Setting Our Agenda
Priorities for Addressing
HIV/AIDS
In the Latino Community

Latino Commission on AIDS

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PREFACE

On November 9, 1995 the First Annual Strategic Planning Conference on Latinos and HIV/AIDS was held at Baruch College in New York City. Over 280 service providers, people with HIV/AIDS, health care professionals, educators, government officials, academicians, community activists, affected family members and interested individuals attended. The shared objective was to come up with a common agenda for addressing the destructiveness of HIV/AIDS in New York's Latino community. It was not a Conference where you could sit, listen to experts, take notes and go back to your home or office. In small groups, Conference participants worked for several hours to reach consensus on recommendations for funding, programmatic initiatives, legislative change and new policy directions. Everyone was asked to make tough choices and focus on the issues that were critical to the Latino community.

Part of the work of the Conference was completed before November 9. For seven months, volunteers worked in issue groups and on the Conference Planning Committee to gather information and refine the issues for discussions. Over 70 Latinos participated in this preparation process. The pre-Conference work made it possible for conferees to focus on recommendations and set priorities.

At the end of the day on November 9, the Latino Commission on AIDS was left with the responsibility of pulling together dozens of notes, tape recordings and recollections of issue group leaders into a report. The completion of this Conference summary took longer than we expected. Between missing tapes, a computer virus, a new baby girl named Catherine, and everything else, there were unexpected delays. We hope this document captures the hard work and energy of everyone who attended.

The Conference Report is called "Setting Our Agenda" because that is what the process was and will continue to be. Each chapter of the Report is divided into three sections—Profile, Areas of Concern and Conference Recommendations. The Profiles were prepared by the Pre-Conference Workgroups and, in a few cases, Commission staff. They were an effort to give the Conference participants background on each of the subgroups targeted by the Conference Planning Committee. The Areas of Concern grew out of these same Workgroup meetings in the months preceding the Conference. They were meant to provide Conference participants with a list of issues relevant to each affected group. The list was not meant to be definitive or scholarly but rather a series of brief issue descriptions to facilitate discussion. The Pre-Conference Working Groups and the Planning Committee had one objective in this preparation—to ensure that the short time allocated for the Conference would be used for arriving at recommendations rather than restating areas of need familiar to most of the conferees. The Recommendations in each chapter reflect the concerns of the Conference participants on November 9, 1995, with a little updating by the Latino Commission on AIDS in consultation with the Issue Group chairs.

A new phase of the Latino Strategic Planning Initiative on HIV/AIDS begins with this publication. Conference participants will be scheduling briefings for elected officials, private funders, government agencies and community organizations. In the months ahead Conference participants will be organizing educational programs, trainings and other initiatives. The Conference and this report are part of a process of Latino leadership development and community organizing that everyone who participated hopes will make a difference.

We would like to extend a special thanks to members of the Planning Committee who came to so many meetings, to the individuals and non-profits that donated funds and in-kind services, to the issue group leaders who guided the policy direction and, finally and most importantly, to the Conference participants.

We would like to extend our gratitude to members of the Planning Committee for coming to so many meetings, to the individual and non-profits the donated funds and in-kind services, to the issue group leaders who guided the policy direction of the entire process and, most importantly, to the Conference participants. Special thanks are owed to the United Hospital Fund for its patient support of the information gathering and needs assessment incorporated in the Agenda (in particular Lenore Glickhouse), to the New York State Department of Health's AIDS Institute for providing support to all of the Latino Commission's community organizing efforts, to the Fund for the City of New York, VIP Community Services, the NYC Department of Health's Office of Gay & Lesbian Health Concerns, Luis Solis, Jeff Soref and ASPIRA for supporting the actual costs of holding of the Conference and the Hispanic Federation for the printing of the Conference Report.

Latino Commission on AIDS

EXECUTIVE SUMMARY

A LEGACY OF LOSS

How can we help the reader of this Conference Report to understand the depth of loss to New York's Latino community due to AIDS? There is no statistical summary that can fairly capture the impact of HIV/AIDS on New York's Latino community or any other population. Although this Report contains an enormous amount of critical (in our view) information, for most people the presence of numbers causes the eyes to race over a page. While personal stories can have an impact, numbness sets in as the sadness becomes overwhelming and repetitive. So how do we communicate the reality of lives lost and the Latino community's response to private foundations, government agencies, legislators and everyone else with life saving resources?

We can't answer this question. Instead we must rely on the unseen compassion and concern of decision makers to read this Report and to make funding and legislative decisions that will address some of the most serious problems. We hope they can sense the passion of a community that came together on November 9, 1995 because we have had enough of other people speaking about the needs of Latinos. We expect these decision makers to hear the voices and ideas of a community that has lost thousands of friends, relatives, lovers and leaders.

PRIORITIES FOR ADDRESSING DEVASTATION IN NEW YORK'S LATINO COMMUNITY

LATINOS, SUBSTANCE USE AND HIV/AIDS

The sharing of HIV-contaminated hypodermic syringe has been the road on which HIV/AIDS has traveled into New York's Latino community. It is the root source of infection for men and women, their sexual partners and their children. Transmission of HIV by intravenous drug (IVD) use represents 56% (13,806) of all Latino cases in New York City and 17% of all Latino AIDS cases nationally. For Latinas the impact of intravenous drug use as a vehicle for HIV transmission has been dramatic. Latina IVD users make up almost 60% of New York City Latina AIDS cases and 46% of all Latina AIDS cases in Puerto Rico. New York City Latinas infected through intravenous drug use are 25% of all Latina AIDS cases nationally.

Priority One—The New York State Legislature must adopt S.1998/A.2810 that would allow the sale of needles and syringes without a prescription. Deregulating the sale of needles would save Latino lives.

Priority Two—State legislators must oppose Governor Pataki's proposals to reduce drug treatment services. The Governor plans to end methadone maintenance programs for Latinos on Home Relief Public Assistance and to cut funding 20% for community-based drug treatment programs. This would increase needle use and result in more HIV infections in the Latino community.

Priority Three—Governor Pataki must increase needed treatment slots for individuals seeking to recover from heroin, cocaine and other types of substance use. This has been a standing request from New York's Latino community for the past 30 years.

Priority Four—State legislators and Governor Pataki must change State law to permit more needle exchange programs, remove bureaucratic obstacles and provide funding to meet the need for expanded exchange services.

LATINO YOUNG PEOPLE AND HIV/AIDS

As with other segments of the HIV infected population in New York City, Latino youth between the ages of 13–24 are a major segment of those affected by HIV/AIDS. Thirty-nine percent of young people between the ages of 13 and 19 with AIDS are Latino. Latino young men make up 44% of all males with AIDS in this age group and Latinas 35%. Among young adults between the ages of 20 and 24, almost 48% are Latino. The truly disturbing nature of these statistics is made even clearer when contrasted with the 19% Latino youth AIDS rate nationally. President Clinton's Office of AIDS Policy estimates that one in four new HIV infections in the United States occur among young people under the age of 20.

Priority One—Private foundations should fund pilot programs that involve schools, parents, young people and community based organizations to address Latino adolescent sexuality.

Priority Two—The New York State Legislature and the Department of Education must mandate that New York City schools provide comprehensive AIDS education to Latino young people.

Priority Three—New York State Legislature and the State Department of Alcohol and Substance Abuse Services must fund more drug treatment programs for adolescents

Priority Four—Latino service providers should be funded by the AIDS Institute and the New York City Department of Health to provide community based prevention and support services for lesbian and gay Latino youth.

