13, 1993), titled "HIV Testing of Children in Foster Care." As I thought, the procedure for requesting testing is somewhat more complicated than merely obtaining the approval of the Commissioner of Social Services. As you can see, there are different requirements for children in foster care (pages 17 - 20) than for children not yet placed in foster care but in the Commissioner's custody (pages 23 - 25). In addition, in all cases, the person or entity completing a request for testing must authorize that a child is free for adoption or that the parents or guardians were identified and counseled (or that attempts were made to identify and/or counsel the parent or guardian).

For your information, I also enclose a copy of ABC's May 28, 1993 criticisms of CWA's draft HIV testing policy. The draft policy was substantially unchanged in the final form before you.

Please do not hesitate to contact me or Gretchen Buchenholz, ABC's Executive Director (212-831-1322), if you have further questions.

Sincerely,

Colin Crawford

CC:ga
Enc.

cc: Dr. Robert J. Haggerty, Subcommittee on Newborn Screening Co-Chair (w/enc.)
Other Subcommittee Members (w/o enc.)
Ms. Eileen Tynan, AIDS Institute (w/enc.)
Ms. Gretchen Buchenholz, Executive Director, ABC (w/o enc.)

D. HIV Testing of Child Without Capacity to Consent

1. Risk Factors for HIV Infection

HIV testing of children who lack capacity to consent may only take place if the child is determined to be "at risk" for HIV infection. The need for such diagnostic testing is based on the child's age, medical history, environmental background and current physical/developmental condition. The risk factors described below are the criteria to be used in making this determination.

For all children from birth to two years of age, a risk assessment for HIV infection must be completed *within 30 days of the child's placement in foster care.* This is also the time period during which all children entering foster care must be given a comprehensive medical examination by a physician, according to New York State Department of Social Services' regulations.

The factors listed below indicate risk of perinatal/vertical transmission and of direct transmission of HIV infection.

Risk Factors Associated with Perinatal/Vertical Transmission

Infant/Child

- has had a positive drug toxicology or displayed symptoms of drug withdrawal at birth
- has had a positive test for syphilis
- has a sibling diagnosed as HIV-positive or who has died of HIV-related illness/AIDS
- displays symptoms consistent with HIV infection
- was abandoned at birth and no risk history is available

Mother, Father or Sexual Partner of Parent

- has been diagnosed as HIV-positive, has symptoms consistent with HIV infection, or has died of HIV-related illness/AIDS
- is known or reported to be a drug injector or engaged in sharing of needles, other equipment (e.g., for injecting drugs or steroids)
- is known or reported to use non-injection drugs (e.g., crack/cocaine)
- has been diagnosed with or has a history of sexually transmitted diseases (STDs), including syphilis, gonorrhea, hepatitis B, genital herpes
- has a history of tuberculosis

- is known or reported to have engaged in prostitution, had multiple sex partners or engaged in the exchange of sex for money, drugs, food, housing, etc., prior to child's birth
- received a transfusion of blood or blood products, including clotting factors, between January 1978 and July 1985 in this country
- received a transfusion of blood or blood products, including clotting factors, in a country where the blood supply is not screened

Sexual Partner of Mother or Father

- is a man who has had sex with other men

Risk Factors Associated with Direct (Non-Perinatal) Transmission

Child or Youth

- was or was reported to have been sexually abused
- is sexually active and not using condoms or other protective barriers during sexual intercourse
- has been diagnosed with or has a history of other sexually transmitted diseases (STDs), including syphilis, gonorrhea, hepatitis B, genital herpes
- is known or reported to have engaged in prostitution, had multiple sex partners or engaged in the exchange of sex for money, drugs, food, housing, etc.
- is known or reported to be a drug injector or engaged in sharing needles, other equipment (e.g., for injecting drugs or steroids)
- is known or reported to use non-injection drugs (e.g., crack/ cocaine)
- has a history of tuberculosis
- received a transfusion of blood or blood products, including clotting factors, between January 1978 and July 1985 in this country
- received a transfusion of blood or blood products, including clotting factors, in a country where the blood supply is not screened

2. Who May Request Consent for HIV Testing

For children in foster care who lack capacity to consent, the following may request consent for HIV testing:

- a foster or prospective adoptive parent when the request for testing is warranted based on the presence of risk factors and is reviewed and recommended by a physician
- a foster care agency physician or other physician caring for the child, or physician's assistant or registered professional nurse qualified to provide primary care services under a physician's supervision when a child's medical history, background or other risk factors warrant such testing.

Note: Foster care agency personnel other than those identified above cannot initiate a request for consent for HIV testing of a child.

3. Who May Consent for HIV Testing

Consent for HIV testing for a child who lacks capacity to consent can only be given by the following persons within the conditions specified:

- Parent or legal guardian* of child in cases of voluntary placement or in cases of placement under **Articles 3 and 7 (JD and PINS)** of the Family Court Act. (The consent of the Commissioner of Social Services is not required and such consent is not sufficient in such cases unless the Commissioner is the legal guardian of the child under sections 383-c, 384 and 384-b of Social Services Law, or unless a parent has provided in writing to the Commissioner express delegation of authority to consent.)

-OR-

- Commissioner of Social Services of New York City, or the Commissioner's designee, *when a child has been taken into protective custody or has been placed in the care and custody of the Commissioner as an abused or neglected child under Article 10 (Abuse/Neglect) of the Family Court Act.*

The Pediatric AIDS Unit of the Child Welfare Administration **is the sole designee authorized** to give consent on behalf of the Commissioner for HIV testing.

* *PARENT*:

A child's birth mother or legally recognized birth father whose legal rights, in regard to the child, have not been legally surrendered or terminated. A birth father is legally recognized if: 1) he was married to the child's mother at the time of the child's conception, gestation or birth, or 2) he has obtained an order of filiation from a court.

A person who has legally adopted the child and whose legal rights, in regard to the child, have not been legally surrendered or terminated.

Does not refer to the child's foster parent.

* *GUARDIAN*:

A person who has been given letters of guardianship for a child by a court of law. Where a person has been named as a "stand-by" guardian of a child by that child's parent, the "stand-by" guardianship must have gone into effect and must have been ratified by a court or must be pending for ratification before a court.

4. Good Faith Effort to Obtain Parental Consent

Once a child who lacks capacity to consent has been placed in the care and custody of the Commissioner of Social Services in accordance with Article 10 of the Family Court Act, as a matter of CWA policy, parent or legal guardian consent alone is not sufficient to proceed with HIV testing. Consent for testing must be sought and received from the Pediatric AIDS Unit (PAU).

However, CWA policy requires that, in addition to consent from the PAU, a good faith effort is made to locate and obtain informed consent from the *parent or legal guardian* of the child.

Good faith effort consists of:

- a personal visit and mailgram to the last known address if there is reason to believe a parent or legal guardian still lives there

-OR-

- a mailgram to the last known address if the present address of a parent or legal guardian is unknown.

Note: Three business days must be allowed for a response to a mailgram.

5. Pre-test and Post-test Counseling of Foster or Prospective Adoptive Parents and Parents or Legal Guardians

In compliance with New York State Public Health Law, pre-test and post-test counseling are an integral part of the HIV test consent process. *Pre-test counseling* must be made available to foster or prospective adoptive parents and parents or legal guardians on a one-to-one basis when a request for testing is made either by a physician or a foster or prospective adoptive parent. *Post-test counseling* must be made available to foster or prospective adoptive parents and parents or legal guardians to explain the test result and explore its implications.

HIV pre-test and post-test counseling can be provided by a trained agency staff person or by an off-site health or human service professional certified as an HIV counselor. When off-site services are used, foster care agencies must identify geographically accessible resources where foster or prospective adoptive parents and parents or legal guardians can receive HIV counseling and testing services and appropriate linkages to care (see Appendix E).

Training for foster care agency staff on pre-test and post-test counseling may be obtained through various resources in New York (see Appendix F).

Two attachments, adapted from informational literature prepared by the New York City Department of Health, provide basic considerations for pre-test and post-test counseling of Parents and Foster or prospective adoptive parents:

- Special Considerations for HIV Counseling of Foster Parents and Parents of Children in Foster Care (see Appendix G)
- Important Information for Foster Parents on HIV Infection, Diagnosis and Care (see Appendix H)

A. Request from Foster Care Agency

1. Introduction

The Pediatric AIDS Unit (PAU) is the Commissioner's designated agent for giving consent for HIV testing when *a child lacks "capacity to consent" and a child is placed with the Commissioner pursuant to Article 10 of the Family Court Act.* A foster care agency must comply with the following requirements when requesting consent for testing from the PAU:

- complete Form PAU-1, "Request for Consent for HIV Testing for Child in Foster Care" (see Attachment 1), providing the PAU with the information required to review and respond to the request for consent for HIV testing, including:
  - identification of risk factor/reason for HIV testing
  - signature of physician recommending HIV testing (physician's name may be written by a person whom the physician has expressly authorized to provide physician's signature)
  - information concerning pre-test counseling of foster or prospective adoptive parents
  - information concerning pre-test counseling of child's parent(s) or legal guardian(s)
- complete arrangements for actual testing if PAU consent is obtained
- report HIV test result to the PAU
- notify the child's CWA case manager of the consent for HIV testing and of the test result
- if the child was not HIV tested at a specialized pediatric HIV center, immediately refer a child who tests HIV antibody positive to such a center for care; the child's HIV status may be definitively confirmed through direct viral tests now available at most of these centers
- arrange for HIV re-testing as appropriate.

2. Risk Assessment Requirements

A risk assessment is an evaluation of a child in order to make an informed determination about whether a child should be tested for HIV based on the risk factors described in section I-D, pages 7 and 8 and on Form PAU-1. A risk assessment must be completed in the following circumstances:

- for children from birth to two years of age, *within 30 days of the child's placement* in foster care (this is also the time period during which all

children entering foster care must be given a comprehensive medical examination by a physician)

- for children more than 2 years of age, *if any of the following request a test* for HIV:
  - foster or prospective adoptive parent upon a recommendation of or review by the child's physician
  - agency physician or other physician caring for the child, or a physician's assistant or registered professional nurse qualified to provide primary care services under a physician's supervision, who judges a need for such diagnostic testing on the basis of the child's age, medical history, environmental background, and current physical/developmental condition.

For children meeting **one or more of the risk criteria**, a request for consent for HIV testing **must** be initiated.

3. Completing Form PAU-1

The following are instructions for completing Form PAU-1, "Request for Consent for HIV Testing for Child in Foster Care."

Identifying Information

- **Agency identifying information** - enter the name and address of agency

- **Child Identifying Information**
  - enter the child's name, date of birth, CWA number, ethnicity, and sex
  - enter the CWA case name
  - check if the child is placed on an Article 10, or is legally freed for adoption, or placed voluntarily, or on an Article 3 or 7
  - enter the CIN number (WMS Client Identification Number)
- **Placement Information**
  - enter the date child was placed with the agency
  - check if the child is placed with a relative (Y = yes, N = No)
  - enter the placement facility type (FBH, AOBH, GH, GR, INST) and the zip code of the placement home or facility

A. Risk Factors - place an (x) in each box that pertains

- **Physician Signature:** print and sign the name of the physician who determines that there is a risk for HIV infection (the physician's name may be written by a person whom the physician has expressly authorized to provide physician's signature)

B. Agency Certification - agency staff must attest on Form PAU-1 to the following statements before CWA's Pediatric AIDS Unit can consent to testing (when the child lacks capacity to consent and the Commissioner has authority to consent):

- Foster or prospective adoptive parent received pre-test counseling

-AND-

- Child legally freed for adoption

-OR-

- Parent or legal guardian received pre-test counseling and gave informed consent for the HIV test

-OR-

- Parent or legal guardian was located and agreed to appear for pre-test counseling, and then failed to appear

-OR-

- Parent or legal guardian's whereabouts are unknown: Good faith effort as defined in section I-D Page 9 to locate the parent or legal guardian was unsuccessful

-OR-

- Parent or legal guardian was located but refused to give informed consent for HIV testing of the child. Checking this box certifies all of the following:
  - Efforts have been made to counsel and educate the parent or legal guardian about benefits to the child of HIV testing; and,
  - Counseling/education was conducted by a physician, psychologist, nurse, or trained and certified HIV counselor; and,
  - Counseling/education occurred no more than three weeks prior to date of the certification.

Note: If, as certified, the parent or legal guardian will not give permission to test a child, the PAU will honor the parent or legal guardian's decision unless the child's physician attests that, because of problems with the child's health or wellbeing, an HIV test is medically exigent. If the child's physician attests that an HIV test is medically exigent, the Commissioner will give consent to the administration of the test based on the Commissioner's authority pursuant to Article 10, court ordered guardianship, or written delegation of parental authority.

To show that an HIV test is medically exigent, the physician must send the PAU a written statement containing all of the following:

1) *The specific problems that the child has experienced; and*
2) *That the physician knows that the parent or legal guardian has refused to consent to the child's test; and*
3) *The reasons why an HIV test is required for the child's care despite the fact that the parent or legal guardian has refused to consent to the test*

In cases where a physician determines there is an immediate and urgent medical necessity for HIV testing of a child in foster care, the case may be brought to the attention of the PAU by phone/fax for prompt review.

- **Agency Representative Signature** - print the name and telephone number of the foster care agency representative; the representative must sign and date the form attesting the "Agency Certification"

4. Form Distribution

Form PAU-1 is distributed as follows:

- file one copy in the child's medical record
- send one copy to the PAU (or call to obtain fax information):

Child Welfare Administration
Pediatric AIDS Unit
80 Lafayette Street - Room 1701
New York, N.Y. 10013
Telephone (212) 266-3028

5. Pediatric AIDS Unit Review and Consent

Upon receipt of Form PAU-1, the PAU will review and evaluate the request to determine if it meets the criteria set out above. If on review the request meets all criteria, the PAU will issue a consent in a timely manner. The PAU may contact appropriate legal or medical consultants for further information before granting consent. If the request is denied, the reasons for the denial will be sent in writing by the PAU to the foster care agency representative.

If the HIV test consent request is approved, the PAU sends the "Consent to Testing" package described below to the foster care agency. Upon receipt of consent, the foster care agency must complete all arrangements to take the child for the drawing of the blood specimen.

Consent to Testing Package:

- Form PAU-3, letter indicating the Commissioner's consent to an HIV test
- Form PAU-4, "Notice of Disclosure of HIV-Related Information," (see Attachment 2) warning against further disclosure of HIV-related information without specific written consent or as otherwise permitted by law

- Form PAU-4a, "Initial Test Tracking Form for Child in Foster Care," (see Attachment 3) for use in reporting child's test result to the PAU
- Form DOH-2556z, "Informed Consent to Perform an HIV-Related Test," completed and signed copy of official New York State Department of Health AIDS Institute form required by the health facility that draws the blood specimen for testing
- Form DOH 2557, "Authorization for Release of Confidential HIV-Related Information," completed and signed copy of New York State Department of Health AIDS Institute form required by the health facility to release the test result

6. Notifying the PAU of Test Results

For purposes of program planning and resource development, the State Department of Social Services requires that localities maintain a system for monitoring HIV-positive children in foster care. The PAU maintains a computerized database for this purpose.

Foster care agencies must notify the PAU of the results of any HIV testing approved by the PAU. In addition, the PAU must be notified of any HIV testing where the result is positive or inconclusive, regardless of whether the initial action was initiated in accordance with this Bulletin (i.e., when a parent or legal guardian consents to testing prior to placement in foster care, the testing is court ordered, a child with "capacity to consent" agreed to confidential testing, etc.). The PAU is responsible for tracking all HIV-positive foster children.

When the test result is known, the agency must fully complete and forward to the PAU the following:

- Form PAU-4a, "Initial Test Tracking Form for Child in Foster Care," to report the test result (positive, negative, or inconclusive)

-OR-

- Form PAU-8a, "Addition/Change of Status of HIV-Positive Child," to report HIV-positive children for whom consent for testing was not given by the PAU (see Attachment 4).

The foster care agency must enter the child's test result as well as all other information relating to HIV testing in the child's medical record. (See section I-F page 14 on Confidentiality.)

7. Notifying the Case Manager

In addition to the above, the foster care agency must forward a copy of the consent form and the test result to the CWA case manager for the child's record.

8. Retesting

The foster care agency must schedule retesting at least every six months for children two years of age or under whose HIV antibody test result is positive or inconclusive and who are not proven by direct viral tests to be HIV infected. Retest results must be reported to the PAU on form PAU-7A (see Attachment 5).

B. Request from Hospital For Child Not Yet Placed in a Foster Care Facility

1. Introduction

The Commissioner's consent through CWA's Pediatric AIDS Unit (PAU) is required for HIV testing of hospitalized children who have not yet been initially placed in a foster care facility. The child must lack "capacity to consent" and be remanded by the Family Court to the care and custody of the Commissioner of Social Services under Article 10 (abuse/neglect) of the Family Court Act. A remand is a court order temporarily placing a child in the legal care and custody of the Commissioner of Social Services. As a matter of CWA policy, *the Commissioner will not consent for HIV testing of newborns or hospitalized children not yet remanded to the care and custody of the Commissioner of Social Services.*

Hospital staff must confirm that a remand has been issued. This information may be obtained from the CWA Field Office caseworker responsible for the case. If the caseworker is not known, the assigned caseworker and telephone number may be obtained from CWA's Automated Case Retrieval System at telephone number (212) 266-2500.