LATINAS AND HIV/AIDS

New York City is the national epicenter of Latinas with AIDS. The impact of HIV on Latinas in New York City is unfolding day by day, in home after home, in workplaces, in every profession and in every community. New York City Latinas account for almost 40% of all female Hispanic AIDS cases nationally and 34% of all New York female cases of AIDS. AIDS is the leading cause of death for Latinas ages 25 to 44 in New York City and Puerto Rico. According to estimates prepared by the New York City Department of Health, from 1988 and 1993, between 21,000 and 50,000 females over the age of 13 were living with HIV in New York City.

Priority One—New York State legislators must explicitly reverse regulatory provisions issued by the Department of Heath that give a doctor the authority to direct an HIV test of a newborn when the mother has not decided whether to permit the test.

Priority Two—New York State Office of Substance Abuse and Alcoholism Services must set aside more funding for drug treatment for pregnant women, women with families and all other women.

Priority Three—Mandate that primary care providers make aggressive efforts to integrate HIV/AIDS information into their service delivery and that the information be provided in Spanish and English.

Priority Four—Fund training for all publicly financed reproductive health program staff and rape/incest crisis centers on HIV infection and medical/treatment interventions.

LATINOS, PRISONS AND HIV/AIDS

Latinos in New York State prison constitute the most affected group in a system ravaged by AIDS and HIV infection. Latinos make up about 30% of the over 66,000 current inmates but 47% of the cumu-

lative incarcerated population with AIDS. HIV seroprevalence surveys of men and women entering the New York State prison system have consistently shown that HIV infection in New York State prisons remains primarily a problem among Latinos. To constitute one-third of the State's inmates but one-half of its diagnosed cases of AIDS is distinction with implications for every aspect of the New York State prison system, the parole system and sentencing laws for repeated drug-related offenses.

Priority One—State legislators must require that all medical, peer, support group, education, treatment and prevention services be offered in Spanish for monolingual and bilingual prisoners.

Priority Two—New York State Medical Parole Law must be amended to fulfill its original intention. The law must be changed to cover "state ready" inmates awaiting transfer to State facilities and inmates whose parole eligibility has expired. In addition, the law must be extended for three years as opposed to one.

Priority Three—Adopt legislation requiring the New York State Department of Corrections to bring prison medical care facilities up to New York State Department of Health standards for hospitals and clinics.

LATINO FAMILIES AND CHILDREN

HIV/AIDS has created a crisis in countless Latino families. While the actual number of children and adolescents whose parents have died from HIV disease has never been collected, all estimates point to an unfolding tragedy. In 1994, the estimated numbers of orphans was set at 7,000 children and 6,700 adolescents by the New York City Department of Health's Prevention Planing Group. The Centers for Disease Control has estimated that between 93,000 and 112,000 uninfected children will be born to mothers who die of HIV/AIDS between 1992 and the year 2000. Almost none of the private and public funding provided to date has addressed the critical role of the Latino family in responding to HIV infection. Most current treatment and prevention modalities thus far developed are addressed to the individual rather than to the family unit. For Latinos this neglect has sometimes been disastrous.

Priority One—New York State Legislature must amend the Social Services Law to enable parents who have not found a guardian to retain custody while putting voluntary foster care in place prior to death or incapacity.

Priority Two—Governor Pataki and the New York State legislators must amend social service laws to enable new and second families to receive maximum financial support and continued benefits to children orphaned by the death of a parent.

Priority Three—The New York City Child Welfare Agency must improve its responses to the needs of Latino families by developing a specialized Early Permanency Planning Program Unit of trained bilingual/bicultural staff, by providing "new" families with all the legal options available and by making sure that foster care and adoptive parents are provided with supportive services.

LATINO IMMIGRANTS AND HIV/AIDS

Like many other Latino immigrants, immigrants with HIV/AIDS typically reside in economically depressed areas of the city, hold low-paying blue collar jobs, lack any form of health insurance, lack an understanding of the health and social services systems, and lack fluency in the English language. Almost 50% of male and 30% of the female immigrant AIDS cases are from Spanish speaking countries in South America and the Caribbean. Within this group, most male immigrant cases come from

Cuba, the Dominican Republic, Columbia, Ecuador and Mexico (in that order) with the primary mode of transmission being sex between men. For female immigrants almost one-half of the cases reported from a Spanish speaking country are from the Dominican Republic with transmission primarily through sex with a man.

Priority One—Secure legislative and executive commitments from New York State and City governments to continue current types and levels of benefits and services to immigrants with HIV/AIDS, despite anticipated Federal welfare reform.

Priority Two—Fund neighborhood naturalization clinics that allow CBOs to conduct group processing sessions for legal permanent residents who wish to become naturalized citizens.

Priority Three—Fund training for hospital personnel and post-test counselors, community-based case managers, and other service providers regarding services and benefits available to immigrants with HIV/AIDS.

HIV/AIDS AND GAY, BISEXUAL, TRANSGENDERED, AND OTHER MEN WHO HAVE SEX WITH MEN (MSM)

Latino men who have sex with other men have been ignored in virtually all primary and secondary prevention efforts and suffer indifference and rejection by most service providers. The absence of prevention efforts was underscored in a recent report from the Centers for Disease Control, which documented the steady increase of new AIDS cases among Latino and African-American men who have sex with men over the past five years. The New York City Department of Health reports that as of October 1995, 21% (5,849 of 28,250) of all cases of MSM AIDS cases were Latin/o. On a national level, the CDC reports 23% of all cases of Latino MSM transmissions were New York City Latino males. Latino gay men have shown significantly higher seroprevalence rates than white gay men year after year.

Priority One—Expand funding for HIV prevention funding developed by Latino gay men and require that the service provider staff reflect the population being served.

Priority Two—Repurpose existing prevention messages and programming to target all segments of the Latino MSM population. Funding for these messages must be created and distributed by Latino MSM.

Priority Three—Initiate expanded prevention programs that target Latino men who identify as bisexual and transgendered.

NEW FORCES CHANGING LIVES OF LATINOS WITH HIV/AIDS

There are profound changes in the so-called government "safety net" being implemented in Washington, D.C., Albany and New York City that will negatively affect the quality of life for the Latino community. Some of the basic services Latinos living with HIV/AIDS have relied on for the past twelve years are rapidly disappearing. Long-held assumptions about the availability of health care, housing, prevention services, financial support, and treatment are called into question precisely when our AIDS-ravaged community is most in need of these life-saving benefits and services.

The focus of the 1995 Conference was on target populations within the Latino community. It was be impractical to take on each of the critical issues listed below during a one-day Conference. It is hoped that these issues can be integrated into the subsequent discussions about the Conference Report and can be revisited during the 1996 Conference.

Cutting a Life Line for the Uninsured

New York State's HIV Uninsured Care Programs provide critical medications (ADAP), primary care (ADAP Plus) and home care (Uninsured Fund) to Latinos with HIV and AIDS who are not covered by Medicaid. These are often immigrants and Latinos with low paying jobs that do not provide health insurance. The Uninsured Care Programs are totally funded by the Federal government through Ryan White I and II dollars. However the program has proven extremely popular and is outgrowing these funds. The State has responded by cutting off access to 129 medications that were offered through ADAP and reducing home care services. New York State must contribute a substantial share of funding for HIV Uninsured Care Programs. If it does not meet its obligation, the lives of Latinos with HIV will be shortened. Without this assistance uninsured Latino/as would lose crucial care and would become sicker and poorer. This would impose other financial burdens on the City health care system as emergency rooms are used for avoidable health crises. The State should not require New York City to spend more and more of its Ryan White funding for the Uninsured Care Programs. Such a strategy would totally deplete crucial funding to agencies providing care and case management services.