Note: For children currently in foster care placement who are hospitalized, a request for consent for HIV testing is made through the child's foster care agency. The agency's responsibilities, including counseling of parent or legal guardian and foster or prospective adoptive parent, are outlined in Section IIA. Contact the child's foster care agency, or contact the PAU for further clarification.

When requesting consent from the PAU, the Commissioner's designated agent for giving consent for HIV testing, a hospital must comply with the following requirements:

- Complete Form PAU-2 "Hospital Request for Consent for HIV Testing for Child Not Yet Placed in a Foster Care Facility" (see Attachment 6) providing the PAU with the information required to review the request for HIV testing and to give a consent, including:
  - identification of risk factor/reason for HIV testing
  - signature of physician recommending HIV testing (physician's name may be written by a person whom the physician has expressly authorized to provide physician's signature)
  - information concerning pre-test counseling of parent(s) or legal guardian(s);
- arrange for actual testing if PAU consent is obtained
- report HIV test results to the PAU

- report HIV test results to the foster care agency with whom the child is eventually placed.

2. Risk Assessment Requirements

A risk assessment is an evaluation of a child for risk of HIV infection based on risk factors described in section I-D, pages 7 and 8 and on Form PAU-2. A risk factor for HIV infection must be present in order for the PAU to review a request and to issue a consent for HIV testing of a child.

3. Completing Form PAU-2

The following are instructions for completing Form PAU-2, "Hospital Request for Consent for HIV Testing for Child Not Yet Placed in a Foster Care Facility". Copies of Form PAU-2 may be obtained from the Pediatric AIDS Unit.

Identifying Information

- **Hospital identifying information** - enter the name and address of hospital
- **Child Identifying Information**
  - enter the child's name, date of birth, CWA number, ethnicity, and sex
  - enter the CWA case name, child's chart number, and medical ready date
- **Case Management Information:** enter the CWA caseworker name, telephone number, and unit/worker number
- **Remand information:** enter the court docket number, date remand was issued, and borough of Family Court issuing the remand.

A. Risk Factors - place an (x) in each box that pertains

- **Physician Signature:** print and sign the name of the physician who determines that there is a risk for HIV infection (physician's name may be written by a person whom the physician has expressly authorized to provide physician's signature)

B. Hospital Certification - hospital staff must attest on Form PAU-2 to the following statements before CWA's Pediatric AIDS Unit can consent to testing (when the child lacks capacity to consent and the Commissioner has the authority to consent):

- Child legally freed for adoption

-OR-

- Parent or legal guardian received pre-test counseling and gave informed consent for the HIV test

-OR-

- Parent or legal guardian was located and agreed to appear for pre-test counseling, and then failed to appear

-OR-

- Parent or legal guardian's whereabouts are unknown: good faith effort as defined in section I-D Page 10 to locate the parent or legal guardian was unsuccessful

-OR-

- Parent or legal guardian was located but refused to give informed consent for HIV testing of the child. Checking this box implies the following:
  - Efforts have been made to counsel and educate the parent or legal guardian about benefits to the child of HIV testing;
  - Counseling/education was conducted by a physician, psychologist, nurse, or trained and certified HIV counselor;
  - Counseling/education occurred no more than three weeks prior to date of certification.

Note: If, as certified, the parent or legal guardian will not give permission to test a child, the PAU will honor the parent or legal guardian's decision unless the child's physician attests that, because of problems with the child's health or wellbeing, an HIV test is medically exigent. If the child's physician attests that an HIV test is medically exigent, the Commissioner will give consent to the administration of the test based on the Commissioner's authority pursuant to Article 10, court ordered guardianship, or written delegation of parental authority.

To show that an HIV test is medically exigent, the physician must send the PAU a written statement containing all of the following:

1) *The specific problems that the child has experienced; and*
2) *That the physician knows that the parent or legal guardian has refused to consent to the child's test; and*
3) *The reasons why an HIV test is required for the child's care despite the fact that the parent or legal guardian has refused to consent to the test*

In cases where a physician determines there is an immediate and urgent medical necessity for HIV testing of a child in foster care, the case may be brought to the attention of the PAU by phone/fax for prompt review.

The hospital should contact the CWA Field Office caseworker to assist in locating and referring the parent or legal guardian to the hospital for pre-test counseling. If the hospital has made a good faith effort to locate the parent or legal guardian prior to a remand, and has been unsuccessful, notation of such

- **Hospital Representative Signature** - print the name and telephone number of the hospital representative; the representative must sign and date the form attesting to the "Hospital Certification"

4. Form Distribution

Form PAU-2 is distributed as follows:

- file one copy in the child's medical record
- send one copy to the PAU (or call to obtain fax information):

Child Welfare Administration
Pediatric AIDS Unit
80 Lafayette Street - Room 1701
New York, N.Y. 10013
Telephone (212) 266-3028

5. Pediatric AIDS Unit Review and Consent

Upon receipt of Form PAU-2, the PAU will review and evaluate the request to determine if it meets the criteria set out above. If the request meets all criteria, the PAU will issue a consent in a timely manner. The PAU may contact appropriate legal or medical consultants for further information before granting consent. If the request is denied, the reasons for the denial will be sent in writing by the PAU to the hospital representative.

If the HIV test consent request is approved, the PAU sends the "Consent to Testing" package described below to the hospital. The hospital is then responsible for completing all arrangements for the drawing of the blood specimen.

Consent to Testing Package:

- **Form PAU-3**, letter indicating the Commissioner's consent to an HIV test
- **Form PAU-4H**, "Initial Test Tracking Form for Child in Hospital," for use in reporting child's test result to the PAU (see Attachment 7)
- Form PAU-4, "Notice of Disclosure of HIV-Related Information," warning against further disclosure of HIV-related information without specific written consent or as otherwise permitted by law
- Form DOH-2556z, "Informed Consent to Perform an HIV-Related Test," completed and signed copy of official New York State Department of

Health AIDS Institute form required by the health facility that draws the blood specimen for testing

- Form DOH 2557, "Authorization for Release of Confidential HIV-Related Information," completed and signed copy of New York State Department of Health AIDS Institute form required by the health facility to release the test result

6. Notifying the PAU and Foster Care Agency of Test Result

When the test result is known, the hospital has the following responsibilities:

- complete and forward Form PAU-4H, "Initial Test Tracking Form for Child in Hospital," to the Pediatric AIDS Unit to inform the PAU of the test result
- for a child remaining in the hospital, post-test counseling must be made available to the parent or legal guardian on a one-to-one basis to explain the test result and discuss its implication
- for a child placed in a foster care facility from the hospital prior to the return of an HIV test result, notify the foster care agency medical director of any HIV test request/result, regardless of whether the initial action was instituted in accordance with this Bulletin (e.g., the parent(s) or legal guardian(s) consented to testing prior to a remand). Under New York State Public Health Law, HIV-related information may be given without written authorization to an authorized agency providing foster care or adoption services.

ASSOCIATION
TO BENEFIT
CHILDREN

Merricat's Castle and
Main Office
316 East 88th Street
New York, NY 10128
(212) 831-1322
Fax (212) 410-0992

All Children's House
135 East 90th Street
New York, NY 10128
(212) 996 2263

Rosie and Harry's Place and
Alcanthus/206 East 124th Street
New York, NY 10035
(212) 996 7734
Fax (212) 996-7738

The Variety House for Children
404 East 91st Street
New York, NY 10128
(212) 369-2010
Fax (212) 369-2107

May 28, 1993

By Telecopy

Carol Marcus, Esq.
Child Welfare Administration
80 Lafayette Street
New York, New York 10013

Comments of the Association to Benefit Children Regarding CWA "Draft Bulletin: HIV Testing of Children in Foster Care"

Dear Ms. Marcus:

These are ABC's comments regarding the Child Welfare Administration's ("CWA") "Draft Bulletin: HIV Testing of Children in Foster Care" ("Draft Policy"). In accordance with your request during our May 5 conference call, we wanted you to have our comments when you returned to the office on June 1. The comments reflect ABC's thorough analysis of the Draft Policy and incorporate both the information you provided to us on May 5 and recent advice from several medical experts.

As we expressed to you during the May 5 call, ABC is generally pleased and encouraged by CWA's determination that a substantial policy change is required concerning HIV testing of children in foster care. However, a number of issues raised by the Draft Policy warrant ABC's comment and CWA's further attention. Our underlying premise is that, in order to provide adequate medical care to children in its

custody, CWA must identify and provide appropriate treatment for all HIV-infected children. We believe that diagnosis and treatment of HIV infection among children entrusted to the Commissioner's care is required by both the United States and New York State Constitutions as well as by applicable statutes and regulations. We are concerned that the Draft Policy falls short of meeting these requirements by limiting the number of children within the Commissioner's custody to whom the policy would apply and by establishing procedures that will unduly delay diagnosis and treatment.

We discuss below a number of specific deficiencies in the Draft Policy that we hope the agency will correct.

1. The Policy Should Cover All Children Within The Commissioner's Custody

As noted at the outset, we believe that CWA should (and is legally required to) identify HIV infection in any and every child committed to the Commissioner's custody. Given the remarkable percentage of HIV-infected children in New York who are in foster care, we do not believe it is sensible or wise to limit HIV identification to those children exhibiting a risk factor enumerated in the Draft policy. All infected children should be identified so that none is denied necessary treatment. Additional advantages in this more uniform approach would be to eliminate (i) the possi-

bility of inconsistent risk assessment procedures or standards among different medical or social service professionals, and (ii) the overlong period which the Draft Policy now provides for the performance of risk assessments.

2. **The Age Range of Children Covered by the Policy is Too Narrow.**

The Draft Policy provides the opportunity for testing of all infants up to two years of age who have one of the enumerated risk factors. This age limitation is unwarranted because (i) substantial numbers of children enter the foster care system at an older age and (ii) the initial onset of AIDS and ARC in older children has been noted with increasing frequency. In light of these facts, the two-year cutoff seems arbitrary and might deny these older children the potential benefits of prophylaxis and other medical treatment that cannot and will not be administered without testing. The government's affirmative legal obligations to provide adequate health care to children within its custody do not lapse after a child's second birthday. Waiting for symptoms of HIV infection to appear in these children unconscionably postpones effective prophylaxis. After conferring with medical professionals, ABC recommends that the age range of children covered under the Draft Policy be expanded to include all children within

the state's care and custody who do not yet possess the capacity to consent to HIV testing. The same risk assessment procedures thus can be used for the expanded age range as for the covered group.

3. **The 30-Day Period for HIV Risk Assessment Is Too Long.**

The Draft Policy prohibits an HIV test in the absence of at least one identified risk factor, and provides 30 days within which to complete the required risk assessment. ABC believes that the 30-day period is too long and lacks any medical justification for its length. Instead, ABC understands that administrative factors have influenced the framing of the 30-day risk assessment period.

In our view, administrative expediency is an insufficient justification for delaying HIV tests, especially when the lives of children are at stake. To allow such concerns to take priority over the right of children in the Commissioner's custody to receive adequate medical care would contravene the government's legal obligations to provide such care.

Infant PCP can occur at any time after birth, with the most prevalent period of onset being between the ages of three and nine months. A delay of 30 days before requesting consent for an HIV test, when added to the numerous other

delays before diagnosis and treatment, will place HIV-infected children at serious risk by forestalling the earliest date on which prophylaxis can begin until those children are perilously close to or beyond the critical age of three months.

The Draft Policy sets forth a multi-step process that will inevitably result in substantial delays from the inception of the process to its conclusion.

- First, many infants will not enter the foster care system immediately and thus will be several weeks closer to the critical age when the 30-day risk assessment period begins to run.
- Second, after the risk assessment is completed, CWA will need time to make a good-faith effort to obtain parental consent to the HIV test.
- Third, whether or not such consent is obtained, more time will pass before CWA approves the request for testing.
- Fourth, additional time will pass before the test can be performed.
- Fifth, two to three more weeks will pass before the test results can be obtained, and another week will then be needed to complete cell cultures to determine a child's HIV status and the medical advisability of prophylaxis.

Our estimate of the total delay built into this process is thus 70-80 days for an infant entering the foster care system immediately after birth, assuming the process works smoothly. The total time between birth and the beginning of

prophylaxis might be even longer for infants whose entry into the foster care system is delayed.

ABC discerns no medical rationale for such a delay. We recommend a risk assessment period of five days, assuming there is the need for a risk assessment at all. See supra at ¶ 1.

4. **The Opportunity for Testing Must Be Provided to Children on "Hospital Hold."**

HIV testing of children under the Draft Policy extends only to children remanded to the custody of the Commissioner by the New York Family Court pursuant to Article 10 of the New York Family Court Act. While the number of "hospital holds" (children kept in the hospital without a court order authorizing the retention) has apparently decreased in recent years, it is our understanding that the problem persists. Under the Draft Policy, these children may be doubly disadvantaged: (i) they are kept in an institutional setting without legal authority, and (ii) because of their custody in a hospital without an authorizing court order, they might actually be denied the HIV-related screening, testing and treatment they may desperately need.

The Draft Policy should be modified to ensure that all children retained in a hospital receive the full benefits of the policy and the potential for effective prophy-

laxis it offers. One way of achieving this goal would be for CWA to ensure (and document) that it has obtained a court order before separating any child from his or her parent.

5. **The Policy Lacks a Mechanism to Evaluate Its Effectiveness.**

The Draft Policy contains no mechanism for CWA to evaluate the effectiveness of the policy as it is implemented. ABC believes that a new policy -- particularly one with a fairly elaborate and potentially cumbersome administrative structure -- requires extensive, ongoing evaluation to ensure that it is properly, effectively, and efficiently implemented. Such monitoring, of course, requires the collection and compilation of accurate information about the policy's effectiveness in practice to determine whether foster children are (i) screened and tested in accordance with the policy and (ii) given the treatment they need following testing. No provision, however, is made to collect or analyze such information.

In our view, which we believe CWA shares, the consistent CWA monitoring undertaken pursuant to the Baby Jennifer and Baby Angel consent decrees allowed the agency to identify, track and remedy problems in an effective, efficient way. Similarly comprehensive monitoring is

required here to determine whether and where implementation problems exist and, ultimately, whether the policy is adequate to achieve the desired goal. Yet the policy omits this essential ingredient.

6. The Policy Fails to Identify or Assure the Resources Necessary for its Success.

While the Draft Policy specifies the personnel who will be charged with carrying out the new policy, it does not indicate how CWA would obtain or assure the sufficiency of resources needed to implement the HIV testing program. This is a significant omission under present political and budgetary conditions. If sufficient resources have been identified, they should be identified in the policy. If they have not been identified, the policy might be destined for failure.

7. The Policy Contains No Effective Date for Its Implementation.

The Draft Policy provides neither an anticipated date of adoption nor an effective date of implementation. ABC presumes and anticipates that CWA will promptly adopt and immediately and vigorously implement the policy in order to satisfy CWA's legal obligations with respect to the medical care of children within its custody. Failure to so

would be the equivalent of failing to promulgate and adopt the policy at all.

* * * *

We offer the foregoing comments as the product of our firm convictions and considerable review and research. As you know, we have been concerned for some time that children infected with HIV have not been identified and provided with available medical treatment. Apparently, CWA shares the concern. The Draft Policy, if implemented promptly and properly, would be a major step forward. If the inadequacies we have pointed out are corrected, then more effective, comprehensive and necessary care would be provided to needy children. This is, in our view, the City's legal and moral duty.

Thank you for your consideration. We await your response.

Very truly yours,

Gretchen Buchenholz
Executive Director

Mitchell St Bernard, Esq.
Special Counsel

Of Counsel:

John W. Cioffi, Esq.
Jonathan E. Richman, Esq.
Mary Beth Hogan, Esq.
DEBEVOISE & PLIMPTON
875 Third Avenue
New York, New York 10022

10778637

NOV 6

(2)

Testimony to:
New York State AIDS Advisory Council:
Subcommittee on Newborn Screening
November 8, 1993

Mandatory HIV Screening for Newborns:
Implications for Care and
Implications for Adolescents

Donna Futterman, MD
Acting Director and Medical Director
Adolescent AIDS Program
Montefiore Medical Center
Assistant Professor of Pediatrics
Albert Einstein College of Medicine

Good Morning. I would like to thank the AIDS Advisory Council and in particular the Subcommittee on Newborn Screening for holding these public hearings as well as providing me the opportunity to testify this morning. My name is Donna Futterman and I am a pediatrician at the Adolescent AIDS Program at Montefiore Medical Center in The Bronx. I have many years experience working with HIV-infected infants and children and for the last 5 years have been the Medical Director of the Adolescent AIDS Program and this year the Acting Director. I speak both from a personal perspective as well as on behalf of several physicians who work together in the Medical Issues Committee of the AIDS & Adolescents Network in New York City including physicians such as Dr. Linda Levin from Mt. Sinai, Dr. Jeff Birnbaum from Kings County, Dr. Steve Tames of Westchester County Medical Center, Dr. Carmen Martinez of Morrisania Health Center, and Teri Lewis the Executive Director of the AIDS & Adolescents Network of NYC all of whom share the perspectives I offer today.

Today I would like to speak against mandatory testing of newborns. I have great dismay that we need to revisit this issue because I feel it is quite a divisive one. There are relatively few providers in the medical system who care about and provide care to HIV infected children, adolescents and adults, and we are fighting among ourselves over this issue, instead of recognizing the much larger problem of involving more health care providers to improve access to care for HIV-infected and at risk children and adults. We need to form a united front and not a battle ground in order to increase resources and access to care. I would like to address 5 points briefly today.