Mandatory Managed Care for Latinos with HIV/AIDS

Managed care is a potentially valuable resource for delivering limited medical resources to people living with AIDS. To date, however, some managed care companies have spoiled their entry into Medicaid with duplicitous marketing practices and a seeming lack of concern for the health and rights of Medicaid recipients as consumers. While the State Department of Health has interceded to address the most egregious abuses there is much more that must be done to make managed care work for people with AIDS.

Commercial HMOs must not be allowed to separate Medicaid enrollees from their commercial counterparts by providing "two lists"—one for private customers and the other for Medicaid enrollees.

There must be a meaningful "bill of rights" for Medicaid managed care clients to guard against long travel time, delayed access to specialty care, long waits for primary and secondary care appointments and assignments to inaccessible primary care providers.

The AIDS Institute must begin funding programs to train Latino and other Medicaid recipients on how to effectively use managed care to their advantage.

Community-based organizations serving Latinos can play a vital role in managed care through prevention and case management services. The difficulty will be in getting managed care systems to attach financial value to these services and to give CBOs and people living with HIV/AIDS a decision-making role.

Whatever safe guards might be implemented, we need to remember that there is no significant experience anywhere in the United States with providing mandatory managed care services to persons with HIV/AIDS who have been on Medicaid. No one really knows whether it will work for the thousands of Latino New Yorkers with HIV/AIDS. All of our decision making must be made with this reality in mind.

Cutbacks in Housing for People with AIDS

The range of housing alternatives for people living with AIDS is being narrowed. While Housing Opportunities for People with AIDS (HOPWA) survived possible elimination this year, it is not anticipated that funding levels will be sustained in future years. Housing for Latinos living with AIDS is critical to leading a healthy life. Homeless persons with the virus may face an elimination of scattered site, supported, and other forms of housing.

Privatization of Public Hospitals

For the past several decades, New York's system of public hospitals has been a mainstay for health care in the City's minority communities. As other medical provider options have become more restricted, Latinos with HIV/AIDS have turned to these care givers for basic medical care and acute conditions. Concurrent with this increased reliance has been dramatic contractions of resources and funds for the hospitals. Changes in Medicaid funding, shorter hospital stays, improved homecare services, a campaign of disinvestment and decapitalization by the City and more effective pharmacological interventions have caused health care professionals to explore new ways public hospitals can serve minority communities. Mayor Guiliani has refused to support the public hospitals in this struggle for a redefinition, focusing instead on wholesale transfers of these community resources to private providers. People with HIV/AIDS will lose out as the obligation to provide community care is shifted to profit driven health care providers and private hospitals.

Elimination of Division of AIDS Services' Case Management Functions

As this Conference Report is being issued, the Guiliani Administration is implementing plans for the effective elimination of case management services through the Human Resources Administration's Division of AIDS Services (DAS). Specifically, the Administration hopes to provide case management only for the first 90 days after enrollment with follow-up by a "monitoring panel." While DAS has several shortcomings, the ability to have a case manager has largely proven useful in responding to the rapid changes which are part of this disease. The so-called "restructuring" raises serious questions under the Americans with Disabilities Act and other anti-discrimination laws which protect the disabled. Legislation introduced by City Council Members Thomas Duane and Stephen DiBrienza to give the Division of AIDS Services a statutory base deserves broad support from the Latino service provider community.

Reducing the Effectiveness of the NYS Department of Health's AIDS Institute

The AIDS Institute has been at the center of policy and programmatic responses to the epidemic in the Latino community. It has provided timely and creative solutions to some of the most difficult issues faced by communities of color. Recent personnel changes in the AIDS Institute by the new State Health Commissioner caused grave concern among community based organizations. There was additional confusion when the Health Commissioner introduced a budget for the AIDS Institute which seemed to sharply reduce program funding. Many of these initial concerns were dealt with by Commissioner DuBuono and Governor Pataki when additional funds were restored to the AIDS Institute budget and the AIDS Advisory Council was reactivated. There are still legitimate questions about the direction of the AIDS Institute and its commitment to maintaining its leadership role in addressing AIDS in New York State.

Less Research on HIV/AIDS Treatments

Since the beginning of the epidemic, there has been an intense effort to increase funds for biomedical research and to create a research infrastructure that is coordinated and targeted to HIV/AIDS. The result of these efforts was the creation of the Office of AIDS Research. Legislative initiatives in the United States Congress threaten the authority of the Office of AIDS Research to require that funded research specifically AIDS.

Elimination of New York's AIDS Clinical Trial Group Sites in Minority Communities

In 1995 New York City lost funding for the Community Program for Clinical Research on AIDS. This was the only AIDS clinical trials program that provided targeted access to trials for Puerto Rican New Yorkers who were homeless or enrolled in substance abuse programs. Then the Department of Health and Human Services decided to eliminate all but three of the city's AIDS Clinical Trials Groups. The remaining three programs are all in Manhattan. This two year record of reducing access to clinical trials in Brooklyn and the Bronx harms those persons with the least access to new medical treatments.

Declining Funds for Ryan White CARE Act

There was an enormous struggle this year to maintain services funded through the Ryan White CARE Act. The outcome of the House/Senate Conference Committee remains uncertain. In any case, there will be some reductions on a local level as a result of legislative changes adversely affecting New York City. Further, it is likely that more Ryan White funding will be directed toward maintaining aspects of the "safety net" for people with AIDS as cutbacks in SSI and Medicaid are implemented.

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LATINOS, DRUG USE AND HIV/AIDS

PROFILE OF SUBSTANCE USE AND HIV INFECTION AMONG NEW YORK CITY LATINOS

The sharing of HIV-contaminated hypodermic syringes has been the road on which HIV/AIDS has traveled into New York's Latino community. It is the source of infection for men and women, their sexual partners and their children. Transmission of HIV by intravenous drug (IVD) use represents 56% of all Latino cases in New York City and 17% of all Latino AIDS cases nationally.[1] It has been identified as the primary risk factor in 13,806 cases of Latinos with AIDS in the York City.[2] Over three-quarters of all new drug-related AIDS cases among Latinos have been reported in the last five years.[3]

For Latinas the impact of intravenous drug use as a vehicle for HIV transmission has been dramatic—Latina IVD users make up almost 60% of New York City Latina AIDS cases and 46% of all Latina AIDS cases in Puerto Rico.[4] New York City Latinas infected through intravenous drug use are 25% of all Latina AIDS cases nationally.[5]

For Latinos who do not inject drugs, unprotected sex with a drug user is the primary connection to HIV—Over 20% of New York Latino AIDS cases in New York are the result of sex with an intravenous drug user.

Most mothers of HIV-positive infants (55%) became infected through sex with an IVD user.