1. Common goal: Increase access to care.

All of us, whatever side we are on this issue, share a common interest and that is the desire to improve access to care for HIV infected and at risk people. This is urgently needed. I think many people will speak to the needs of this for babies and infants and others will speak to the needs of this for all women. From my perspective, working with teenagers and adolescents, I feel this need every day. Two summers ago the Adolescent AIDS Network did a survey in NYC of all the major providers and identified only 350 HIV+ adolescents in care. 150 of these were from the Regional Hemophilia center. Even at that time, we believed there was a great disparity between the number of infected youth and those who were in care. We urgently need to develop more effective strategies to bring infected and at risk

adolescents into care. But I feel that this mandatory testing would work against this goal, is discriminatory against women and certainly has no guarantee of success. In fact we have a tremendous room for improvement in the voluntary programs that do exist.

As an important background piece, I would like to call everyone's attention to the recent analysis by Drs. Mofenson and Moye of the National Institutes of Child Health & Human Development a summary of which appeared in the September 1993 issue of the American Academy of Pediatric News. In this article they stated that pediatric HIV infection, even given recent advances in treatment, does not fit neatly into the traditional framework for screening. HIV infection testing of newborns really serves to test the mother's HIV status and therefore in addition to the health needs of the infant, issues relating to the implication and treatment of HIV infection in the mother need to be addressed in the context of neonatal HIV screening programs. In summary, Mofenson and Moye, leading pediatric investigators from the NIH, felt that we were not at the point medically, where the needs of the infant could be separated from the needs of the mother and did not endorse a mandatory testing program. I have submitted copies of this article.

2. Adolescents have unique service needs.

The 2nd point is that not all mothers are grown-ups. Most people when they think of mothers, think of this uniform concept of women in their 20s and 30s. Working with teenagers, I would like to speak to the special needs that teenagers might have in a mandatory screening program. Those of us working with adolescents with HIV, have developed an understanding that there are special programmatic needs to provide medical care as well as HIV counseling and testing for teenagers. Teenagers are different, therefore any kind of notification program would have to be developmentally appropriate so that the teenagers would understand what's being talked about. Confidentiality issues are also very different for teenagers. Teenagers are allowed on their own to provide consent for HIV testing and many of them have chosen, in the early days of knowing they're HIV+, not to notify their parents because their parents don't always act in their best interests. On the other hand, we feel that teenagers do need a supportive adult during the time when they are notified they're HIV+. Any mandatory testing program that informs teenagers of their HIV status needs to take these complicated issues into account.

Many barriers exist for teenagers who attempt to access care. For example, financial barriers, teenagers do not have independent access for Medicaid separate from their parents. And while there are innovative programs like PCAP or automatic Medicaid eligibility for pregnant teens, those programs do not exist for teenagers who are HIV+. The AIDS Institute has come up with an innovative solution in developing ADAP Plus and allowing teenagers to register for ADAP Plus which would pay for their medical care. But I think we need to recognize that there are unique programmatic needs that will help engage teenagers, because the system as it exists does not always provide that access.

Another issue in which teenagers are different is in risk reduction. We have a tremendous battle taking place in New York City right now in the public schools. There are a quarter of a million teenagers in high schools in NYC and many of us feel we've lost a great chancellor over his willingness to bring realistic risk reduction messages to our youth. There's a realistic possibility that these risk reduction programs will be diminished. For example, the new chancellor has proposed instituting "parental OPT OUT" from the condom availability program.

In summary, risk reduction programs, care programs, counseling and testing programs have unique issues for teenagers and these must be addressed in any kind of new systems that are created.

3. Adolescents with HIV are a growing problem.

The 3rd point is that there are growing numbers of infected teenagers so these programmatic issues will grow in importance. Worldwide, the W.H.O. estimates 12-14 million people are HIV+ and that half of them were infected while they were between the ages of 15 and 24. Among women, we see a shift to younger ages such that the peak of infection for women is usually 5-10 years younger than that of men and we feel that this is reflecting increasing trends in the U.S. as well. A recent Job Corp study looking at kids from 1988-90 found an increase from 2% overall to 4% overall in the HIV+ rate for young women while it went down for young men nationally in the same period. The HIV epidemic is clearly growing and we need to develop more effective ways of engaging youth and all people in care.

The NYSDOH blinded serosurvey, looking at the period November 1987 - March 1990 found that one third of the deliveries were in young women up to the age of 24: 31,000 women were less than 20 years old and they had a

seroprevalence rate of .58 for a total of 180 seropositive women under 20. 72,000 women were between the ages of 20 and 24 they had a seroprevalence rate of 1.18 or 848 HIV+ women. A dramatic increase from 1 in 624 HIV+ 14 year olds to 1 in 71 HIV+ 24 years olds was seen.

4. Mandatory testing programs for adolescents already exist and do not increase access to care.

The 4th point is that mandatory programs already exist in this country and they differentially target youth. The Job Corps, a federally sponsored training program has tested over 300,000 youth. Overall they've found a 1% seroprevalence rate or over 3,000 youth who are HIV+. The military similarly tests all youth who come into the service. These mandatory programs exist and we need to study the impact of these programs on increasing access to care. Anecdotally, we have found that there is delayed treatment seeking. Several youth have come to our clinic months or years after testing HIV+ in the Job Corp or the military which informed them that they had bad blood and needed to see a provider. These mandatory testing programs appear to delay access to care, and certainly do not facilitate it. I would like to know if anyone can find those 3,000 kids who've tested positive in the Job Corps and tell me what percentage of those mandatorily tested youth are in care programs today.

5. Mandatory newborn testing will transform the birthing experience for all mothers in New York State.

The final point is that I think we all need to recognize the implications of this policy. If a mandatory testing program for newborns is implemented, it will transform the birthing process in New York State. HIV testing will become the experience of all women at the time of delivery. Many women, as you know, harbor fears and anxieties about HIV and its role in their lives. This policy, mandating testing at delivery will affect all of them: Every woman in this room whose going to have a baby, you, your wives, your daughters, and your granddaughters. Such a social experiment is not warranted as the solution to the current problem we face with HIV. Thank you.

AIDS experts examine HIV-intervention pros, cons

by LYNNE MOFENSON, M.D., FAAP and JACK MOYE, JR., M.D.

In recent years, a variety of technological and medical advances in the detection and treatment of pediatric HIV infection have occurred. With increasing recognition of the clinical importance of early identification of HIV-infected children, public debate has gained new momentum regarding potential use of universal newborn screening programs as a mechanism for identification of children with perinatally-acquired HIV infection.

Incorporation of HIV testing into existing newborn screening programs is appealing for simplicity for the physician and assurance of patient compliance, and advances in HIV treatment and prophylaxis for opportunistic infections now provide more compelling arguments for early intervention. However, it has not yet been proven that early initiation of these therapies prolongs life for the infant, and there continue to be practical, legal, ethical, social and financial issues fueling the controversy regarding neonatal HIV screening.

The purpose of newborn screening is to prevent the development of disease or to allow physicians to begin treatment for symptoms of disease as early as possible, and to permit counseling of parents of an affected infant. Following the axiom "first do no harm," public health and preventive medicine experts generally consider that preventive interventions should be of proven effectiveness.

In general, the inclusion of a disease in a neonatal screening panel has been justified by the severity, magnitude and public health significance of the condition; the availability of presymptomatic treatment or intervention that is efficacious in preventing serious injury; and an acceptable cost to benefit analysis. Pediatric HIV infection, even given recent advances in diagnosis and treatment, does not fit neatly into this traditional framework for screening.

Pediatric HIV infection is clearly associated with significant morbidity and mortality: the development of symptoms diagnostic of AIDS are estimated to occur during the first year of life in 20 percent of infants with perinatally-acquired HIV infection, with a median survival time after diagnosis of just over six months.

Identification of HIV-infected infants at earlier stages of disease in the United States currently appears to be relatively poor; data from a population-based study in Massachusetts indicate that only 35 percent to 65 percent of perinatally-infected infants have been identified by the health care system by ages 3 years to 4 years.

While pediatric HIV infection is clearly a serious condition, current therapy is ameliorative, not curative. The two licensed anti-retroviral drugs for treatment of HIV infection in children, zidovudine (AZT) and didanosine (ddI), have been shown to improve immunologic and clinical symptoms of HIV infection, including neurodevelopmental abnormalities. However, both drugs may be associated with toxicity (hematologic for AZT, while ddI maybe associated with pancreatitis, peripheral neuropathy or retinal depigmentation). There is currently no data regarding efficacy of early anti-retroviral therapy in asymptomatic HIV-infected children for prevention of disease.

However, a number of pediatric experts point out that early identification of infected infants would allow for more effective medical management which could prolong survival, analogous to the rationale which led to the initiation of newborn screening for sickle cell disease. Similar to pneumococcal infection in infants with sickle cell disease, pneumocystis carinii pneumonia (PCP), the most frequent opportunistic infection associated with pediatric HIV infection, occurs most commonly at an early age (the first three to six months of life), may be the initial disease episode in previously unrecognized pediatric HIV infection, and is associated with high mortality, with median survival from the first episode of only one to four months.

Like penicillin prophylaxis for pneumococcal disease, effective prophylaxis is available to prevent PCP. In March 1991, the U.S. Public Health Service issued guidelines for PCP prophylaxis in pediatric HIV infection. These guidelines recommend initiation of lifelong PCP prophylaxis beginning after the first month of life in all pe-

diatric patients with known HIV infection or indeterminate infection status whenever CD4+ lymphocyte count falls below age-specific limits and for all patients with a prior episode of PCP.

Despite an increase in the proportion of pediatric patients with symptomatic HIV infection receiving PCP prophylaxis from 22 percent to 23 percent in 1989 to 61 percent to 70 percent in 1991, PCP continues to be the presenting manifestation of unrecognized HIV infection in a high proportion (65 percent) of cases, and the proportion of AIDS cases in which PCP is the indicator disease has not significantly decreased (30 percent in 1990-1991).

While these findings may reflect overly conservative existing recommendations for prophylaxis, and/or that further passage of time is required in order to detect temporal differences in PCP associated with changes in medical practice based on recent guidelines, they also suggest that early identification of patients requiring prophylaxis is still inadequate.

Early treatment

Proponents of screening further point out that early identification of infected infants may permit initiation of other adjunctive therapies, such as intravenous immunoglobulin for the prevention of bacterial infections; appropriate modifications and additions to the routine schedule of pediatric immunizations; early monitoring of nutritional status and implementation of aggressive nutritional supplementation at early stages of growth failure; careful monitoring of immunologic and neurologic/neuropsychologic function to evaluate need for initiation or change in antiretroviral therapy; screening and treatment for tuberculosis; and appropriate management of communicable disease exposures.

Those who question the wisdom of incorporating HIV into existing newborn screening programs point out that diagnosis of HIV infection in the newborn remains problematic. Currently available tests for newborn HIV screening measure passively acquired maternal IgG antibodies. These maternally-derived HIV IgG antibodies are not diagnostic of HIV infection in the infant, and may persist up to 15 to 18 months in infants who escape transmission of HIV infection from mother to child. Testing newborns for HIV antibodies is therefore a surrogate measure of maternal HIV infection status, and may for many women be the first time HIV infection is recognized.

While several techniques to facilitate early diagnosis in the newborn are under critical evaluation (such as HIV DNA polymerase chain reaction [PCR]) none are yet licensed for screening purposes. Additionally, even using highly sensitive PCR methodology, 50 percent of infants ultimately found to be infected may be negative by PCR during the first days to months of life. Therefore, a negative test in the neonatal period would not rule out infection in an infant. Using a panel of diagnostic tests (eg., culture, p24 antigen, and/or PCR) the majority of infected infants can be identified by 6 months of age; however, definitive identification of infants as *not* infected requires follow-up until maternal HIV antibody is lost (which may be 12-18 months). Therefore, to identify those infants with actual HIV infection, prolonged follow-up of all HIV antibody-positive infants identified through a screening program would be necessary.

Unlike current newborn screening programs, in which infants are screened for disorders for which their parents are not themselves at risk of morbidity or mortality, HIV testing of newborns really serves to test the mother's HIV status. Therefore, in addition to the health needs of the infant, issues relating to the implications and treatment of HIV infection in the mother need to be addressed in the context of neonatal HIV screening programs.

The Section of Epidemiology of the American Academy of Pediatrics is sponsoring a panel symposium on November 2 at the Academy's 1993 Annual Meeting in Washington, D.C., to review and analyze the various medical, legal and ethical issues that surround the public health policy debate on universal screening of newborns for HIV infection, such as the applicability of general screening program standards to HIV screening, the potential effects of neonatal HIV screening on generic newborn screening programs, and the effects of universal prenatal HIV screening on the participation of women in prenatal care programs. Please join us at this symposium to participate in discussion of this important topic.

Editor's note: Drs. Mofenson and Moye are physicians at the Pediatric, Adolescent & Maternal AIDS Branch at the National Institute of Child Health and Development of the National Institutes of Health in Rockville, Md. The views expressed in this Commentary *do not reflect those of the Public Health Service, nor are they AAP policy.* Commentary *addresses issues of clinical and other technical in-*

TESTIMONY BEFORE THE NEW YORK STATE AIDS ADVISORY COUNCIL NEWBORN SCREENING COMMITTEE

MARGARITA ROSA
COMMISSIONER
NEW YORK STATE DIVISION OF HUMAN RIGHTS

November 8, 1993

Thank you for the opportunity to speak to you this morning about the critical and complex issues regarding the HIV testing of newborns in New York State. On behalf of the New York State Division of Human Rights, I want to thank Assemblywoman Mayersohn for her concern on this matter of vital importance to the people of New York State. The issues related to HIV infection of infants are many and complex, and I commend Assemblywoman Mayersohn for her thoughtful work.

The proposed legislation is intended to accomplish the following goals; to reduce HIV transmission from mothers to babies; to improve and lengthen the lives of HIV-infected babies; and to advise mothers of their own and their infants' HIV status. However there are some serious questions regarding confidentiality, privacy and the potential for discrimination which must be addressed.

HIV testing of infants is indirect, but automatic, testing of the mothers. All of the concerns and difficulties which accompany mandatory testing and disclosure in general are therefore raised by the "unblinding" of the infants' tests. Experience has shown that mandatory testing, rather than providing an avenue for identification and treatment, instead often drives people to totally avoid those situations which will require them to be tested. In Indiana, when HIV testing was made mandatory for the issuance of marriage licenses, many people responded by going out of state to get married. Should New York institute a policy which would essentially have the effect of mandatory HIV testing, it is probable that some women would forego medical treatment entirely for fear of being tested for HIV, and being discriminated against because of the results.

This is not an unwarranted fear. As the agency charged with enforcing the law against discrimination on the basis of disability, the Division of Human Rights is acutely aware that discrimination can and does occur against people whose HIV status is disclosed. From cases brought before it, the Division has documented that breaches of confidentiality have taken place in medical settings, and that the subsequent care level and treatment of people whose HIV seropositive status is disclosed is often very adversely impacted. Breaches of this confidentiality outside of the medical setting itself have resulted in losses of housing and of employment.

In protecting the rights of infants, great care must be exercised that the mothers do not become the "throw-away" population in the equation. The issue of addressing the HIV status for both mothers and infants should not be a "snap-shot" event at the time of birth, but rather should be approached in the context of providing a continuum of pre and post-natal health care, education and support for mothers and their children.

The advice and expertise of the medical, legal social and advocacy communities must be sought and utilized in developing any legislation or programs to deal with this critical matter. Medical issues should not be placed in opposition to legal issues of privacy and confidentiality, and weighed on a scale of priority. A solution must be found which encompasses all of these valid and vital concerns, and insures that the well being and rights or all parties are fostered and protected.

Thank you for your time and attention.

(3)

TESTIMONY BEFORE THE NEW YORK STATE AIDS ADVISORY COUNCIL
NEWBORN SCREENING COMMITTEE

MARGARITA ROSA
COMMISSIONER
NEW YORK STATE DIVISION OF HUMAN RIGHTS

November 8, 1993

Thank you for the opportunity to speak to you this morning about the critical and complex issues regarding the HIV testing of newborns in New York State. On behalf of the New York State Division of Human Rights, I want to thank Assemblywoman Mayersohn for her concern on this matter of vital importance to the people of New York State. The issues related to HIV infection of infants are many and complex, and I commend Assemblywoman Mayersohn for her thoughtful work.

The proposed legislation is intended to accomplish the following goals; to reduce HIV transmission from mothers to babies; to improve and lengthen the lives of HIV-infected babies; and to advise mothers of their own and their infants' HIV status. However there are some serious questions regarding confidentiality, privacy and the potential for discrimination which must be addressed.

HIV testing of infants is indirect, but automatic, testing of the mothers. All of the concerns and difficulties which accompany mandatory testing and disclosure in general are therefore raised by the "unblinding" of the infants' tests. Experience has shown that mandatory testing, rather than providing an avenue for identification and treatment, instead often drives people to totally avoid those situations which will require them to be tested. In Indiana, when HIV testing was made mandatory for the issuance of marriage licenses, many people responded by going out of state to get married. Should New York institute a policy which would essentially have the effect of mandatory HIV testing, it is probable that some women would forego medical treatment entirely for fear of being tested for HIV, and being discriminated against because of the results.

This is not an unwarranted fear. As the agency charged with enforcing the law against discrimination on the basis of disability, the Division of Human Rights is acutely aware that discrimination can and does occur against people whose HIV status is disclosed. From cases brought before it, the Division has documented that breaches of confidentiality have taken place in medical settings, and that the subsequent care level and treatment of people whose HIV seropositive status is disclosed is often very adversely impacted. Breaches of this confidentiality outside of the medical setting itself have resulted in losses of housing and of employment.

In protecting the rights of infants, great care must be exercised that the mothers do not become the "throw-away" population in the equation. The issue of addressing the HIV status for both mothers and infants should not be a "snap-shot" event at the time of birth, but rather should be approached in the context of providing a continuum of pre and post-natal health care, education and support for mothers and their children.

The advice and expertise of the medical, legal social and advocacy communities must be sought and utilized in developing any legislation or programs to deal with this critical matter. Medical issues should not be placed in opposition to legal issues of privacy and confidentiality, and weighed on a scale of priority. A solution must be found which encompasses all of these valid and vital concerns, and insures that the well being and rights or all parties are fostered and protected.

Thank you for your time and attention.

(4)

L·A·T·I·N·O
COMMISSION ON AIDS
80 FIFTH AVENUE, SUITE 1501, NEW YORK, NY 10011
TEL (212) 675-0238 FAX (212) 675-0466

Public Hearing on Newborn Screening

November 8, 1993

Good morning, my name is Diana Correa, I am an attorney and presently the Senior Associate and policy analyst for the Latino Commission on AIDS. Thank you for the opportunity to speak with you today.

The Latino Commission on AIDS, functions as the advocacy arm to those Latino AIDS organizations that provide direct service throughout the state. Our mission is to effectuate public policy, build local and national coalitions, advocate on behalf of community-based organizations, participate in legislative initiatives and give testimony before committees such as this one.

Let me begin with some basic guidelines and truths which will set the framework for the discussion at hand. The face of AIDS has changed. Ten years ago we anticipated that the public health crisis confronting us, that is, the AIDS epidemic would affect the general population. Well, ten years later we know that this is just not the case. AIDS remains an epidemic among gay males and has affected lesbian and heterosexual communities across class and racial lines throughout the state, but in New York as in the rest

of the United States, AIDS is now endemic to Latino and African-American populations. A fact which is critical to how we understand the implications of "unblinding" the New York State newborn seroprevalence study.

With this as the backdrop, we believe that it is incumbent on the Subcommittee to view the prospect of "unblinding" the newborn seroprevalence study through lenses that accommodate not only a public health perspective but incorporate the political and social realities that make up this city and state. I implore everyone here to wear these lenses throughout the day as it will help guide all of us through this important and difficult process.

The goals behind unblinding the study includes identifying HIV infection in infants to provide early medical intervention, prevent HIV transmission from mother to infant and to give women the opportunity for early diagnosis and treatment. I'm positive that there is no one in this room today that doesn't think these goals are important or that they shouldn't be met. The central questions here are whether unblinding the study is the only way to achieve these goals and whether the ends justify the means. Simply put, "unblinding" the study at what cost and who will pay.

Going back to our guiding principles, that is, the face of AIDS in 1993, it is clear who is going to pay. According to the New York State Department of Health Surveillance Report during the period of 1987 through 1992 over 2700 babies born to Latino families and over

5300 babies born to African-American families tested positive of which 10-20% have or will become HIV infected. These numbers are disproportionately high as compared to babies born to white families throughout the States.

Now that we know who will be directly affected, at what cost? "Unblinding" the seorprevalence survey, that is linking the HIV test with the name, and telling the parents of the HIV test result would mean the women who didn't even know that they or their babies were being tested would be told that their infants tested positive for HIV before they left the hospital.

What are the implications here? 1) Unblinding means that it makes women, primarily women of color, the first group to receive mandatory testing other than federal prisoners. 2) Unblinding means that without counseling and support services it will only serve to discourage people from seeking HIV-related care, services and health care generally. This will be particularly true of undocumented and immigrant families who shun traditional health settings for fear of deportation. 3) Unblinding means that scared families will never return to health care settings, making tracking impossible.

Whether inadvertently or by design the fallout from such a proposal wreaks of all the ism's - sexism, classism, racism and maybe most importantly de-humanism. I urge everyone on the committee and in the audience to take it outside what we have categorized here as

the "profiled" group and literally take this scenario home with you - personalize the experience. That is, imagine yourself just giving birth to a baby and without warning, you and your partner are told your baby had been tested without your knowledge or consent and that your newborn is HIV positive. I predict you would feel not only devastated, but unprepared, deceived and scared.

The proposal to "unblind" the seroprevalence study is a poor substitute for the expansion of prevention education, and treatment programs which work hard to create a safe and confidential environment so women can feel comfortable about getting tested or treated on their own accord and without punitive repercussions. Therefore, we urge you to oppose any attempts to unblind the newborn seroprevalence study and to understand this issue within the context of social justice which needs a humane response, not one that is "blind" to the realities of women and families infected and affected by the epidemic.

STATEMENT OF ASSEMBLYWOMAN NETTIE MAYERSOHN
(PRESENTED AT A PUBLIC HEARING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL SUB-COMMITTEE ON NEWBORN AND PRE-NATAL HIV TESTING)
NOVEMBER 8, 1993.

I would like to thank the committee for giving me the opportunity to testify on behalf of my legislation, Assembly Bill 6676, which was introduced during the last session of the legislature and which shall be reconsidered again during the upcoming session.

As you know, the Assembly Health Committee, by a vote of 10 to 9, held the baby AIDS bill pending a study by a panel convened by Dr. Rogers, Chairman of the AIDS Institute Advisory Council. There were at least two members of the Health Committee who were persuaded to withhold their votes in support of my legislation pending the panel's reviews of the Health Department's current policy on newborn testing. As far as the Senate is concerned, there is clear support for this legislation and I have been assured by Senator Velella, the bill's senate sponsor, that it will be considered again in that house during the coming year.

My introduction of this legislation has succeeded in making a previously uninformed public aware of the D.O.H. practice of anonymously testing newborns for the virus without any attempt to report back to parents about the results of those tests. As awareness of this policy has grown, it has become obvious that there is overwhelming support for unblinding these tests so that we can begin to try to give infants the same kind of medical care you would give to any human being who is the victim of a terrible disease. That growing opinion is evidenced by editorials written in support of my legislation by both The New York Times and Newsday, informed and respected newspapers that are considered part of the progressive establishment that supports protecting women's rights and gay rights on every other issue, as do I.

Because of this new public awareness, the policy of the Department is no longer a secret--and no longer can it avoid public scrutiny. I have received countless letters on this issue--and the support for my position is close to unanimous among your average citizen who cannot understand and will never accept a policy that conspires to deny medical treatment and care to any human being, particularly to the most vulnerable among us. Within the medical community, both the New York State Medical Society and the New York City Chapter of the American Academy of Pediatrics have urged passage of my legislation.

All the rationalizations created by the AIDS Institute and the Health Department can never explain to our satisfaction, the fact that, as a result of your policy, doctors have been unable to give HIV positive infants the medical care to which they are entitled or

to provide mothers with the information they need to protect their babies. The policy has been in effect since 1987 and while it is clear that voluntary testing, a process supported by many who oppose my legislation, has been a failure, they would ask you once again to cling to a policy that puts so many babies at risk.

In approaching the task which has been assigned to you, I urge you to disregard the dire predictions of a very small, but vocal group, of public health professionals about suicide rated among HIV mothers going up and women avoiding hospitals when giving birth and on and on. These arguments make little sense to those of us who understand that all you are doing is delaying the inevitable. Those mothers will eventually have to face their own medical condition and that of their babies. Despite all the medical information that has been placed before us, that clearly states that babies with HIV infection must be brought into treatment as soon as possible in order to save their lives or to enhance the quality of their lives--despite all this, this same group of care givers is attempting to dominate the debate by insisting that we ignore the medical truths in order to create some king of illusion that says: WHAT YOU DON'T KNOW WON'T HURT YOU.

So far, I have attended two meetings of the panel and I must tell you that it was an experience I will not soon forget. I have great respect for the people who work in the field of public health--but again I found the reaction of these health care professionals to my proposal very curious. While the medical evidence is conclusive on the benefits of early treatment of HIV infected children-and I will leave most of that testimony to pediatricians who will testify here today--I found myself looking at charts and studies and projections about the dire consequences of letting parents know that their infants have tested positive and may be victims of a deadly disease. After all, I'm told, isn't the suicide rate for male AIDS victims in California higher than that of cancer victims. I find it extraordinary that a health care professional was able to study the statistics on suicide rates among gay men infected with AIDS in California, and speculate on a parallel increase in suicides among pregnant women and mothers. And I have received telephone calls telling me how cruel it would be to give new mothers the terrible news of the child's condition at a time when they may be suffering from post partum depression. One very vocal public health professional whispered to me at a meeting--"Why are you going after the women; why not go after the guys?"

I am also very concerned about the climate of intimidation that seems to hang over the entire debate. I have been told by several people who oversee Health Department programs that they would like to see the tests unblinded--that voluntary programs are not effective and are not reaching enough mothers whose babies have tested positive--but they cannot make a public statement. There seems to be a very real concern about careers or programs or funding. And I have made it clear to Dr. Rogers and Dr. Britton that I do not know whether there can even be an honest debate and

an honest expression of opinion when people state a reluctance to publicly express their views on this issue.

To the public Health Profession who said to me,"go after the guys", in spite of the rather large document you produced, you are way off base on the issues involved in this debate. It isn't about going after the guys or the women; it's not a feminist issue. I consider myself to be an ardent feminist--and hanging on my wall in Albany is the National Organization for Women Legislator of the Year Award that I received two years ago for my strong position on women's rights. No, this is not about women's rights. It is about the morality of allowing babies who have tested positive for the AIDS virus to go home without informing the mother of their condition. It is about allowing babies to go home without an attempt to bring them into treatment which may save their lives. It's about denying treatment to infants because they are too young to line up outside the halls of the AIDS Institute to demand the treatment which has been denied them.

And most important, it's about changing a policy that allows healthy babies to go home to be exposed to the AIDS virus by their infected mothers--only because we think the mother's mental state might be so delicate that she might become suicidal. As a woman who has had children and grandchildren, I have a very different perspective of women who have just given birth. There's a deep sense of concern that almost every woman experiences that her child be normal--have ten fingers, ten toes and be perfect in every way. There's also a knowledge that a certain number of children are born each year with handicaps, disabilities, Down Syndrome--and you pray that your child will not be among them. And there's a certain strength that you gain instantly with the realization that you are now completely responsible for the well being of another precious human being, and no matter what the circumstance, you are consumed with the determination to protect and care for that baby.

I have tried to understand why this disease is viewed so differently, why presumably good people are willing to collaborate to create an illusion--in the so called best interest of the mother--that everything is fine--and if you don't ask for the information, we're not going to do anything that will make you unhappy. The attitude seems to be that if you go home with your illusion and your denial intact, then we have served you well; We're not sure how that will affect the anticipated suicide rate in the long run, but for the present, we have discharged a happy mother.

But what about the long term tragic consequences to the mother and the infant? Will our good intentions in any way help that family survive a dread disease? We have the opportunity to provide that family with support services, with medical care, with counseling. We have the opportunity to help them make plans for the future. These are people who desperately need help--not happy illusions.

And what about the infant. What about his or her right to medical treatment. What about his or her right to be protected from the virus. Let's look at the statistics the Centers For Disease Control have provided. Not projections, not dire predictions, but hard statistics on the number of infants who are being needlessly exposed to the virus as a result of breast feeding by an infected mother.

I would like to read part of a paper presented at the AIDS Conference in Berlin this past winter. The paper was presented by Dr. C.C. Pekham of the Epidemiology And Biostatistics Unit of the Institute of Child Health in London.

"Children of mothers infected prenatally could be at a lower risk of infection from breast milk because of transplacental acquisition of IgG antibodies and because their mothers, unless symptomatic are probably less infectious.HOWEVER, OUR ANALYSIS SUGGESTS THAT, CONTRARY TO THE PREVAILING VIEW, THERE IS A SUBSTANTIAL RISK OF TRANSMISSION FROM MOTHERS WITH ESTABLISHED INFECTION. THE ESTIMATE OF AN ADDITIONAL RISK OF INFECTION THROUGH BREAST FEEDING OF 14% HAS A WIDE CONFIDENCE INTERVAL AND THE POSSIBILITY OF SYSTEMATIC BIAS CANNOT BE EXCLUDED."

And even way back in 1985, the Centers for Disease Control, recognizing the risks of transmission of the virus through breast feeding, recommended that women who are HIV infected must not breast feed their infants.

And I would like to read further the conclusion of the summary of and Italian Study recently provided by the C.D.C..

"RESULTS: BREAST FEEDING INCREASES THE RISK OF HIV-1 TRANSMISSIONS. THE ESTIMATED ADJUSTED ODDS RATIO FOR 1 DAY OF BREAST VERSUS BOTTLE FEEDING WAS 1.19 (95 confidence interval.1-1.28). THE INFECTION ODDS RATIO OF BREAST VERSUS BOTTLE FEEDING INCREASED WITH THE NATURAL LOGARITHM OF THE DURATION OF PRACTICE.'

"CONCLUSIONS: THESE RESULTS ARE THE FIRST TO PROVIDE AN APPRAISAL OF THE ADDITIONAL RISK OF HIV-1 TRANSMISSION ASSOCIATED WITH A SEROPOSITIVE MOTHER BREAST FEEDING HER CHILD. BIOLOGICAL SIGNIFICANCE OF THIS ROUTE OF TRANSMISSION WAS SUPPORTED BY DEMONSTRATION OF A RELATIONSHIP BETWEEN DURATION OF BREAST-FEEDING AND RISK OF HIV-1 TRANSMISSION"

More and more we are seeing statistics that healthy babies--infants who have a chance at escaping the virus--are being needlessly exposed to the virus by an AIDS policy that puts a higher priority on the mother's right not to know than on the life of the infant.

In conclusion, I ask each and everyone of you on the panel who are parents and those of you who are not parents --if this were your child, wouldn't you be outraged at the knowledge that your baby was infected or at risk for an infection, and the AIDS

Institute, in conjunction with the Health Department, had created a policy that, in effect, denies you the information you needed to protect your child?

Any responsible, caring parent would want to have that information. Why do some caregivers take the patronizing position that poor women who give birth in city hospitals feel differently. At Harlem Hospital we were told that they had a very high success rate on voluntary testing, and they believe they were successful because they posed the question in a manner directed towards the child rather than the mother. They did not simply ask the mothers if they themselves wanted to be tested for the AIDS virus. Instead, the mothers were asked,"do you agree to have your child tested for the virus?"... and the overwhelming majority of those mothers agreed because the concern that they had for the wellbeing of the infant overwhelmed any fears that they might have regarding their own condition. To me, that's a very clear indication that given a choice, these parents do not want illusions that put the lives of their babies at risk.

We have an opportunity now to address this issue--and no one recognizes better than I do--the stress and the pressures that many of you are subject to. But this is your opportunity to change a senseless policy of illusion and denial. I appeal to you. Help us change this policy and let's do it now. Let's not add any more helpless victims to our list.

What policy should New York State employ to maximize access to healthcare services by HIV positive women and children and prevent transmission of HIV from mothers to children?

My name is Terry McGovern and I am the Director of the HIV Law Project. The HIV Law Project provides free comprehensive legal services to low income persons living with this virus. We handle the day-to-day issues, but we also try to address the underlying policy problem which leads to the daily discrimination caused by our clients. Thus in 1990, after watching low income women, persons with a history of drug use and persons from communities of color die without meeting the CDC definition of AIDS or the SSA disability criteria for HIV related disability, we filed a class action lawsuit. We also helped to lead a campaign against the CDC to expand the AIDs definition because it did not recognize the spectrum of HIV related conditions our clients were experiencing. In 1992, we filed an action against the FDA challenging a 1977 Guideline which restricted the access of women of childbearing potential from the early phases of clinical trials. Prior to the litigation just described, almost all of the litigation in the AIDS arena focused on protecting the confidentiality litigation had remarkably good results, and as you all know, AIDS has been treated like no other sexually transmitted disease. While this review of history may not seem relevant to the instant issue, it is completely relevant.

We engaged in that struggle with the CDC and SSA because we understood the importance of women acknowledging their risk, perhaps choosing to be tested and getting into care. Unfortunately, with women we had to fight to establish that care and we are still fighting to establish that care. I believe history will prove that the government has been tremendously shortsighted in its treatment of women in the HIV epidemic--it is tragic that women with HIV and their advocates have spent ten years trying to force the government to acknowledge that the disease with affecting them, that their symptoms were often different, that the natural history of the disease in women needed to be studied, that a new prevention message was necessary to effectively reach women. Ten years when the government should have been dialoguing with women was spent litigating, demonstrating and developing severe distrust.

THE GOVERNMENT HAS CONSISTENTLY CHOSEN TO TREAT POOR WOMEN AS THE ENEMY RATHER THAN AS PARTNERS IN THIS EPIDEMIC-- why is it that gay men can gain so much ground on confidentiality while we are now considering a proposal for mandatory testing of all pregnant women.