IVD use is a critical route for infection for Latino young people—Intravenous drug use is not a relic of the 1960s, found exclusively among older Latinos. As many as 30% of the AIDS cases among young people (below the age of 25) are due to IVD use. For young women, IVD use accounted for 37% of the cases. One reason for this high rate of injecting drug use maybe that younger IVD users are the most likely to share needles and to inject in a group setting.[6]

Racial discrimination within the Latino community may be an important variable in determining levels of HIV infection among IVD users—Black Latino IVD users have significantly higher levels of HIV infection than other Blacks or White Latinos. Black Latinos report higher levels of risk behavior, are more isolated from medical information, and show lower rates of accessing medical and treatment services.[7]

Latino male IVD users born in Puerto Rico report the highest levels of HIV infection—Exposure through intravenous drug use accounts for 35% of the cases among Latino men born in the United States, 27% of those born in the Dominican Republic, and 61% among men born in Puerto Rico. This is in sharp contrast to the reported 10% of AIDS cases attributable to intravenous drug use among other Latinos and non-Latino white men.

Location of injection behavior can be predictive of the extent of infection risk—Shooting galleries (especially outside settings) are the most popular venues for many Latino IVD users and showed the highest levels of HIV-positive status among participants.[8] When compared to Puerto Rican women residing in the United States, Puerto Rican women residing in Puerto Rico are more likely to start injecting drugs at an older age, to use shooting galleries and to be HIV-seropositive.[9]

The highest levels of infection have been tracked among IVD users who regularly inject cocaine or cocaine and heroin—Cocaine injection frequency has the highest predictive strength for determining HIV status. IVD users who inject only heroin have shown increasingly lower levels of HIV infection

1 U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, *HIV Surveillance Report* (June 1995).

2 New York City Department of Health, *AIDS in New York City: AIDS Surveillance Update* (October 1995).

3 *Health Emergency, The Spread of Drug-Related AIDS Among African-Americans and Latinos.* Report of Commonsense for Drug Policy, Criminal Justice Policy Foundation, the Dogwood Center Drug Policy Foundation, Harm Reduction Coalition and Lindesmith Center (October 1995).

4 It should be noted that much of this data is anything but precise given the ambiguities of reporting categories. For Latinas reportedly infected through IDU use, no information is routinely collected on whether they also may have had heterosexual contact with another intravenous drug user. Another example would be men who have sex with men and are also intravenous drug users. The New York City's quarterly AIDS Surveillance October, 1995 Update reports a total of 2476 cases of MSM/IDU (4% of total reported male AIDS cases) with 31% (776 reported AIDS diagnoses) of these cases being Latino.

5 Distinctive risk patterns have been reported among Latina injecting drug users. First, when compared to Puerto Rican women residing in the United States, Puerto Rican women residing in Puerto Rico are more likely to start injecting drugs at an older age, to use shooting galleries, to be HIV seropositive and to use treatment programs. Robles, RR, et al., *Comparison of Risk Behaviors and HIV Infection Among Drug Injector Women: Puerto Ricans in Puerto Rico and Puerto Ricans and non-Hispanic Whites Residing in the United States.* Int. Conf. AIDS 1992 (Abstract No. PoD 5495). Second, Latinas with a history of IVD use who believe that luck plays the largest role in getting AIDS were less likely to report a change in their sexual behavior because of HIV. The death of a family member from HIV disease was also found to be a key factor in reporting changes in sexual behavior. Hadden, B., et al., *Predictors of Sexual Behavior in Women on Methadone.* Int. Conf. AIDS 1992 (Abstract No. PoD 5517). Third, lesbian IVD users have been found to have a higher level of seroprevalence than other women IVD users. Friedman SR, et al., *HIV Seroconversion Rate Among Street Recruited Drug Injectors in 14 United States Cities.* Int. Conf. AIDS (Abstract No. PoC 4251). Fourth, Latinas are more likely than men to inject with a sexual partner in group contexts than to inject alone or in an anonymous group. Sotheran, JL, et al., *Gender Differences in the Social context of Syringe Sharing among New York IVDUs.* Int. Conf. AIDS 1992 (Abstract No. PoD 5093).

6 Humfleet, GL, et al., *Age and Ethnic Differences in HIV Risk Behaviors and Knowledge of IV Drug Users.* Int. Conf. AIDS 1990 (Abstract No. 3017).

7 Friedman, SR, et al., *Multiple Minority Status as an HIV Risk Factor Among NYC Drug Injectors.* Int. Conf. AIDS 1993 (Abstract No. PO-DO5 0).

8 Neagius, A. et. al., *The Emergence of Outside Injection Settings as Sites for Potential HIV Transmission in New York City.* Int. Conf. AIDS 1992 (Abstract No. PuD 9132).

9 Robles, RR, et al., *Comparison of Risk Behaviors and HIV Infection Among Drug Injector Women: Puerto Ricans in Puerto Rico and Puerto Ricans and non-Hispanic Whites Residing in the United States.* Int. Conf AIDS 1992 (Abstract No. PoD 5495).

over the last ten years. The reason for the high HIV levels among cocaine injection is the frequency of injections. Cocaine injectors may average as many as seven injections a day. While cocaine injectors are mostly African-American, there are a substantial number of Latinos who follow this pattern.[10]

HIV/AIDS can permeate the sexual, familial, and household relationships of Latina IVD users—Drug use and HIV infection are inter- and intra- community problems rather than exclusively the problem of one individual. An injecting drug user is likely to have a domestic partner that uses drugs and is more likely than others to have siblings that are drug users. One study of IVD user siblings found that one third of the siblings were drug users with 10% testing HIV-positive.[11]

Harm reduction as a means of reducing HIV infection among IVD users has been shown to reduce sharing needles and the frequency of injection—Harm reduction programs attempt to meet the IVD user where he or she is rather than insisting on an abstinence from all drugs. The goal is to provide incentives for the user to adopt less risky behavior. Harm reduction has been defined to include a wide range of interventions including methadone maintenance, drug treatment programs, needle exchange, the use of bleach kits and acupuncture.

Needle exchange programs have proven extremely successful in reducing the primary risk factor for HIV transmission among IVD users—the sharing of needles. There are seven needle exchange sites in New York City. These programs have proven critical in reducing the levels of risk taking behaviors and of seroconversion for hundreds of IVD users.[12] The existing needle exchange sites offer a variety of services in addition to providing clean needles. Many provide nutritional counseling, acupuncture, and other programs that engage the user in HIV care and prevention programs. Some programs facilitate the entry into drug treatment programs if that is what the individual wants.[13]

Deregulating the possession and the over-the-counter sale of needles and syringes is one of the most inexpensive but effective means for the reducing the spread of HIV through sharing needles. In September 1995, the Connecticut Department of Public Health and the Centers for Disease Control and Prevention reported on the results of two studies of Connecticut's 1992 law allowing over-the-counter pharmacy sales and possession of needles.[14] The first study found a tremendous jump in syringe sales after the law was passed in areas with higher levels of intravenous drug use as compared to other areas with little injecting drug use. The second study surveyed drug users shortly after the passage of the law and one year later to gauge the extent of needle sharing. The injecting drug users reported a 40% decrease in sharing needles over the year of the survey. Over two thirds of the drug users surveyed were reportedly aware of the law within 11 months after passage.

Participation in traditional drug treatment programs and various peer "self-help programs" are effective in reducing injection drug use by as much as 30%.[15] While this may sound obvious, it is important to remember that drug treatment programs can, like more contemporary harm reduction efforts, continue to play a role in reducing HIV infection.

Therapeutic communities have long been mainstays in reducing levels of drug addiction in the Latino community. Drug treatment in therapeutic community settings ranges from harsh, depersonalizing approaches to those that work with the drug user to reduce consumption in a more compassionate way. These humane therapeutic communities are more effective because the drug users desire for change is the motivation rather than debasement of the individual. The humane approach is a form of harm reduction because the program participant is not using drugs during the program and is learning to value themselves as an individual. For needle injecting users, reduction in drug use has been shown to result in lower levels of HIV infection. For other forms of drug use which are associated with HIV transmission (crack or alcohol), these programs can lower the risk of HIV infection through sexual transmission. This does not mean all IVD users are appropriate for such a treatment modality.

Enrollment in a methadone drug substitute program can be critical in maintaining HIV-negative status among Latinos. Methadone maintenance has been demonstrated as effective in reducing seroconversion among Latino IVD users. While it may not be the therapy of choice of many Latino IVD users, methadone programs have played an important role for users who are either not ready or unable to access residential treatment openings.[16]

If used properly, bleach kits can reduce HIV infection in users that reuse or share needles. Education on how to use the bleach is critical to its effectiveness for HIV prevention.

10 Hudgins R, et al., *Cocaine Use and Risky Injection and Sexual Practices.* Drug Alcohol Depend. 1995 Jan;37(1);7–14.

11 Pivnick A, et al. *AIDS, HIV Infection and Illicit Drug Use Within Inner City Families and Social Networks.* Am. J. Public Health 1994 Feb; 84(2):271–4.

12 Des Jarlais, Paone, et al., *Regulating Controversial Programs for Unpopular People: Methadone Maintenance and Syringe Exchange.* Amer. J. of Public Health 85; 11 pp. 1577–1584.

13 In 1992, the United States Congress passed legislation to request a study by the National Academy of Sciences on needle exchange programs. Results of this study, as reported by the New York Times on September 20, 1995, "open the way for the Clinton Administration to lift a legal ban on Federal financing of such programs if it wishes. The panel of experts recommended that it do so and also said states should rescind laws restricting the sale and possession of needles and syringes." Leary, Warren, "*Report Endorses Needle Exchanges as AIDS Strategy,*" New York Times, 9/20/95, front page.

14 Journal of AIDS (September, 1995).

15 Stark, M. et al, *The Effects of Facilitation of Attendance at Drug Treatment and Self-Help on HIV Risk Reduction with IVDUs.* Int. Conf. AIDS, 1994 (Abstract No. PC0463).

16 Williams A, et al., *Methadone Maintenance, HIV Serostatus and Race in Injection Drug Users in San Franciso, CA.* Int. Conf. AIDS 1990 (Abstract No. S.C. 748) and Kerdt PR, et al., *HIV Seroprevalence Among Injection Drug Users Seeking Methadone Treatment in Los Angeles.* Int. Conf. AIDS (Abstract No. PC0128).

The connection between drug use and HIV cannot be limited to intravenous drug use. There are clear connections between HIV infection and the use of other drugs, including alcohol. First, IVD use and the use of other drugs have been well-documented. Crack is consumed by IVD users and frequently continues to be used after a course of treatment. Further, there is an increased risk for HIV transmission when crack smoking becomes an additional drug use behavior among IVD users.[17] Second, heavy alcohol use has been shown to be a key predictive variable in likelihood of HIV infection. Heavy and light drinkers differ in sexual behavior and choice of partners. Heavy drinkers report that their primary partner is more likely to have a history of injection drug use and that those partners were more likely to share needles when injecting. Heavy drinkers also report more frequent sex with their primary partners when they are drinking.[18]

AREAS OF CONCERN

Number of available treatment slots is grossly inadequate to meet need and slow the spread of HIV infection—Every year activists, Latino community leaders and a wide spectrum of health professionals advocate for more substance use treatment admissions. Yet virtually every year the political process fails deliver the needed increases. New York State legislators and executive officials have not responded with increases in funding. Drug use is increasingly seen as solely a criminal offense which requires incarceration rather than treatment. The number of slots for residential and other treatment programs is minuscule compared to the need. In fact, resources have decreased for the estimated 250,000 drug users in New York State. The product of this neglect will be ever increasing rates of HIV infection among Latino drug users.

Proposed cutbacks in funding to community-based drug treatment programs ensures that HIV infection will remain in New York State's Latino communities—New York State's funding for drug and alcohol treatment is acknowledged to be inadequate by everyone. For the entire State of New York there are an estimated 54,000 treatment slots available through the Office of Alcoholism and Substance Abuse Services (OASAS) funding. While some of these programs are hospital-based, most have grown from a community response to a need. Governor Pataki has proposed to reduce OASAS funding to localities by $42,000,000 (20%) and to block grant all funds currently provided by OASAS to New York State drug treatment providers. In addition, the Governor would end any requirement that counties and cities make any contribution to State funded drug treatment programs. The 20% reduction means less treatment and increased risks of HIV infection at a community level. While no one knows how much local contributions to drug treatment programs will be reduced, recent budget cutbacks at local levels makes it extremely unlikely that more local funds will be included.

In addition, block granting of OASAS funds to localities starts drug treatment down the "slippery slope" that typically follows with such grants. Block granting has generally meant a yearly reduction in funding levels as government loses responsibility to individual programs and notches down assistance.

Proposed changes in Home Relief assistance will cause new HIV infections among Latino IVD users enrolled in methadone maintenance programs—Governor Pataki's FY97 budget will deprive thousands of Latino IVD users of access to methadone maintenance programs. Most methadone programs for people on home relief are funded through Medicaid reimbursement to community and hospital providers. The Governor has proposed the elimination of Medicaid and all other benefits to home relief recipients after 60 days. The termination of methadone will mean a certain increase in injection drug use and consequently greater opportunities for sharing needles and spread of the virus.

Needle exchange programs reach too few IVD users—The major problem with needle exchange programs is that there are not enough of them. The New York State Legislature and the Department of Health have established a licensing process which is extremely difficult for many community-based programs to navigate. Further, there is very little funding which specifically supports these efforts. Most sites depend on a patchwork of private funds and government grants to sustain their efforts. There has been little or no leadership at the City, State or Federal level for expanding the number of programs or providing them with needed operating expenses.

Another difficulty has been the uncertainty program must face each year. Needle exchange is authorized by the New York State legislature each year. There has never been any serious leadership effort to secure authorization for more extended periods. This uncertainty has the effect of making it more difficult to raise private funds. In addition, the other restrictions in the current legislation on the location of sites makes it more difficult to reach all the affected populations.

Misinformation about needle exchange blocks expansion in some areas—There is a tremendous need for community education about needle exchange. In several instances over the past year misconceptions about needle exchange programs have caused neighbors of the programs to level unfounded charges. Some politicians or their political stand-ins have sought to make political points out of these controversies by harassing exchange programs with a torrent of minute complaints.

The insistence by some service providers that users must "become drug-free" is a barrier to client engagement—The

17 Chitwood, DD, et al., *A Longitudinal Study of Change in Crack Use Among a Cohort of Injecting Drug Users in Treatment Programs.* Int. Conf. AIDS (Abstract No. PoC 4690).

18 Woods WJ, et al., *Alcohol Intoxication: Associations with HIV Risk.* Int. Conf. AIDS 1992 (Abstract No. PoD 5497).

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historical rigidity of the drug-free/abstinence philosophy has kept many substance users from accessing services. More often than not, some users cannot conceive of being drug-free at the very outset. Becoming drug-free can be a goal to be achieved over time, but all service providers must be more flexible in their treatment modalities and include some form of harm reduction in their programs.

Too many health and HIV service providers fear and dehumanize substance users—As substance users seek health and social services, they are often regarded with disdain and mistrust. This attitude perpetuates low self-esteem and creates barriers to engagement in life-prolonging HIV treatment. *In addition to health service providers, many HIV community-based programs are afraid of the drug user and therefore unable to engage them in programs. If the service* delivery community is to make an impact, it must modify its behavior to attract and engage substance users on a positive level.