THIS PROPOSAL SUFFERS FROM THE SAME SHORTSIGHTEDNESS WHICH AS CHARACTERIZED THE GOVERNMENT'S RESPONSE TO WOMEN AND CHILDREN IN THIS EPIDEMIC. It is punitive, treats women as untrustworthy, ignores them, and it addresses the problem way after the damage has been done. The essential issues are ignored. I consider it beneath my dignity to debate how many infants this proposal would actually help, or whether treatment exists that can help these infants, how many infants are actually positive. Of course, every mother and child struggling with this virus should receive the maximum care

available. But mandatorily testing the child and then informing the parent is not the way to achieve this objective. After years of observing HIV positive mothers, observing their trauma about the possibility of having an HIV positive child, watching them struggle with their own hopes and dreams for their young lives and the lives of their community versus their knowledge of living with the virus, watching others suffer through the death of a child when they only learned of infection at the birth of the child--I am convinced that this proposal overlooks the greatest resource the state has in facing this problem--the mother. To cut the mother out of this process which involved her body, her child, her future, violate her rights, treat her as though she has harmed her child and will stand in the way of treatment, is the best way to insure that this problem will not be addressed. Forget the medical model, and talk to a woman as if she is a person with dignity--involve her in the process, provides services to her in a meaningful fashion, that child will get care. Now people ask, what about drug addicts with a history of abuse and neglect, shouldn't the State be able to test those children, after the mother has a record of not providing care--after interacting a great deal with the Child Welfare Administration over the last year, I must assert, so does the State--to pretend that any large, overtaxed agency of this city will insure adequate treatment and care for children is a huge mistake. My office has spent lost of time in Family Court over the last year, and we have seen lots of evidence of neglect of children placed in foster care--I might even offer that in some cases the foster caretaker is more interested in the stipend that in the disabled child. CWA is a massive system with lots of breakdowns, to take authority from the mother and give it to that system is a nightmare.

If the state takes control of this information from the mother, there will be tremendous consequences in the woman's life, not the least of which is potential abuse, isolation and a lack of services to meet her psychological needs--I believe that this proposal violates the state and federal constitutions.

The state's interest in the welfare of children does not outweigh a mother's right to privacy and this is certainly not carefully tailored plan designed to cause the minimum amount of intrusion upon the mother's rights--it denies equal protection under the law to childbearing women--you will be sued, it is vulnerable and once again we will be litigating rather than dialoguing about the rights of poor women in this epidemic. Wouldn't the time be better spent assessing effective aggressive outreach strategies. Evaluating the woefully inadequate existing services for women and children in this epidemic.

My recommendations are that New York State should more aggressively utilize its funding mechanism to insure that services and care are being provided to women and children. Why don't you create a mechanism whereby women can complain of the myriad abuses and actually get results--offending institutions will lose funds. Work with HIV positive women with children on designing effective strategies, recognize their expertise and ask them to come up with effective solutions to the harder cases. Mandate peer reviews, and I mean HIV positive women of the content of all outreach programs, counseling messages, prevention strategies.

Thank you.

(7)

NEW YORK STATE AIDS ADVISORY COUNCIL
NEWBORN SCREENING SUBCOMMITTEE

PUBLIC HEARING - Monday, Nov. 8, 1993
TESTIMONY Given by Stephan Koblick

My name is Steve Koblick. I am a Social Worker and Director of Social Work Services at a Community Based Organization called Community Family Planning Council. CFPC provides family planning, prenatal, and HIV care to women of color in the communities that they live in at various sites in NYC.

On Nov. 1, 1993 the New York State Dept. of Social Services began its implementation of co-payments for Medicaid recipients. I am very upset that a $3 copay has been implemented for HIV Counseling and Testing. Although I do believe that individuals need to take some responsibility for their health care, we must examine the cost to society such a step as this will make.

The recent International Conference in Berlin reiterated the fact that we have no cure for HIV/AIDS. The only tools we have currently to combat the epidemic are: **Prevention, early detection and early treatment.**

We are currently watching the epidemic spread to women of child bearing age, particularly in communities of color.

We at CFPC are receiving a mixed message from Albany. The NYS Dept. of Health mandates that we provide universal counseling around HIV issues.
NYS Dept. of Social Services mandates that we charge all Medicaid recipients a $3 copay for HIV counseling.

We make a point of providing counseling about all Sexually Transmitted Diseases (STDs) for all New and Annual Family Planning visits. Under the current mandate we are able to counsel around all other STDs without a copay (the copay is waived for Family Planning Services). Once we mention HIV we must charge $3.

All of our CFPC clinics are Confidential HIV Counseling and Testing Sites. Recently we have had an increase in "walk in". That is, people from the community "walking in" to volunteer for Counseling and Testing. This is a very difficult decision for an individual to make and many are not really certain that they want to go through with the testing when they walk in the door. When the word on the street gets out that CFPC is charging $3 (a great majority of our clients are Medicaid eligible) it will have a major effect on those who are ambivalent to begin with.

Of course we would never turn away any client from any service because of their inability to pay even a $3 copayment. For those clients who would be willing to come in and receive the service without the copay, the agency would then absorb the difference.

With these $3 copays, although a small amount can build up over a period of time. For any small CBO that operates on a tight budget with marginal cash flow, these copays could spell disaster.

Other services like Family Planning, Prenatal Care and Mental Health have been excluded from the $3 copay. HIV Counseling and Testing must also be excluded. There is too great a risk not to exempt Counseling and Testing.

(8)

AIDS Advisory Council Subcommittee
on Newborn Seroprevalence Screening
November 8, 1993
Ms. Eleanor Mitchell
Person Living With AIDS

My feeling is that if you are going to protect infants and not inform the mother that the baby is HIV positive, then lets go ahead and change a few more policies and laws as far as kids are concerned. Let them get married whenever they want without the consent of the parents, let them start driving at whatever age, let them drink alcohol at whatever age, let them be drafted at whatever age without the parents' consent.

If a child is born with Cancer, Multiple Sclerosis, Downs Syndrome or any other life threatening disease, the mother is automatically told of this disorder. By keeping an HIV status confidential for newborns, you are not really giving the HIV+ infant a chance to receive the kind of pediatric treatments available. Infants can't talk, reason, worry, provide shelter, clothing or food for themselves. They rely on parents, particularly mothers, because we are the care givers.

I, personally, do not care about the statistics around this issue. I am speaking as a mother of four children and a grandmother of six. This issue is more personal to me than you can imagine. I am a person living with AIDS, and I have been living with this disease for the past 14 years. (PAUSE) If the state of New York is going to continue to test these babies without giving the test results to the mothers, then there will be many tragedies in the not too distant future. Not knowing your HIV status is worse than knowing. Because if you know you can act on it, you can deal with, and you can pray--which is most important--during the 18

month period where the child has a fairly good chance for seroconversion.

If the child's mother is alerted early, there are treatments for these children. The mother is the one who is with this infant day and night; she knows how the baby eats, when it coughs, and if a baby is presenting with some sort of illness, that mother is going to seek medical care for this child. Let there be no mistake!

Since I was invited to give testimony at this hearing, I have taken time to speak with at least 25 mothers--all of African-American or Latino background--who had no idea that this kind of testing was going on in this state. They were shocked by this information. The fact that they would not have the right to know that their baby has tested positive and that the infant could seroconvert within 18 months, and that there are effective pediatric treatments is a gross invasion of privacy. When you consider a mother's love for her child, that eliminates all concern for self.

Now that it is becoming common knowledge among women that this formerly undisclosed testing has been going on, it could be catastrophically detrimental to the HIV infected mother who has no idea that she is HIV+. Now she already knows her child has been tested, she also has been tested through the child, and she does not know the results of either test. She is left to wonder and worry and stress herself to the point where, if she is HIV+, she could turn from HIV+ to full blown AIDS within that some 18 month period. She will not be receiving care, counseling or any form of treatment. Her nutritional intake will not be what it should be, all

due to the fact that the legislature of the State of New York, who are mostly men, have decided that its best to protect the confidentiality of some and secretly test others without ever informing these women of their status.

Until the day comes when a man--whether he is a legislator, gay or both--can carry a child for nine months, go through the labor and give birth to that child, they will never know about the invisible umbilical cord that all the mothers I know have with their children. They do not have the right--once they have tested these babies--not to tell these mothers about the results. If this committee does not strongly recommend to the legislature that this procedure be changed immediately, you will have the blood of these children and these mothers on your hands for the remainder of your lives.

I realize it is not a comfortable position for the members of this committee to make recommendations to the state legislature on such a difficult issue, but these mothers deserve to know. In 1992, some 1,900 infants tested positive for HIV antibodies. We all know this means that there are 1,900 mothers out there who are HIV+ with no chance for seroconversion. They need to know their status and the status of their babies.

My name is Wendy Chavkin. I am a physician whose training is in Obstetrics/Gynecology and Public Health. I am currently working primarily on policy research regarding the perinatal HIV and drug epidemics at both the Columbia School of Public Health and Department of Obstetrics/Gynecology, and at Beth Israel Medical Center.

I am very concerned about the proposal to unblind the anonymous newborn heelstick serosurvey. I fear that such a move would compromise individual rights of both women and children while not advancing the ostensible medical and public health goals. My position on this issue would change if we had a cure for AIDS. Even then, the treatment would have to be available to those who could benefit. As the current tuberculosis epidemic illustrates, medications do not suffice to control a disease. Moreover, we currently have only treatments for specific opportunistic infections, some of which are experimental. As the sophisticated, expensive technology used to distinguish the truly infected 15-30% of neonates from those with passively acquired antibody is not available everywhere, many uninfected infants might receive treatment with unknown long term consequences.

Society might decide that infringement of individual rights was warranted if identification led to enrollment into services. Unfortunately, it has been repeatedly documented that the services HIV women and children need are lacking.

Policies relating to HIV and pregnancy tend to subordinate women's health care needs to those of the infant. In general, the focus has rested on the prevention of vertical transmission, rather than on preventing or treating maternal infection. A major justification for screening women for HIV has been the hope that women identified as seropositive would then avoid conception, either through contraception or sterilization. The purpose of screening in pregnancy has been less clearly articulated due to a reluctance to confront the abortion controversy. Moreover, the New York City Human Rights Commission documented that many abortion providers refuse to serve HIV infected women. Concern for the fetus or newborn is the rationale expressed for testing during pregnancy for the sake of: (1) avoidance of future pregnancy, (2) termination of pregnancy, (3) medical care to improve birth control and (4) medical care of the newborn. Overall, despite the fact that women are far more likely to be infected than infants, HIV-related services for women continue to be framed by their relationship to the fetus.

<u>New Data- lack of services</u>

According to a 1992 survey, four fifths of states have no policy regarding women with HIV infection and pregnancy. The

remaining 20% recommended that HIV positive women be advised to avoid pregnancy. Almost all the states offered services only to pregnant women; only 6 states had services for women who were not pregnant.

In 1993 we completed a survey of Maternal Child Health Directors of all 50 states plus the District of Columbia. Forty-eight reported state initiatives to reduce infant mortality. In forty-four states this included prenatal care and in thirty-nine states infant medical care. Only five states included medical care for the women herself and only eleven had a formal link to HIV related services.

We conducted a similar survey of the AIDS Service Directors in all 50 states. Just over half (27/51) reported that their states offered services for HIV positive women and children. Twenty-eight of these directors reported that their state policy was to support and maintain families and yet four of these added that the state had no such services in place. Moreover, women already receive confused, unfriendly messages about HIV infection: the importance of learning their HIV status when pregnant is stressed but not followed by systematic linkage to prenatal care, family planning, abortion, or drug treatment. According to our survey, only twelve states' HIV programs have formal links with prenatal care programs, eleven with family planning services and only three with abortion. Eight states advise HIV infected women to avoid pregnancy.

At the same time that services regarding HIV and women continue to be framed in terms of pregnancy, pregnant HIV infected women have generally been excluded from clinical trials on the grounds that these experimental interventions may have unknown consequences for the fetus. The percentage of female enrollment in AIDS clinical trials in 1992 was only 7.8%. Even treatments not considered experimental, such as pentamidine prophylaxis, have been denied to HIV infected pregnant women because of unknown effects on the fetus. Data from the New York area indicate that pregnant women are excluded from roughly 80% of AIDS clinical trials, which often constitute the only route to care. Although adolescent girls are becoming HIV infected at a frightening rate, most school systems fail to provide the education and health services needed to protect them. The legislative proposal to unblind the anonymous newborn heelstick serosurvey would effectively make newly delivered women the only category of people to be HIV tested without informed consent, other than Federal prisoners. This has implications for women that extend beyond this situation.

<u>Public Health- rejection of mandatory testing</u>

A key reason mandatory HIV testing has been rejected is to avoid frightening people at risk away from health care. When Illinois made obtaining a marriage license contingent upon a HIV test, a significant number of Illinois residents got married in neighboring states. One justification offered for mandatory newborn testing has been that some pregnant women refuse testing or

do not come back for the test results. These women may really not want to know; perhaps they fear such a verdict or perhaps they fear the discriminatory consequences. There is already concern about the high proportion of pregnant women receiving inadequate prenatal care. Do we now want them to resort to delivering at home? And what might we do to their relationship with this baby?

The ability to conduct surveillance activities is also threatened. Distrust of monitoring efforts that involve reporting to the government led to the establishment of special protection of confidentiality,and anonymous techniques for tracking the pattern of spread within populations. It is mixing apples with oranges to take one of these epidemiologic measures and unblind it after the fact. Such a move may compromise a host of surveillance and research efforts.

Since we do not even come close to providing the necessary services for HIV infected infants, women or families, I fear that this proposal actually serves a diversionary role. Rather than bolstering services for infants and women and making them available and attractive, we waste time in making hollow gestures.

The identification of maternal antibody status through the newborn will not,and currently cannot, translate into saving babies lives. Let's have this conversation again in a few years when we really have something to offer. But let's reframe it next time around, so that we reject this unnecessary and false opposition between maternal and newborn interests and respond concretely and supportively to both simultaneously.

Once a "real cure" becomes an option the meaning of learning of one's own or one's child's serostatus changes dramatically. If we could design programmatic linkages between services for HIV infected infants and services for their mothers, we could convert an apparent moment of potential conflict into a moment of joint opportunities.

NEW
YORK
AIDS
COALITION

231 West 29th Street, Suite 1002
New York, NY 10001
(212) 629-3075
FAX (212) 629-8403

Amy Herman, Executive Director

MEMORANDUM IN OPPOSITION

"Unblinding" of the New York State Department of Health's Newborn Serosurvey

The Need

The New York State Department of Health has carried out a seroprevalence survey of HIV infection in women giving birth in the New York since 1989; the serosurvey is done by running HIV antibody tests on the heelstick blood drawn from every infant for genetic screening. These HIV test results are never given to the physician, hospital or parents; they are sent in aggregate to the health department to track changes in the epidemic.

There is widespread agreement that women, especially those who live in high-prevalence areas, should be offered voluntary HIV antibody testing, with counseling and informed consent, early during their prenatal care, as well as before becoming pregnant. There are many state-and federally-funded programs to do this at family planning clinics and during prenatal care, including the New York State Family Planning Program, the Prenatal Care Assistance Program, and the Obstetrical HIV Counseling-Testing-Care Initiative. In addition, Medicaid funds voluntary HIV testing by physicians, and both New York City and New York State fund anonymous HIV counseling and testing sites.

The Legislation

This proposal would amend the public health law to allow disclosure of confidential HIV-related information to the parents of a newborn child and would allow the "unblinding" of the New York State Department of Health's newborn serosurvey, which aggregates anonymous HIV test results for every infant born in New York State in order to track the spread of HIV among women of child-bearing age.

Why New York AIDS Coalition Opposes

While this bill seems aimed at increasing knowledge of HIV status among infected women and children and at getting them into health care -- extremely desirable goals--we believe that the bill would actually hurt women and babies.

Because all infants are born with their mothers' antibodies and may not develop their own before 18 months of age, HIV-antibody testing of infants does not indicate whether an infant has been infected with HIV. All infants born to HIV-positive mothers will test positive for HIV; however, only 10 to 20 percent of those infants will actually be infected with HIV. All such testing can indicate is whether the baby's mother is HIV-infected. Thus, testing babies amounts to testing mothers.

Results of the newborn serosurvey are only returned to the health department (with no identifying information), and therefore the test is exempt from the counseling and testing requirements of New York State's model HIV confidentiality law. "Unblinding" the serosurvey, amounts to mandatory testing of women who give birth, in violation of their right under New York State law to consent to HIV testing. No other group of individuals in New York State is denied that right. (Only federal prisoners, under a federal law, are tested against their will.) Such involuntary testing raises serious constitutional issues.

This bill will not prevent HIV transmission to infants: HIV testing after birth is too late to prevent perinatal transmission because the infants with HIV already have it when they are born. Nor will this bill prevent HIV transmission through breast-feeding. Women who breast-feed begin to do so in the hospital; results of HIV antibody tests are not available until approximately three weeks later. Moreover, it is most likely that HIV will be transmitted through breast-feeding during the period when a woman is first infected, particularly during the period between infection and seroconversion, when she would test negative. The only safe message is to tell all women at risk is not to breast-feed; the New York State Department of Health already does this.

Moreover, this measure would label all infants born to HIV-infected mothers as positive when in fact only 10 to 20 percent actually are. Studies have shown that infants identified as HIV-positive may actually get less care in neonatal intensive care units.

Nor will the proposal identify many new HIV-infected infants: Studies indicate that the majority of HIV-positive mothers giving birth in New York State have already been tested voluntarily and already know their own status and the possibility that their baby may have HIV.