Forced enrollment in a treatment program is usually counter-**terproductive and harmful**—Most people in treatment do not want to be there if it has been mandated by one source or another. Enrollment has not been an individual choice to become drug free. Therefore, the likelihood of real change is minimized.

Few family-based programs—Most drug treatment and harm reduction programs deal with the drug user as an individual. The reality for the Latino community, however, is that Latinos using drugs are members of our families. Issues of unmanaged drug use are often family concerns. Drug users typically have siblings, parents or children with drug addiction problems. This means successful treatment or harm reduction may require an effort to bring the whole social network into a change process.

Too few programs meet the needs of Latinas—Latina substance abusers confront innumerable obstacles in seeking drug treatment. They often have child care issues which affect the ability to access outpatient care. Substance abusers who may be pregnant have few choices when it comes to drug treatment. Relatively few programs care for children while a mother is in residential treatment programs. Female users are often faced with the dilemma of seeking treatment for themselves at the cost of losing their children (who may have to be placed with a child welfare agency or in foster care) or not seeking treatment at all in order to maintain a precarious family situation.

Too little funding for programs providing HIV health education and outreach to drug users—For non-injecting drug users, the risk of infection through sexual intercourse with an IVD user continues to be a major source of HIV transmission. Crack dens and other similar settings for cocaine use typically bring together men and women with long histories of IVD use. The level of sexual activity in these settings makes them a vector for HIV transmission. There is a need for programs that will send HIV educators into these sites to provide non-judgmental information on lowering the risk of infection through the use of condoms and other techniques. The ability to meet the drug user where he or she uses is critical to preventing the spread of HIV and other related sexually transmitted diseases.

CONFERENCE RECOMMENDATIONS

***The New York State Legislature must adopt S.1998/A.2810,* that would allow the sale of needles and syringes without a prescription**—Deregulating needle sales will save Latino lives. *The Gottfried/Montgomery bill restricts the sale of needles to persons 18 years or older, requires that only licensed pharmacists (and other such controlled settings)* engage in sales, provides for the safe disposal of needles, commissions a study on the impact of the law on drug use and HIV transmission and sets reauthorization after a three year period.

Change State law to permit more needle exchange programs and provide funding to match need for exchange services—Existing needle exchange programs are estimated to serve less than ten percent of the population of injecting drug users. There must be a dramatic expansion of such services if HIV is to fade from New York's Latino community. Current State law still requires that needle exchange programs be designated as emergency exceptions with tight restrictions on location and licensing. It currently takes anywhere from one to two years to complete the application process. In addition, the funding for these programs from private foundations and the New York State Department of Health is minuscule compared to the need.

Oppose Governor Pataki's plans to end methadone treatment programs for Latinos on Home Relief—Proposed reductions in the FY97 Executive Budget would terminate all Medicaid for persons on Home Relief after 60 days. Without Medicaid, the thousands of intravenous drug users that turn to methadone maintenance as a means of harm reduction would be cut off from hope for a change. Until there are meaningful increases in the number of residential treatment slots, people wanting to stop using heroin by injection will have few choices. The end result will be more Latinos becoming infected with HIV through the use of contaminated needles.

Oppose Governor Pataki's 20% reduction in funding to community-based drug treatment programs and the elimination of requirements that localities contribute to local drug treatment programs in return for State assistance—The proposed reductions in New York State's Office of Alcoholism and Substance Abuse Services funding to localities will further increase the chances that more Latinos will return to the use of contaminated needles for injecting drugs.

Increase needed treatment "slots" for individuals seeking to recover from heroin, cocaine and other types of substance use—This has been a request of New York's Latino community for the past three decades. In more ways than can ever be known, the lack of access to treatment has destroyed Latino families, careers, hopes, and the aspirations of so many potential leaders. HIV transmission is the latest manifestation of government and private funders inability to see drug users as human beings. Public and private institutions have not "stayed the course" with a community in crisis.

The increase in treatment slots must extend to more funding for the treatment needs of cocaine/crack users. These needs are basically unmet, as most existing treatment slots are severely limited and made primarily available to heroine users. There must be an increase in treatment vacancies, particularly for those using cocaine/crack and those who are polydrug dependent. Funders must provide resources for treatment slots in different modalities, and these must be diversified to include greater out-patient interventions.

Fund training and education of service providers (managed care providers, residential treatment programs, harm reduction services, outpatient treatment facilities, etc.) about the range of treatment modalities—Different programs have specific philosophies that dictate their internal training and staff orientations. If staff training does not cover the range of alternative approaches to treatment the client may be put at risk of infection with HIV. It is critical that clients understand that failure in one approach does not mean the end of progress in dealing with drug use—in particular, unsafe drug use practices. Communicating the importance of fitting the treatment to meet the client is critical.

Fund more peer education programs to provide health education and outreach to substance users.

Abolish coercive and mandated drug treatment—Treatment under duress does not engage the substance user and leads to little or no change in behavior. Court orders or directives from New York City's Child Welfare Administration rarely accomplish the objectives of long term abstinence from drug use. New approaches are required which bring the drug user into the decision-making while protecting the interests of the child.

Fund safe lodging for HIV-positive substance users, in particular women with children—While funds are available provide to provide enhanced rental assistance to persons with AIDS, many Latinos using drugs do not qualify because they are homeless. Homelessness guarantees a rapid progression to disease and an early death. It also makes it extremely difficult to end destructive drug use habits. State and City homelessness assistance must extend the availability of housing for Latinos who are HIV-positive but have not had a qualifying opportunistic infection. In addition, State support for scatter site and new specialized residential development must be increased.

LATINO YOUNG PEOPLE AND HIV/AIDS

PROFILE OF AIDS AND HIV INFECTION AMONG LATINO YOUTH

As an adolescent embarks on self-discovery, issues of peer pressure and sexual activity become all-involving. The ability to deal with these central concerns in an open and frank manner can guarantee a well-informed population of young people immunized against HIV infection.

New York Latino youth compromise an enormous part of the population with AIDS between the ages of 13 and 24—Thirty-nine percent of young people between the ages of 13 and 19 with AIDS are Latino. Latino young men make up 44% of all males with AIDS in this age group and Latinas 35%. Among young adults with AIDS between the ages of 20 and 24, almost 48% are Latino. The truly disturbing nature of these statistics is made even clearer when contrasted with the 19% Latino AIDS rate nationally in this age group.[19]

To date, there have been almost 90,000 diagnosed cases of AIDS in the United States among adolescents and young people—Over 11,000 (12%) of these cases represent teenage and young adult New Yorkers. Although adolescents constitute roughly less than 1% of all reported AIDS cases in the U.S., young adults between the ages of 20 and 29 account for 20% of AIDS cases. Given the long incubation period for HIV, most researchers assume that many of these individuals were infected as adolescents.[20] A recent report by President Clinton's Office of AIDS Policy states that one in four new HIV infections in the United States is estimated to occur among young people under the age of 20.

For young women, drug use has been identified as the primary risk factor in over 50% of reported AIDS cases. For young men drug use is primary risk factor in 30% of the cases—Drug use and HIV infection among adolescents typically start with what are referred to as "gateway" sub-

19 Hispanic AIDS Forum, HAF BY FAX (1995).

20 The Center for Population control, FACT SHEET, July 1991.

stances such as alcohol and marijuana. Some percentage of this user group will progress to a wider diversity of narcotics and other mood altering drugs. The use of substances like alcohol and marijuana places adolescents at risk for sexual and drug related behaviors that expose them to HIV infection.[21] To address drug use most prevention programs directed at youth have adopted a peer education approach that emphasizes abstinence and ostracization of the adolescent using drugs. These programs reinforce peer disapproval of drug use through activities geared to enhancing self-esteem and building supportive relationships. For many adolescents these programs have made an important contribution in maintaining drug use abstinence.

For young women (13–29) heterosexual transmission accounts for over 40% of all AIDS cases—This figure reflects the reality of adolescent sexuality. A study conducted at STD clinics in a high incidence New York City neighborhood showed a higher portion of female adolescents who had a history of syphilis, chancroid, or herpes (15.8%), than male adolescents (7.2%). "The most common risk factor among this group was unprotected vaginal sex, however, a significant proportion of adolescents also engaged in anal sex."[22]

For young men from 13–19 almost 45% of the AIDS cases occur among men who have sex with men (MSM), from 20–24 the percentage rises to 65%, and from 25–29 about 60%—For young gay Latino men the world can be a very unwelcome place. There are few programs in their communities from which to seek help and few professionals who understand their culture. Many of the young people are forced to travel to lower Manhattan for services. The price for this isolation has been HIV infection. Issues of self-esteem, identity, accessing needed social services and finding peer support occupy much of their life.

AREAS OF CONCERN

HIV testing is threatening for Latino young people—Testing is the first step to acknowledging the personal nature of the risk. In addition, test results will enable infected adolescents to access treatments. The problem has been that most test sites are intimidating and isolating to young people.

Prevention messages on sexual transmission are irrelevant to most young Latinos—Education and prevention around sex and sexuality have been reduced to two messages: abstain from having sex and have sex with a condom. Such insensitivity to the complexities of adolescents can only leave these messages as abstract, adult-ordered "Don'ts" in the minds of youth. Education will continue to be meaningless and uninformative until service providers and educators develop an approach to education which is more expansive.

New York City schools have squandered countless opportunities for meaningful HIV prevention and bear significant responsibility for the growing AIDS epidemic among some young people—The New York City Board of Education and Community School Boards have failed to put the welfare of children over politics. The Board has not lived up to mandates that require HIV prevention lessons in every grade, to provide lesbian, gay and bisexual youth with life saving information and to support youth peer educators. One of the most irresponsible recent decisions by Chancellor Rudy Crew was to eliminate in-class condom use training.

Peer educators are underutilized—The subject of sex and related issues of birth control and sexually transmitted diseases (STDs) can be embarrassing to many young people, so broaching these matters is best handled by peer educators. Even when peer educators are involved, self-consciousness is still heightened when dealing with physical and psychological changes brought on by puberty. Young people themselves have recommended that information related to STDs, birth control, AIDS, and other potentially sensitive subjects be presented to youth in a setting that encompasses a global perspective, so that individual issues like pregnancy or HIV-testing are not immediately evident as the service that is being sought out by an adolescent.

Health care workers need training on discussing drug use and sexuality with Latino young people—Most health providers know little about the concerns of young people and how they see the world. This communication breakdown results in alienation that leads to an unwillingness to return to that or a similar setting to receive vital services. For gay, lesbian, and bisexual Latino youth, the isolation and alienation is even greater as many of them must struggle with homophobia as well as with general adult insensitivity to youth development.

Sex education for adolescents should promote a positive view of sexuality, help young people to understand and respect different sexual orientations, and provide appropriate information and skills about health. Safe sex messages should give adolescents an opportunity to acquire decision-making skills, without employing scare tactics. Unfortunately, the use of realistic messages about sex practices is the exception rather than the rule. While virtually all adolescents are familiar with the role of the condom to prevent HIV infection, few are trained to negotiate with a partner prior to or during the sex act. Studies have demonstrated that education between sex partners is far and away the most successful tool available to preventing the spread of the virus.

Drug use prevention programs typically demonize drug use and ignore harm reduction—Young people are fully cognizant of the double messages being sent out by AIDS

21 Ford, K. & Norris, A., *Urban Minority Youth: Alcohol and Marijuana Use and Exposure to Unprotected Intercourse*, J. Aquir. Immune Defic. Syndr. 1994 Apr;7(4):389–96.

22 NYC Department of Health, HIV Prevention Planning Group, *Workgroup Reports*, August 1995.

prevention programs on drug use. For adults that use drugs, the harm reduction approach puts forward a message of tolerance and non-coercion for the user in an effort to encourage safer injection and other drug use practices. For young people the message about drug use remains largely "just say no." While both messages are correct in the separate context in which each is used there is no doubt the duality leaves young people confused. The absence of an integrated approach that both discourages drug use yet does not demonize the drug user still eludes most prevention programs.

Latino service providers have not been given adequate resources to provide prevention services to lesbian and gay youth—Neither the AIDS Institute nor the New York City Department of Health have sought to build community-based programming for Latino gay and lesbian youth. With the exception of a few small grants, money for gay and lesbian youth has been targeted to gay-identified organizations in lower Manhattan. Latino gay youth must leave their communities because there are no services for them locally.

For their own survival, youth need to be guaranteed the right to information about HIV/AIDS without restrictions from institutions—For young Latinos working to change current social conditions, there is a strong sense of frustration and anger regarding their treatment by adults. Youth are not included in decision-making processes that affect them. The rights of young people in matters related to their health, especially HIV/AIDS issues, are constantly being violated. For example, there are now mandatory testing requirements for youth in foster care, leaving unresolved questions about confidentiality and adequate follow-up care.

With funding decreases of youth programs and increases in funding for juvenile justice and custodial care, Latino youth are in serious jeopardy—Emphasis is being placed on the wrong priorities. Youth in congregate care (foster care, prisons, detention centers, etc.) are overcrowded. Facilities to serve these young people are often driven by punitive rather than rehabilitative or therapeutic goals. HIV/AIDS prevention and care are not funding priorities and, in fact, have been cut. Culturally sensitive service delivery systems are not being targeted for funding as they should be in order to reach the population most in need.

Spanish and English language media must be held accountable for presenting accurate and timely information on HIV/AIDS targeted to Latino youth—The presence of Latino youth is needed in public service announcements because young people of Latino heritage need to see themselves positively represented in the media in health messages. Emphasis on sex and violence on television is detrimental to young people.

There has been no Latino community embrace from religious leaders, educators and other community leaders to tell young people most at risk that they matter and are important to their communities—Young people made most vulnerable by this virus have not heard from adults and important figures in New York City that there is concern about their futures. If young people who are gay, using drugs, or engaged in an active sex life sense their lives are not valued, why should they take prevention messages seriously? Why should they follow guidance from an authority who does not respect them as human beings?

Youth service agencies are too dependent on government contracts—Agencies which provide services to adolescents are often restricted in their ability to provide creative, culturally sensitive prevention and treatment services because of restrictions in government contracts. These restrictions limit agency activities to a preset range of functions which often leave little flexibility.

There is little funding targeted for outreach to immigrant youth—Immigrant youth present a unique challenge for prevention educators. They typically are not connected to any of the community-based youth programs and therefore miss important prevention education opportunities. Special outreach programs targeting these young people are needed to prevent the spread of infection. Educating immigrant youth also has the benefit of educating their family members.