Finally, in addition to imposing involuntary HIV testing on mothers, this legislation would permit disclosure of a mother's HIV status to her baby's father's, creating a serious risk of domestic violence, family destruction and further harm to both infant and mother.

(11)

STATEMENT OF TRACIE M.GARDNER,
POLICY ASSOCIATE, GAY MEN'S HEALTH CRISIS,
TO THE NEW YORK STATE AIDS ADVISORY COUNCIL
SUBCOMMITTEE ON NEWBORN SCREENING
NOVEMBER 8, 1993

Members of the Subcommittee,

My name is Tracie Gardner and I work at Gay Men's Health Crisis (GMHC). GMHC is the nation's largest voluntary agency responding to the HIV epidemic. We provide medical information, legal services, hot meals, recreation and support services to over 4,500 men, women and children with HIV-illness, and their families. GMHC provides a broad range of HIV prevention education services to nearly 200,000 people each year. About 45 percent of our clients are people of color and about 10 percent are women and children. GMHC has been actively involved in HIV/AIDS education, care, and advocacy for more than ten years. In that time, we have served over a quarter of the people with AIDS in New York -- the epicenter of the epidemic. We have developed and distributed more educational materials than any other single agency -- including the U.S. government.

The issue of unblinding the seroprevalence study is certainly not a new one, and as we have moved on in the epidemic, it has become an issue that is of increasing importance and of increasing complication. GMHC has been in the past and remains opposed to proposals to unblind. Efforts to unblind have been proposed with the aim of increasing knowledge of HIV status among infected women and children and at getting them into health care -- extremely desirable goals which we wholeheartedly support. We want to see transmission of HIV from mothers to babies reduced, we want the lives of HIV infected babies to be improved and lengthened and we feel that moms should be aware of their antibody status. However, we believe that these proposals, if implemented, would actually hurt women and babies.

The underlying but key issue here is that women giving birth should consider taking an HIV test. Every woman seeking prenatal care should be counseled about HIV testing and why it can be important. If a woman hasn't had any prenatal care, she should get counseled about HIV testing when she gives birth.
We also believe that two equally-important goals should drive policies regarding HIV testing and the disclosure of HIV test results: (1) Decrease the spread of HIV, and (2) use individuals' knowledge of their HIV status as the first step in linking them with the medical and other services necessary to maintain and prolong both life itself and the quality of that life.

We all agree that it is important to decrease the spread of HIV from mother to baby and we also agree that it is important and best when the mother knows her HIV status and is able to make decisions for her baby's health and her own. Unblinding the newborn serosurvey will not reduce transmission from mothers to newborns during birth. Testing after birth is too late to prevent perinatal transmission. The infants with HIV already have it when they are born. If the test was done earlier during prenatal care, it is possible to reduce transmission, because half of perinatal transmission occurs during delivery. If women knew they had HIV before giving birth, they could consider special procedures to disinfect the birth canal or caesarian section delivery (C-sections) to lower the chances of transmission during delivery.

Unblinding the newborn serosurvey will not reduce transmission from mothers to newborns during breast feeding. Although there is some evidence that HIV transmission from breast-feeding has occurred in Africa and Europe (a total of 26 cases have been reported worldwide); the likelihood of transmission increases with the duration of breast-feeding.[1] The New York State Department of Health recommends that women with HIV and women at risk for HIV not breast-feed.[2] If women want to breast-feed, they begin in the hospital, so results of newborn screening are too late. If a woman is at risk but tests negative in the hospital, she should still not breast-feed because she could already be infected or could get infected during the period of breast-feeding. No testing is necessary to tell all women at risk not to breast-feed; and the New York State Department of Health already does this.

Back to the issue of the use of an individuals' knowledge of their HIV status as the first step in linking them with the medical and other services necessary to maintain and prolong both life itself and the quality of that life. Testing women's babies reveal these women to themselves be HIV infected; do we really believe that the women will suddenly be able to see a doctor once a month for maintaining her health care, T- cell monitoring, PCP prophylaxis or to get drugs for any other type of HIV-related infections or ailments? And what are we saying that these services be mandated to be available for the baby but not for the mother?

Unblinding the newborn serosurvey will not necessarily improve health outcomes for infected babies:

***PROPHYLAXIS:** There is growing agreement (though no conclusive proof) that PCP prophylaxis is effective for infants with declining CD4 counts.[3] Legislators argue that identifying each baby with HIV could help them get preventive care. However, prophylaxis is only indicated as CD4 counts drop; prophylaxis is **not** indicated for the babies who test positive (80-90% of whom do not even have HIV). Therefore, the proportion of babies who both need and get prophylaxis will only increase if the mothers bring the infants in for constant monitoring, follow-up, and care.

Studies show that once infants are sick, mothers are very good at bringing them in for care. Therefore, only the very small number of babies who meet all of the following conditions could theoretically be helped: (1) the infant actually is HIV-infected; (2) the infant's mother refused all HIV testing prenatally; and (3) the infant's mother would bring him/her for

prophylaxis before he/she gets sick. A more effective way to reach those babies is to work with their mothers before they give birth so that they understand the importance of both HIV testing and follow-up health care for themselves and their babies.

HEALTH CARE IN GENERAL: There is another big problem. A study has suggested that babies identified as having HIV may actually get less care in neonatal intensive care units.[4] This means that this proposal would actually put the babies that it identifies (including the 80-90% that do not actually have HIV) at risk of getting LESS care when they get really sick. This in conjunction with the fact that many of the women most at risk for HIV have poor or no access to primary health care or other essential health or support services" and this I quote from the Advisory workgroup to the Obstetrical Initiative of the New York AIDS Institute.

Stringent confidentiality protections have been demonstrated to be one of the most important factors encouraging people to undergo HIV testing. Most studies, including examinations of mandatory reporting programs in South Carolina and anonymous testing programs in Oregon, show that people will not utilize HIV testing if they are afraid that their confidentiality and/or anonymity is in jeopardy. It is those at greatest risk of HIV infection who have the most to fear from government intrusion into their privacy. If people are frightened away and are not tested in the first place, we lose the opportunity to counsel them about behavior changes, we lose the opportunity to do early intervention and delay the onset of disease, and we lose the opportunity to learn of partners who might have been exposed to HIV as well.
The public health cost of not protecting confidentiality is high: those who are HIV-positive but avoid testing because of fears regarding confidentiality cannot be counseled about behavior changes; they cannot take advantage of early interventions which can delay the onset of disease; and they cannot inform any sexual or needle-sharing partners who might have been exposed to HIV themselves.

I am sure that we have nor forgotten that there is still also potential risk to the individual identified as having HIV: emotional and psychological trauma; discrimination in employment, housing, insurance, and health care access; and potential for family disruption and violence. Therefore, we believe that the decision to receive HIV antibody testing must be controlled by the individual -- the only person that can balance his/her own specific life circumstances and decide to test. Therefore, responsible public health policy requires continued availability of anonymous testing, and continued scrupulous protection of confidentiality of HIV antibody test results.

In New York State, the law requires that anyone getting an HIV test must receive counseling before and after the test, and must give his or her written informed consent. This is vital to keep in mind when we are talking about moms or moms to be with HIV or at risk for HIV. Proposals to unblind do not seem to respect that everyone, including women of child bearing potential must have a chance to understand what the HIV test reveal (and what it doesn't tell), that an individual can start to learn about medical

treatments and health care for people with HIV, and that one can begin to plan the things needed to take care of if one is positive. For pregnant women, it means that this is a opportunity to learn about the chances of their baby being infected (about one in three) and about moms-to-be need to do to take care their baby's health and their own.

There are a number of new problems created by proposals to unblind including:

They would inform mothers of their own antibody status, but there is no provision to link these mothers with the health care services, mental health services or social supports they need.

A significant risk of domestic violence exists as a result of informing the fathers that the mother of their child and their child have HIV.

Serious family disruptions could occur and no system of support is proposed.

Involuntary testing will create significant psychological and emotional problems for some women; the 10-15% of women who refuse testing when it is offered do so because they know they cannot handle the test results.[5]

There is evidence that people who are tested without their request or consent do not believe or act on the test results even when they are provided.

Some mothers will do everything possible to avoid being tested -- including home birth -- creating a risk to mothers and babes. (This has already happened once, when HHC required drug testing for all deliveries for a brief period.)

This proposal makes women (primarily women of color) the first group targeted for mandatory testing under NYS law: This is a serious breach of civil rights and will produce minimal or negligible improvement in health outcome.

The legislature is not the appropriate body to set standards of medical practice for HIV: this sets a bad precedent.

In summary, we propose more and better prevention, including counseling and testing before pregnancy and early in prenatal care. Link effective provision of voluntary HIV counseling and testing to pregnant women to funding or sanctions for providers. In sum, find the ways to expand voluntary counseling and testing for all women at risk, in GYN settings as well as prenatal and OB settings.

The development of prophylaxis and treatment for AIDS-related opportunistic infection underscores the need for people at risk to be tested for HIV infection. Strong measures protecting confidentiality are an essential reassurance for people seeking HIV testing. Therefore, the best way to encourage people to utilize HIV testing is to ensure their confidentiality. Voluntary testing programs provide an essential means of providing AIDS

education, the only effective way of preventing HIV transmission and of helping those who are HIV-infected initiate appropriate medical care. Mandatory reporting and contact tracing will only serve to keep people from utilizing HIV testing, and the education and counseling that accompanies it. Knowledge of HIV status is only useful if it is accompanied with access to primary medical care and support services. Creating more and better services for women and their children, for all people with HIV must be the first priority for all of us if we are to meet the challenge of AIDS in New York State.

Proposals to unblind are not merely an issue of a women's confidentiality versus a baby's need for treatment as early as possible. The false division of camps on this issue is just that: false. You can not separate the need to ensure a HIV infected mother's confidentiality and a baby's need for treatment as early as possible. Proposals to unblind are fundamentally punitive: Women are becoming infected in this state and across the country at alarming rates. It is as if we are punishing women, primarily women of color, for the failure of the public health system to educate people adequately about their risk for HIV. Proposals to unblind are built on the assumption that mothers will not do what is in the best interests of their babies. If anything, we see that the opposite is true: that a mother's concern for her child is paramount to anything, including her own health. We need to look seriously at ways to enable mothers with HIV to provide the best care: for themselves and their children and families.

1. Martino et al., AIDS, 1992.

2. New York State Department of Health: "Policy on Breastfeeding and HIV" (March 6, 1991).

3. Centers for Disease Control: "Guidelines for prophylaxis against Pneumocystis carinii pneumonia for children infected with Human Immunodeficiency Virus," MMWR Vol. 40, No. RR-2 (March 15, 1991).

4. Levin, BW et al., "Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS," JAMA 265:22 (June 12, 1991), pp. 2976-2981.

5. See "HIV Testing Among Women and Children: Variables Associated with Accepting or Declining Testing; Lessons from an Inner-City Hospital," Bamji, M., Healton, C., et al. (pre-publication draft).

(12)

New York State AIDS Advisory Council
Newborn Screening Subcommittee

Public Hearing - Monday, November 8, 1993

Testimony Presented by:

Miguelina Maldonado,
Executive Director

Hispanic AIDS Forum, Inc.
121 Avenue of the Americas Suite 505
New York, New York 10013
Telephone Number: (212) - 966 - 6336

Introduction:

Good afternoon. My name is Miguelina Maldonado. I am the Executive Director of the Hispanic AIDS Forum, Inc. (HAF). HAF is the first and largest Latino community based AIDS Service Organization in New York City. Established in 1985, HAF, a not-for-profit, 501(c)(3) corporation, has developed and implemented a variety of culturally appropriate and effective HIV/AIDS related programs since 1987. HAF operates its programs out of offices in Lower Manhattan, and two neighborhood based HIV Service Centers located in Jackson Heights, Queens and in the Hunts Point/Mott Haven area of the South Bronx. HAF's programs include outreach (on the streets, in cruise areas and bars), HIV prevention and risk reduction education, counseling, support groups, HIV/Alcoholism counseling, case management services, community and professional education, training and technical assistance to CBOs on culturally competent program designs for Latinos, and advocacy. Community based services are offered to Latino gay and bisexual men and men who have sex with men, women at risk including Latinas who are injection drug users or the sexual partners, Latino families including men, women, children and caregivers, and male and female injection drug users. Since 1989, HAF, through its De Mujer A Mujer (Woman to Woman) Program, has been providing a range of outreach, prevention, intensive risk reduction, counseling and support and prevention case management services to Latina women residing in the Hunts Point / Mott Haven sections of the South Bronx, an area with high HIV seroprevalence, high rates of substance abuse, female headed households and poverty.

Background:

I am pleased to come before you supported by HAF's experience in the provision of HIV prevention, support and care services to Latinos in New York City, to address the critical policy questions related to maximizing access to health care services by HIV - infected women and their children and the prevention of HIV transmission from infected mothers to their children. Let me begin by stating unequivocally that the Hispanic AIDS Forum, Inc., opposes the proposed Act, introduced in the New York State legislature, to amend the public health law which will allow disclosure of

confidential HIV related information to the parents of a new born child (introduced in the Assembly by Assembly person Mayerson). This proposed legislation will essentially "unblind" the newborn seroprevalence survey conducted by New York State since 1987. The newborn seroprevalence survey was designed to **anonymously** test all newborns for the presence of HIV antibodies for the purpose of determining HIV seroprevalence - the rates of infection, and epidemiological trends in childbearing women. The proposed legislation would be **tantamount to de facto mandatory HIV testing of all childbearing women in New York State,** since the infant's HIV status at birth, invariably, indicates the mother's HIV status. This proposed legislation raises a wide range of social, legal and ethical issues including: violations of a women's right to informed consent, rights to privacy, reproductive choice, coerced abortions and sterilizations, stigmatization and discrimination, and removal of children by child welfare authorities, among others.

In New York , as in the nation as a whole, the issue of public health policies for pregnant and childbearing women with AIDS or HIV infection, is of major concern to women of color because close to 82% of the cases of women with AIDS in the state are reported among African American (51%) and Latina (31%) women. In New York City, the proportion of cases of AIDS among women of color is slightly higher than the statewide proportion: 85% (33% Latina, 52% African American). On a national level, American American(19,544 - 53%) and Latina (7,451 - 20%) women make up 73% of the total number (36,690) of women reported with AIDS (CDC: July 1993). The implications of drug use and abuse and the prevalence in communities of color must also be taken into account in the development of public health policies. The primary mode of HIV infection among women of color and particularly African American and Latina women is injection drug uses. In New York City 60% of the cases of AIDS among Latinas and 62% of the cases among African American women are due to the women's injection drug use. Approximately 58% of the cases of maternal transmission of HIV to infants are a result of maternal injecting drug use. An additional 20% are due to mother's sexual contact with an injecting drug user(NYC DOH July 1993). Any policies that are considered must take into account the possible adverse impact on women of color, particularly Latina and African American women who represent the largest segment of the female population affected by HIV infection and AIDS. Policies which are designed to maximize access to health care to HIV infected women and their children and to prevent the transmission of

HIV from mothers to their children must be framed within a context that affords women equal protections under the law and does not pit women against their children. All too often, in this society, the zeal which drives legislation to protect the best interests of children has tended to violate the rights of parents, particularly poor and disenfranchised ones who have few resources to pursue legal recourse.

When considering the issues related to HIV/AIDS policies, we must be mindful of the following past abuses of the rights of women of color and the potentially dangerous implications of these trends for the development of the policies in question:

- **Trends to criminalize HIV** - the 1992 case of CM, an African American woman in her early 20's, on public assistance and allegedly a long time sex worker and drug user, in North Carolina, who was arrested and convicted of "failure to follow public health warnings" to advise her sexual partners that she was HIV positive and to use a condom whenever she had sexual intercourse, raises red flags regarding the potential for government to intrude into reproductive activity of HIV positive women. CM was arrested and convicted following a positive result of a pregnancy test performed at a public health facility. While the original conviction was later overturned on appeal, CM had an abortion and tubal ligation while her case was pending. She indicated that she took these actions in part to appease the public health officials. This case is an extreme example of the possible abuses and coercive measures which government can engage in while carrying out policies to prevent HIV transmission.

- **Trends to criminalize drug use during pregnancy** - within the last six years there have been a series of attempts to prosecute women who used illicit drugs during their pregnancies. While being addicted to drugs cannot be construed as a crime, the new wave of cases has focused on the concept that a pregnant women who uses illicit drugs while pregnant is doing damage to another person. According to Wendy Chavkin,..."Despite persistent battles over the status of the fetus, it is not legally accorded the status of a citizen, and thus all of these efforts at prosecution have eventually foundered. Of 19 such cases in which women contested the charges only Jennifer, Johnston, (a Florida woman convicted in 1989 of a felony on the grounds of having supplied illicit drugs to a minor... through the umbilical cord in seconds after delivery prior to the clamping of the cord), was convicted.... later the conviction was overturned." The efforts

to convict women who are using drugs during pregnancy of crimes continues. Chavkin cites over 167 such prosecutions in 24 states in her article entitled "Enemy of the Fetus? The Pregnant Drug User and the Pregnancy Police" (Health/PAC Bulletin, Winter 1992). The overwhelmning number of women prosecuted under these cases were women of color(70%).

Child protective legislation has also been invoked to "protect" infants whose mother has used drugs during pregnancy or have tested with positive toxicology, by identifying these situations as a ground to report child abuse and neglect. In New York maternal drug use has been defined as a ground to suspect future parental impairment and can trigger a child abuse and neglect investigation and empower the child protective services to hold a child for protective reasons until the investigation is completed. The boarder baby crisis experienced by the City in the 1980's was in part due to these practices.

- **Coercive Counseling** - There have been a number of cases of HIV positive women who have been coerced by health care personnel to obtain abortions or be sterilized. Doe v. Jamaica Hospital is an example of a case involving a woman who alleges that she was virtually forced against her will to have an abortion.

- **Sterilization Abuse** - One of the major concerns that arises regarding the HIV infection and AIDS in relation to women, is the potential for abuses of reproductive rights. Amaro in her article on these issues highlights major areas of concern:

> "HIV infection and AIDS is fertile soil for encroachment on the reproductive rights of women in general. This entrenchment of the rights of women has been facilitated by the public's fear of AIDS, the stigma associated with the illness, and by the fact that AIDS is a public health problem that affects women who are disenfranchised, not only because of their sex but also because of their social class, ethnicity, and addiction." (Amaro, The Genetic Resource, Vol. 5, No. 2, 1990)

Historically, sterilization of women of color in the United States and in other parts of the world has been used as a method of population control. African-American, Native American and Latinas have higher rates of sterilization than their White counterparts. More than 25% of Native American women are sterilized. 43 percent of women sterilized in federally funded population programs are African Americans. Latinas also have high rates of sterilization. In Puerto Rico, during the 1930's, sterilization was introduced as a strategy to control population and promote economic development within the Island. Puerto Rico ranks among the countries with the highest rates of sterilization in the World with significantly higher rates among poor women. In a 1965 study of uterine cancer, it was found that 34% of the Puerto Rican women between the ages of 20-49 were sterilized.

High rates of sterilization are also found among Latinas in New York where the rates are 7 times that of White women and almost double that of African-American women (Hispanic Health Council).

A 1981 study of women in Hartford Connecticut and Springfield Massachusetts found that 65% and 55% of the Latinas studied in each city were sterilized. Between 1971 and 1974, ten non consenting Mexican American women were sterilized by a public hospital in Los Angeles. Although the women sued and produced evidence that hospital staff pressured the women to consent by withholding medication during labor, not informing the women that the procedure was permanent and pressuring some of their husbands to sign consent forms after the women refused, the judge found for the defendants finding there was a breakdown in communication between the women and the doctors. According to this Federal judge, the doctors could not be blamed for misinterpreting the women's actions (Madrigal v. Quilligan, 1978).

While one would hope that in 1993 these types of abuses would not take place, recent history indicates that any policies developed related to women and HIV/AIDS must necessarily ensure that safeguards are built in to prevent such abuses.

HIV Testing and Screening

The proposed unblinding of the newborn seroprevalence survey, as previously stated, constitutes mandatory HIV testing of women. This proposal which will for all intents and purposes deny women the right to informed consent threatens the rights of all women and women of color in particular. While the underlying intent may be to prevent the transmission of HIV infection to infants such a program will not achieve that goal since testing after birth will be too late - infants if infected will already have the HIV virus when born. What such a program can do is to set the stage for possible coercion of HIV positive pregnant women to have abortions or to be sterilized. Further the labeling of all infants born to HIV infected mothers as HIV positive will engender stigmatization of the children. Studies of neonatal health care providers' attitudes regarding the treatment of HIV positive infants in neonatal intensive care units in New York, indicate that knowledge of the infant's HIV status may in fact deter providers from undertaking non HIV related treatments. Thus, rather than increasing access to care and prolonging the infants' lives this policy may in fact lead to the denial of necessary care/treatment.

Disclosure of an HIV positive woman's status by unblinding the newborn seroprevalence survey may also lead to further marginalization,discrimination, rejection by family members and the risk of domestic violence. These adverse social consequences and their impact on the lives of both the mothers and infants must be carefully weighed when developing an effective public health policy.

Recommendations

Based on the issues and dilemmas presented above we make the following recommendations:

- Increase prevention education for women of childbearing age by providing additional resources for tailored community based outreach, and education approaches which are culturally competent and language specific.

- Increase media and other educational campaigns to inform women about the benefits of voluntary (anonymous or confidential HIV testing) as well as the services available so that they can make more informed choices within a non-directive environment.

- Build in safeguards at all levels of health care delivery to ensure that women are afforded their right to informed consent (to authorize or withhold consent) to HIV testing for themselves and their newborns.

- Increase the availability and accessibility of anonymous and confidential HIV Counseling and Testing sites and staff these sites with HIV pre/post test counselors who understand and can communicate with clients in their primary language and within their cultural frame of reference. Ensure informed consent by providing both training and on-going supervision of staff as well as sufficient time to deal with the complex issues presented by women, particularly those in the childbearing ages who are at risk of HIV infection.

- Expand drug treatment options for chemically dependent pregnant women and women in the childbearing years who also have children.

- Provide training to health care professionals and health educators on non-directive HIV counseling.

- Provide all women with full access to health care for themselves and their families.

PRESENTATION TO AIDS ADVISORY COUNCIL
Public Hearing - Nov. 8, 1993

The Medical Society of the State of New York (MSSNY) takes the position that prevention of HIV infection is currently the only effective means of controlling the AIDS epidemic. We urge the New York State Department of Health to take more effective initiatives to control the AIDS epidemic. We recognize detection and identification of newborns at immediate risk of HIV infection as an essential measure in the battle to control the spread of AIDS. Therefore we strongly endorse assemblywoman Nettie Mayersohn's advocacy of unblinding the HIV status of newborns screened for HIV antibodies at City Hospitals to properly identify those at risk. Since medical strategies now exist which will save lives of newborns at risk, or prolong lives of infected newborns, the HIV status of the newborn must be sought. Most importantly, breast feeding must be avoided if HIV antibody is detected in the newborn since this antibody derives from an HIV infected mother who can now transmit the virus to the infant if the infant is not already infected. Indeed if the newborn acquires a fatal HIV infection from a nursing HIV positive mother, liability would reside with the State for not revealing the risk, allowing the hazardous exposure through breast feeding. Other measures are indicated for HIV infected newborns. Early prophylactic treatment against pneumocystis pneumonia; avoidance of live virus vaccines; anticipatory medical care and entitlements are medical measures to be taken where the physician is aware of HIV infection in the newborn.

The MSSNY 1993 House of Delegates passed a resolution urging the New York State Department of Health to incorporate HIV testing into the routine testing offered as part of prenatal screening, a move which would be even more effective in controlling spread of the virus to the newborn. MSSNY was advised that State Department of Health HIV counselling and testing was a high priority and that 266,000 high risk women were counselled, and 97,000 were HIV tested at state-funded sites. If accurate these figures represent a woefully inadequate testing program for high risk women and argue for adding HIV testing to Hepatitis B and serology testing, and other routine screening procedures required in prenatal care.

MSSNY and most physicians are very sensitive to the very real medical, social and economic problems associated with HIV infection in our patients, and we are privy to the problems of confidentiality which is routinely breached by the systems that we must deal with - governmental, third party payment, legal liability and all administrative activities associated with modern medical care. However where the life and welfare of a newborn is at stake and where a serious epidemic evades control we appeal for medical and public health considerations to take precedence over otherwise worthy social and political pressures.

The Public welfare and the individual lives of infants demand that at the very least, HIV testing, already performed for screening purposes, be applied, if at all possible, to saving lives of newborns. The ethical dilemma pits the admitted need for confidentiality in the HIV infected individual against the opportunity to properly manage the HIV exposed newborns and to protect 70 % of these infants not already infected with the virus from acquiring this fatal infection.

In summary the position of the MSSNY and endorsed by the New York Pediatric Society is as follows:

1. We strongly urge support for Assemblywoman Mayersohn's position to allow unblinding of newborn HIV test results in order to allow proper medical care of newborn infants born with HIV infection or at risk to acquire the infection perinatally or in early infancy.

2. We appeal to the New York State Advisory Council to deal with the devastating HIV epidemic as a medical and public health challenge and to reject political considerations when they interfere with medical decisions urgently needed to combat the disease and the epidemic.

3. We urge the New York State Legislature to support measures to strengthen the traditional confidential doctor-patient relationship not only when dealing with HIV infection but also in all intrusive administrative activities associated with dispensing and financing medical care.

4. We see the need for more aggressive measures to be undertaken by New York State to control HIV infection among our population at greatest risk. We also recognize that vigilance is needed to avoid violating the civil rights of the high risk and infected population.

5. We feel that the New York State Department of Health should incorporate HIV testing into the routine testing offered pregnant women to further protect the unborn fetus and newborn infant from developing congenital or perinatal infection or to control the disease if present in the newborn.

6. We do not see any conflict between the position of organized medicine and the AIDS advocacy groups. We are all committed to combatting a devastating fatal illness which has decimated our patients and continues to kill some of our most gifted children.

Respectfully submitted,

Aaron G. Meislin, M. D.

CONTENTS

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

February 10, 1994

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: prenatal (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 breast-feeding, 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 practice. 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 pneumoccocal 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 dependent 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

obstacles to the provision of timely medical, mental health, and supportive social services. Affected families have consequently had great difficulty accessing critical services. One specific and disheartening example of the gap between need and availability of services is that very few substance abuse programs will accept pregnant women or women with children. When services are available they are too often fragmented. For instance, though women with HIV infection have significant gynecological problems, these services may not be available in clinics where they receive their routine HIV follow-up care. (See Appendix H for a complete roster of family HIV-related services.)

LEGAL AND ETHICAL ISSUES

From the start of its deliberations, the Subcommittee agreed that its goal would be the development of policies that would maximize the number of HIV-infected women and HIV-positive and infected infants identified and placed into treatment. The Subcommittee tried to maintain a focus on HIV as an issue that affects entire families, rather than a matter of the rights of newborns or mothers.

However, HIV screening of pregnant women and newborns does raise important ethical and legal questions. Although in most issues related to medical care of a child, parental decisions are

respected, there are legal and ethical precedents for situations in which the interests of the child can and should limit parental discretion. For example, in New York State, all pregnant women are mandatorily screened for hepatitis B and syphilis. While, like HIV, these two diseases can be passed from mother to child, unlike HIV, they can be prevented or cured with currently available treatment. Screening is also done mandatorily on every newborn, except when parents refuse for religious reasons, for a variety of treatable congenital diseases, mostly metabolic disorders.

New York State Public Health Law, Article 27-F, requires that HIV testing be preceded by detailed counseling, administered with written informed consent, and followed by equally specific post-test counseling. Federal law does provide for HIV testing without informed consent for prisoners, military personnel, and Job Corps applicants.

Since mandatory HIV screening of newborns and/or pregnant women, that is, without informed consent or the specified counseling, would present potentially serious ethical and legal challenges to existing law, the Subcommittee considered legal principles concerning: confidentiality, disclosure, constitutional rights to equal protection, privacy, child neglect, the Americans with Disabilities Act (ADA), and applicable case law, that is, precedents.

Confidentiality is an ancient and venerated principle of medical ethics but is not absolute. It may be strengthened or undercut by case law and by legislation in the interest of protecting a patient, identifiable others, or the public health. The intent of the New York State HIV Confidentiality Law is to empower individuals, enlist their cooperation, and protect their privacy. Since mandatory newborn HIV testing with parental notification is viewed by many as tantamount to testing the mother and revealing her HIV status without consent, it may be inconsistent with the intent of the law.

Disclosure of medical information means making it available to the patient. Under current law, disclosure of HIV status may only follow an adequate informed consent process with pre- and post-test counseling. To be consistent with current law regarding counseling, expanded counseling services would have to be developed and provided under either a mandatory or more aggressive voluntary testing program.

Public health law provides national precedents for the view that the police power of the state is sufficient to protect the public health and can do so as long as the intervention would be effective, as in the case of mandatory immunization of children. The Supreme Court has specified that an intervention must be the least restrictive alternative necessary to achieve the public

health goal, infringing as little as possible on protected rights. While individual states have been given broad latitude to respond to public health problems of local concern, mandatory newborn HIV testing would presumably have to meet the "least restrictive alternative" standard.

Ethically, a public health screening test must meet, at a minimum, two conditions: it should be accurate and effective. "Effective" means both that the test should be cost-effective and that an effective treatment should be available. HIV antibody testing is not an accurate indicator of infection in infants in that at least 70 percent of infants who test positive for HIV antibodies are not infected; PCR (polymerase chain reaction) testing is much more accurate, but much more expensive. Some argue that CD4+ cell counts could be used instead of testing to monitor children for immune suppression. Regarding the efficacy of therapy for HIV, it is currently clearest in relation to PCP prophylaxis.

The fifth and fourteenth amendments to the Constitution provide for equal protection under the law, meaning that any classification scheme for individuals must be fair and equitable. Escalating standards of fairness and equity depend on the importance of the right to be protected and the level of suspicion about the classification. For a racial classification, the state is subject to strict scrutiny and must show that a

compelling state purpose can only be achieved by means of this classification. Since neonatal HIV disproportionately affects minority communities, some have argued that mandatory HIV testing might be considered a de facto racial classification subject to strict scrutiny.

The right to privacy has been considered as both autonomy and solitude. Privacy as autonomy provides for the rights of couples to use contraceptive devices and for women to use abortion services. Privacy as solitude is the legal basis for restricting the state's powers of search and seizure. Some have argued that maternal autonomy is unacceptably compromised by mandatory newborn HIV testing, or that a mother's own HIV status is in effect being discovered through an unwarranted search and seizure.

Legally, a neglected child is one whose welfare is in danger. In medical ethics, beneficence (doing good for the patient) is an obligation of health care providers, though determining what is good for a minor is a parental right abrogated only under highly defined circumstances. The state can intervene if "necessary" medical care is withheld. The burden would be to show that available HIV treatment constitutes necessary medical care for an infant and that a parent who withholds it has neglected the child.

Finally, the Americans with Disabilities Act specifically includes HIV infection as a disability and protects disabled persons against discrimination unless they present a direct threat to others. Multiple-drug resistant tuberculosis is arguably a direct threat that meets the ADA exception, but pregnancy in an HIV-infected woman might not be interpreted as a direct threat to the infant, especially since the infant will probably not be infected. On the other hand, some may argue that failure to diagnose and treat individuals in a class which qualifies under the provisions of the ADA is de facto discrimination. It is unclear how the ADA may affect a program of mandatory testing.

OPTIONS FOR PERINATAL HIV TESTING PROGRAMS

The Subcommittee considered a broad range of possible programs for identifying and bringing HIV-infected mothers and their exposed or infected children into care. These options can be arrayed on a continuum as follows:

1. Mandatory newborn testing with mandatory parental notification of results. This is the option proposed by the Mayersohn bill before the New York State Assembly. It does not include any pre- or post-test HIV counseling provisions.

2. Mandatory counseling of all pregnant women and mandatory newborn testing with mandatory parental notification.

3. Mandatory newborn testing with voluntary parental notification, but access to test results by care providers at a later date, by request, with parental consent.

4. Mandatory newborn testing with parental option to refuse testing.

5. Mandatory counseling of all pregnant and postpartum women with voluntary testing strongly encouraged.

6. Voluntary counseling of all pregnant and postpartum women with voluntary testing encouraged. This is a modification of current programs, which concentrate voluntary counseling and testing efforts in high risk areas and show high variability in acceptance rates for testing.

NOTE: All but option 1 could provide for pre- and post-test counseling.

The Subcommittee discussed the relative merits of various approaches, taking into account the option's likelihood of success, cost, and legal and ethical implications.

Success was defined, first, as the "capture" rate, that is, the percent of HIV-infected pregnant women and HIV exposed newborns who might be identified in any given period of time --

prenatally, within a day or two of birth, or within the first month. Each time period was discussed in terms of its potential for preventing perinatal transmission and its potential for beneficial medical intervention for those identified.

Secondly, success was defined as the rate at which infected and exposed children could be expected to enter treatment. Success in identifying affected women and children does not imply success in delivering HIV services, which is dependent on the variety, quantity, and integration of programs, their accessibility, and the ability of the family to come in for care. Yet, clearly, identification is necessary to target service programs.

In theory, mandatory newborn testing would capture all newborns who carry maternal HIV antibodies. However, there are a number of qualifications to this assessment. It has been suggested that some women may elect to avoid testing by delivering outside of New York State or by avoiding hospital delivery. Further, in any given period, some additional infants may be missed due to inadequate time for laboratory follow-up on insufficient or untestable blood specimens. For example, in the New York State congenital screening program, by the end of one month (although follow-up continues for a total of 13 weeks), four percent of specimens that are not testable or are missing have not been replaced despite repeated requests.

The rapidity with which test results can be reported is critical to earlier HIV treatment. A protocol to return standard antibody test results (ELISA with Western Blot confirmation) in about five days could be developed, but would cost more than current protocols. Even with an optimal five-day HIV test reporting protocol, some samples would be inadequate and HIV results not available before mother and child leave the hospital. Therefore, an appropriately funded, aggressive, and effective follow-up program would need to be established as a part of any program designed to increase identification and treatment of HIV-infected newborns and mothers.

Inaccurate test results, both positive and negative, are a further caveat in designing a program to identify all HIV-exposed infants. Expensive protocols requiring multiple tests of a newborn's blood still cannot eliminate the falsely negative test that occurs when there are not yet detectable levels of maternal HIV antibodies. Most test protocols will also yield a number of false positives and equivocal results. Moreover, distinguishing between those infants who are truly infected and those who carry only maternal antibodies has been a major focus of research in newborn testing technology. Newer tests, such as PCR, which can make this distinction, are considerably more expensive than standard antibody testing and are not yet widely available, although sufficient resources could provide for statewide PCR availability.

Just as testing inaccuracies and delayed results would occur whether testing was voluntary or mandatory, success in contacting parents with test results may depend on the same factors regardless of testing policy. In New York State's congenital disease screening program, physicians, hospitals, or disease specialty centers are required to contact parents following certain abnormal test results in a newborn. In the experience of this program, parental tracing after hospital discharge is in most cases a time and labor-intensive process that depends entirely on staff resources and commitment. Cost and rapid success in contacting parents varies widely by hospital, by geographic location, and by disease. Families who are homeless, highly dysfunctional, undocumented aliens, or who give false information or move often for any reason are, naturally, more difficult to find. It often takes longer than a 13-week tracing period to reach a parent and requires a variety of strategies.

Voluntary HIV counseling and testing programs, while well-intentioned in their aim of convincing pregnant women to have HIV tests, have had widely varying rates of success. Casual or poorly-timed offers of counseling by busy or ill trained staff fail to persuade many women to accept counseling, or testing, or to return for test results or post-test counseling. Although there is no data on the exact number of HIV-infected women who know their status at the time of delivery, it is estimated that through New York State's two main voluntary perinatal testing

programs -- the Obstetrical Initiative and the Prenatal Care Assistance Program -- about 46 percent of HIV-infected pregnant women have learned their status prior to delivery.

However, program directors report that mothers who receive clear explanations of the reasons for and importance of HIV testing rarely decline. Information provided in presentations and materials to the Subcommittee indicates that rates of test acceptance near or above 90 percent (such as those achieved at Harlem Hospital Center and at some neighborhood health centers and family planning facilities) are the result of highly coordinated, interdisciplinary efforts by dedicated personnel and a strong institutional commitment to this approach. With proper implementation of an aggressive voluntary program, it may be possible to achieve Statewide rates of test acceptance and post-test parental counseling that would equal rates postulated for mandatory testing and parental notification.

It is clear that significant improvements in quality and possibly length of life, especially as a result of PCP prevention, can be achieved once an infant is identified and under medical supervision. Once again, success in delivering HIV monitoring and treatment services to exposed and infected infants and their mothers poses similar problems under both mandatory and voluntary newborn testing options. Parental notification, under either a mandatory or voluntary testing policy, does not insure

subsequent care. Although many of the current voluntary programs assert that it is rare for a parent to neglect needed HIV care for a child, there is still the problem of inaccessible, fragmented, or overburdened programs.

The Subcommittee, in trying to insure that the maximum number of HIV-exposed infants and their infected mothers obtain the earliest treatment possible, has had to determine not only whether HIV testing should be mandatory or voluntary, but whether greater benefit would be derived from prepartum or postpartum testing, and how quality programs of any kind can be assured.

Evidence presented to the Subcommittee supports the view that testing to identify HIV infection during pregnancy has some distinct advantages over postpartum testing, such as the possibility of preventing perinatal transmission to the fetus and greater opportunity to preserve a strong family environment for the newborn. According to a presentation by the Centers for Disease Control and Prevention, prepartum interventions to reduce the risk of transmission are the emerging focus of perinatal HIV treatment. Since breastfeeding begins at birth, preventing HIV transmission through this route also has the greatest chance of success if HIV-infected mothers are identified prior to delivery and counseled about the risk of breastfeeding their infants. Regarding treatment for HIV-exposed infants, while PCP prophylaxis does not in any case begin before one month of age,

monitoring for opportunistic infections, timely modification of immunization regimens, institution of antiviral medication, and attention to the child's development would be enhanced by the earliest possible knowledge of HIV exposure.

Given that neither a mandatory nor a voluntary testing program would identify 100 percent of HIV-exposed infants, and that either would have some difficulties tracing parents and providing sufficient and accessible treatment services to every affected family, the advantages of prenatal HIV determination and availability of the mother for counseling would argue for an emphasis on expanded and more consistently successful prenatal testing. Those women who do not seek prenatal care, and may thus require HIV testing after delivery, may also need a revised HIV test protocol that made results available before the mother leaves the hospital.

Mandatory testing during pregnancy would be a legally and ethically questionable practice, involving possible invasion of individual rights. Some believe that mandatory testing of newborns may also be viewed as a violation of maternal rights. A significant expansion of HIV-treatment services for women and children, together with counseling to insure that mothers are referred to appropriate programs, may also be required by ethical and legal concerns, as well as by the practical problems of providing care for greater numbers of women and children

identified as HIV-affected.

Thus, the Subcommittee searched for an option that would avoid the potential legal and ethical concerns of mandatory testing without consent or counseling, but be more consistently successful than voluntary counseling and testing programs have been to date at identifying infected women, especially prenatally.

If it could be replicated statewide, mandatory HIV counseling of all pregnant women with voluntary but strongly encouraged testing in a program similar to the Harlem Hospital model seems, in the opinion of the Subcommittee, to offer the best chance for a high rate of success in testing, preventing HIV transmission, and bringing infected families into care. The Subcommittee is aware that this option poses problems of cost and implementation, but feels that with proper support from the Legislature and health care professionals, these problems are surmountable.

This option would require the active and informed participation of all providers of care to pregnant women and newborns in New York State. But it is warranted by the intensity of the HIV epidemic and the consequences of HIV infection for women and children. Counseling and testing during pregnancy allows the widest range of maternal options for treatment and

planning, the greatest potential to prevent HIV transmission before, during, and after delivery, and the longest lead time to plan medical care for exposed infants. Making this counseling mandatory in well-run, well-supported programs will, in the opinion of the Subcommittee, convince the largest number of women to learn their HIV status. Convincing them to take an HIV test, rather than forcing them, will presumably lead to more cooperative, effective treatment for all affected family members.

The Subcommittee realizes that implementation of a policy of mandatory HIV counseling and strongly encouraged voluntary testing statewide is an ambitious undertaking. Although the Subcommittee believes this is the approach most likely to succeed, it also believes that its efficacy must be regularly analyzed to determine whether the goal of bringing nearly all HIV-infected women and HIV-exposed and infected children into treatment is in fact being met. To this end, the Subcommittee believes that the results of this policy, if adopted, should be reviewed in a timely and regular manner, and alternative strategies considered if it fails in achieving its goals.

The Subcommittee has agreed on the Principles and Recommendations below.

PRINCIPLES AND RECOMMENDATIONS

The Subcommittee's recommendations are based on the following principles:

Principles

1. The goal of New York State policies with regard to HIV-infected newborns and families must be to maximize the number of HIV-infected newborns and families identified and entered into treatment, and to provide them with optimal health care, psychosocial support, and other necessary services.

2. Given the importance of preventive therapy and early treatment for HIV-infected women and infants, all adults and sexually active adolescents, and especially all pregnant and postpartum women, should be informed of the benefits of knowing their own HIV status and that of infants.

3. Regardless of the policy on newborn and maternal HIV counseling and testing, identification of more women and infants with HIV and their subsequent entry into treatment will require that funds be allocated to expand comprehensive HIV treatment and support services for women and children.

4. All counseling, testing, treatment, and supportive service policies must acknowledge and focus on the needs of the family,

and be designed to support the ongoing involvement of the family in caring for HIV-positive newborns and young children.

5. Programs should be designed to maximize the likelihood that women will seek services for themselves and their children, emphasizing accessibility and confidentiality, as well as family-oriented service delivery.

6. The distinct needs of urban and rural communities should be considered in identifying services and costs to implement enhanced counseling, testing, and treatment programs.

7. The State must be prepared to move quickly to respond to innovations in testing and therapy for women and children. The latest HIV testing technology should be utilized to reduce test processing time and to distinguish as rapidly as possible between maternal antibodies and HIV infection in infants.

8. A new standard of care requiring HIV counseling for all pregnant and postpartum women and the provision of HIV services as early as possible to HIV-exposed and infected infants cannot be implemented without the commitment of all providers of health care to women and children. Appropriately trained health care professionals, paraprofessionals, and community leaders, as well as the administrators of health institutions and community health organizations, must firmly support this policy and work to make

it a success. An integrated (interdisciplinary) care model dedicated to optimal care for HIV-infected women and children, such as the Harlem Hospital Center program, is considered exemplary.

Recommendations

Guided by these principles, the Subcommittee on Newborn HIV Screening recommends that the following policies be adopted by order of the Commissioner of Health, by regulation, or by statute, as appropriate:

1. A policy of mandatory HIV counseling and strongly encouraged voluntary testing for all pregnant and postpartum women should be implemented as soon as possible.

Although the Subcommittee does not recommend mandatory HIV testing of newborns at this time, it is imperative that HIV testing should be presented as a standard medical recommendation by providers in all prenatal, obstetrical, postpartum, and pediatric settings.

2. All providers of health care services in New York State should provide HIV counseling to and strongly encourage HIV testing for all sexually active adults and adolescents (males and females).

This should be presented as a standard medical

recommendation and should become part of routine medical practice in all health care settings.

3. Women who have tested HIV-negative prior to their pregnancy must be provided with repeat counseling and strongly encouraged to repeat the test during pregnancy.

4. All providers of care to neonates and young infants must ensure during postpartum or ongoing pediatric care that appropriate HIV counseling has been given to the infant's mother.

If the mother has not been counseled or has been counseled but has not been tested prenatally, HIV counseling must be provided and testing for the mother and/or infant strongly encouraged.

5. Adequate funding must be provided to implement the new policy of expanded HIV counseling and testing programs and for comprehensive medical care and psychosocial support services for all HIV-positive women, infants, and children.

Funds for these services should not be diverted from other critical human service programs.

The AIDS Institute should identify the specific services that will be required to effectively implement enhanced counseling, testing, and access to care programs for women and their newborns, together with the costs of these programs, and report these assessments to the AIDS Advisory Council (See

Appendix I). This assessment may be done on a regular basis in response to changes in testing or clinical care options.

6. Evaluation of the effectiveness of a program of enhanced HIV counseling, testing, and access to services for women and their newborns must begin not later than one year after financing is made available to providers in order to determine whether the program has resulted in an appropriate increase in the number of HIV-infected women and infants who enter treatment.

The New York State AIDS Advisory Council or its designee should monitor the progress of these recommendations and oversee evaluation of the new policy on a regular basis.

Adequate resources and staffing must be provided to support the initial and ongoing evaluation. Performance standards should take into account hospital seroprevalence rates as well as the goal of maximizing the number of HIV-infected women and children in care.

7. Policies and procedures must be in place at all hospitals, clinics, and doctors' offices where pregnant women, postpartum women, and children are seen to:

- implement the new policy of expanded HIV counseling and testing programs,
- provide for the appropriate notation of maternal HIV status in the neonate's record,
- assist women in returning for their post-test counseling

visit and expedited access to care for themselves and their infants.

8. The AIDS Institute should review current regulations to streamline procedures for HIV counseling, testing, and informed consent within existing law.

9. Commercial health insurance carriers should be required to cover and Medicaid should be required to continue to cover the cost of prenatal and postpartum HIV counseling and testing.

HIV counseling and testing should be specifically excluded from co-payment requirements under Medicaid.

10. Literature on HIV counseling/testing, HIV medical care, and supportive services for HIV-infected persons should be readily available in all health care settings providing services to pregnant and postpartum women, other adults, adolescents, and children.

Such literature should be culturally sensitive and linguistically appropriate to the population served by the specific provider. In particular, the Department of Health should prepare and distribute a new Guide for HIV Counseling and Testing in Women's Health Care Settings. This Guide would cover such issues as breastfeeding, immunization, the family's role in caring for the child with or at risk for HIV, and care of the mother to maintain her health and ability to care for her

children.

11. Institutions responsible for the education of health care professionals should include in their curricula instruction concerning the importance of integrating HIV counseling and testing into routine primary medical care, effective counseling methods, the importance of confidentiality, and information to be transmitted to patients.

12. The Medical Society of the State of New York, the New York State chapter of the American College of Obstetricians and Gynecologists, the New York State district of the American Academy of Pediatrics, the New York State Nurses Association, the New York State chapter of the American College of Nurse Midwives, and all other relevant organizations of health services and health education professionals should take an active role in expanding the availability of HIV counseling, testing, and treatment, especially for pregnant and postpartum women and children, and educating both the public and their members on this issue.

Dissenting Comments on the January 31, 1994 Report of the Subcommittee on Newborn Screening to the AIDS Advisory Council, February 4, 1994

Early identification and comprehensive health care now can lengthen and improve the quality of life for HIV infected infants. The Subcommittee on Newborn Screening was created because too many of the infants who need such care are not identified in time to receive these benefits. Resistance to testing newborn infants for HIV, a procedure that would guarantee the benefits of early, appropriate care has been based on fear that such routine testing, as is done for nine other diseases, could subject infants and their mothers to stigmatization, discrimination and even physical harm. In light of current experience that proper care is beneficial and can be provided to such infants and their families, that confidentiality can be maintained and that a well established methodology for testing is at hand, it is time for New York State to exercise its responsibility to vulnerable children by designating early identification of HIV infection as a necessary component of newborn care. The gap between the documented number of children and families who would benefit from appropriate care, 1800 per year, and the number being identified by current efforts at prenatal and postnatal counseling has provided the impetus for the Subcommittee to seek "a better way."

The central recommendation of the Subcommittee Report proposes mandatory prenatal and postnatal counseling which strongly encourages voluntary testing for HIV antibody (rather than routine testing). This recommendation is a valuable step toward reinforcing an accepted standard of care for women and children, but it is insufficient to offer the protection which every infant deserves, protection which has been guaranteed newborn infants in New York State for other serious diseases. Reliance on counseling and that encourages voluntary testing ignores the unacceptably high failure rate of such an approach. In addition, it siphons off resources which could be focused more effectively for needed care. The failure of our health system to identify many of the infants born each year in New York State to HIV infected mothers denies them access to life-saving and life-enhancing care. A substantial body of experience supports our concern that delay in diagnosis is literally a matter of life versus preventable, early death.

In making the case for its central recommendation, the Report contains much information that is

accurate, humane, constructive and practical. However, in our judgement, the Report is distorted by errors of omission, commission, logic and unlabeled speculation . The remarkable accuracy and economy of existing diagnostic tools for identifying infants who can benefit from special care is glossed over, as are the disappointing results of currently funded programs that focus on efforts to "counsel and encourage testing".

The Report does not address adequately the lessons learned from efforts to control perinatal morbidity and mortality from Rh Disease, rubella, syphilis, hepatitis B, sickle cell disease, congenital hypothyroidism, PKU and infectious conjunctivitis of the newborn. Although each of these diseases has its own special characteristics, as does HIV, a uniform message is clear. Infants were subject to preventable harm until an easily monitored requirement for routine testing was supported by Public Health Law and regulation, and in the case of newborn screening, was also accompanied by development of a proper public health infrastructure, . In our judgement, the report falls short by not recommending such an approach.

The "Harlem Hospital Model" espoused by the Report as evidence that effective counseling will bring infants and their mothers into care is not described in detail, nor are its infrastructure, resource base and special characteristics analyzed with regard to its potential for replicability across the State. Based on the available details of that research-oriented and research-funded program and the low acceptance of testing rates achieved in pilot programs involving many thousands of women throughout the State, there is ample evidence for serious doubt that the "Harlem Hospital model" can be replicated on a state-wide basis.

The Report gives insufficient attention to society's responsibility "to act in the best interest of the child" and speculates in an unbalanced and unsubstantiated manner on how testing of newborn infants for HIV infection will be harmful to their mothers. The language of the Report is confusing with regard to issues of confidentiality and disclosure. It equates newborn testing with breach of confidentiality and any disclosure with improper disclosure. While reminding the reader that HIV infected persons are subject to discrimination and stigmatization in spite of existing statutes, the Report offers no evidence (in fact, does not even address) its implied conclusion that testing of infants as part of a voluntary program, rather than as a component of routine newborn care,

would reduce the potentially harmful consequences of improper disclosure and discrimination, both of which are illegal.

The Report gives scant attention to an option presented which is mindful both of parental rights and responsibilities and the hazard to the child of unrecognized HIV infection. That option adds HIV antibody testing to the existing routine Newborn Screening Program, with an "opt out" provision for mothers who, after proper counseling, object to having their infants tested for HIV.

The Report recommends a program which fails to guarantee the protection of timely health services to infants and their families. Even if this were an era of unlimited resources, we would still favor the remarkably cost-effective, easily implemented and monitored alternative provided by the well-established NY State Newborn Screening Program. In addition, the Report is too vague on how additional funds should be allocated, or how the compelling needs of the children (and their families) for services will receive appropriate priority.

In attempting to summarize where we feel the Report falls short, we have tried to avoid the imbalance and inaccuracy which compromise the lengthy document. Given the complexity of the scientific, medical, legal, psycho-social, ethical and logistic issues involved in newborn HIV testing, we recognize that this brief response is also at risk of imbalance. On that basis, we stand ready to offer more detailed information and opinion as public discussion leads us, hopefully, to clarity about the issues involved. Such clarity should assist those who must make well-informed public decisions, decisions in which New Yorkers must act in the best interest of our vulnerable children and their families.

Louis Z. Cooper, M.D.
Keith Krasinski, M.D.
Mark S. Rapoport, M.D., M.P.H.
Nancy Wade, M.D.

\hiv02064.lzc