Permanency planning services targeting adolescents are inadequate—On two fronts, permanency planning affects older children: 1) as children of HIV-infected parents who must deal with the imminent death of their parents; and, 2) as HIV-positive parents themselves, they must seek solutions for their children's future without them.

CONFERENCE RECOMMENDATIONS

Private foundations should fund pilot programs that involve schools, parents, and community-based organizations to address Latino adolescent sexuality—One of the most consistently overlooked issues in HIV prevention education is the need for a broad based education and for counseling initiatives on Latino adolescent sexuality. HIV prevention is frequently ineffective outside of the broader reality of sexual choices faced by adolescents. To be effective this kind of information must be provided as part of a team effort involving adolescents, parents, programs and schools. Private funding could develop models for evaluation of outcomes.

Fund HIV testing programs on-site at agencies providing youth services—Most adolescents see themselves as invulnerable to HIV infection. By providing confidential testing with pre- and post-test counseling at youth service providers the message would be clear—we are all vulnerable. More directly, the immediate availability of testing would encourage young people to find out whether or not they are HIV-positive.

AIDS Institute and New York City Department of Health must fund more peer education programs for HIV prevention—Relatively few young people are trained as peer educators compared to the need for such education. Peer education has been shown to be the most effective at actually changing behaviors and increasing awareness.

New York State Legislature and the Department of Education must mandate that New York City schools provide comprehensive AIDS education to Latino youth—The recent elimination of in-class demonstrations on condom use and the censoring of classroom messages by the Chancellor and the Board of Education demonstrate that politics are guiding health curriculum. The State Board of Education must exercise more of a health oriented oversight role.

Change drug prevention messages to reach Latino youth—The school system and many CBOs seem incapable of reaching both the non-drug using adolescent and the young person that is using drugs. To limit the message to "just say no" effectively demonizes the adolescent drug user and keep him or her from meaningful treatment.

Fund drug treatment programs for adolescents—There are only a handful of drug treatment programs that explicitly target adolescents. The New York State Office of Alcoholism and Substance Abuse Services must fund programs that offer services to adolescents. If possible, these services should enable the attending adolescents to maintain school work and live at home.

Fund Latino community-based organizations to provide prevention services to Latino gay and lesbian youth—Lower Manhattan based organizations have played a critical role in providing services to gay Latino youth. By contrast, organizations in the communities the young people come from have been slow to reach out to gay youth. At one time, this was explainable (but not justifiable) because of a fear of offending community sensibilities. Today, however, many Latino youth organizations deal with gay and lesbian young people and are prepared to assume this outreach and education responsibility.

All youth service programs must be required to provide frank HIV prevention information to program participants—In order to address the coming health crisis among Latino youth, it is critical that every organizational outreach to this population be used. Funding agencies should provide training to all youth service providers (whether funded to do HIV outreach or not) on HIV prevention and mandate that young people be educated and counseled.

Fund more safe haven programs for young people to express themselves—Experience has shown that programs offering "safe space" drop-in services have the best opportunities for providing information to hard to reach adolescents.

Mandate provision of AIDS prevention education in Beacon Schools—New York City's Beacon Schools are an underutilized resource for reaching young people with prevention messages and programs. The City should expand funding for existing youth service programs to provide services in these settings.

Fund internships for young people in HIV/AIDS service and advocacy programs—To develop the kind of leadership that is so critical for peer-to-peer AIDS prevention, an internship program of youth leaders is needed. It would provide the adolescents with substantive knowledge on HIV and help to promote careers in health.

LATINAS AND HIV/AIDS

PROFILE OF LATINAS AND HIV/AIDS

New York City is the national epicenter of Latinas with AIDS—The impact of HIV on Latinas in New York City is unfolding day by day, in home after home, in workplaces, in every profession and in every community. New York City Latinas account for almost 40% of all female Hispanic AIDS cases nationally and 34% of all New York female cases of AIDS. AIDS is the leading cause of death for Latinas ages 25 to 44 in New York City and Puerto Rico. According to estimates prepared by the New York City Department of Health, from 1988 and 1993, between 21,000 and 50,000 females over the age of 13 were living with HIV in New York City.

Latinas affected by HIV/AIDS are not a homogeneous group—They are diverse in economic status, age, sexual orientation, migration and immigration status, education, religion, and substance using history. These differences can affect whether women seek medical services. The NYC Department of Health's HIV Prevention and Planning Group (August 1995) confirmed that "personal preventive, acute and chronic health care are not priority issues" for minority women because of the difficulty in accessing culturally-appropriate and responsive services.

Lesbians with AIDS are remain uncounted and unacknowledged in the HIV/AIDS epidemic—While most Latinas with AIDS are heterosexual others identify as lesbian. This failure to acknowledge the probability of lesbian women with HIV infection results in a lack of access to any number of HIV-related services because programs are targeted to women based on their reproductive functions.

Some Latinas with AIDS are young while some are in a mid-life or elderly stage—The highest proportion of recorded female AIDS cases in the City occurs for those between the ages of 30 and 39. For women between the ages of 40 and 49, there has been a 17% increase in AIDS since 1984. Young women are also at high risk. In 1990, Latina teens accounted for 44.7% of total births to adolescents in New York City. This figure proves that this group underutilizes contraceptives including condoms.

There is no one means of HIV transmission among Latinas—The primary risk factors vary with injection drug use associated in 60% of Latina AIDS cases and unprotected heterosexual contact with a drug users in 33%.

Incarcerated women are seriously affected by HIV/AIDS—Between 1980 and 1990, the number of women in New York State prisons increased from 610 to 2,965, with drug offenses accounting for more than 60% of the incarcerations. Latina and African-American women represent 86% of the female prison population. More than 90% of those found to be HIV-positive used illicit drugs and were from the New York City area. Most women throughout the correctional system, whether they are infected with HIV or not, have either experienced AIDS in a family member, or have seen friends and other inmates die of AIDS in prison.[23]

Highlights from Latina Focus Group

To supplement this profile of Latinas and HIV/AIDS, the Latino Commission on AIDS together with the Partnership for Community Health sponsored a focus group to better understand some of the concerns not covered by statistics and the views of service providers or government agencies. The seven Latinas participating in the discussion group were clients and lay care-givers for people living with AIDS. They were all affected by AIDS. Six out of the seven participants were HIV-positive and one has AIDS. The women had traveled an extraordinary path. Several have moved from drug use and commercial sex work to become community activists. All have committed themselves to the protection of others with HIV and AIDS and their family. Among this informed and activist group, several strong themes emerged from the discussion and the responses to a survey distributed prior to the focus group.

Treatment decisions are based on little and/or poor information, and there is little knowledge of disease progression and appropriate medications—Use of effective prophylactics is non-existent among this group. There is inadequate information about anti-viral treatments, and decisions about medication are made on anecdotal and often misleading information. Alternative medicine is widely used as a substitute rather than as a complement to "mainstream" medicine.

Despite being highly informed, these women continue to engage in high risk sexual behaviors for transmitting the HIV virus—Although misperceptions continue, the strongest motivation for continued high risk is the need to feel accepted by their social network. In general the women feel stigmatized by their friends, family and community and they receive little positive support for prevention and healthy behavior.

Participation in HIV/AIDS organizations leads to self empowerment and a commitment to the development of community—For the most part the women report much improved control of alcohol and drug abuse. An interesting

23 AIDS Institute, "Focus on AIDS in New York State," from the NYCDOH Women: HIV/AIDS Resource Packet #1, May 1995.

outcome of increasing self-efficacy, is the likelihood that prevention and treatment advice is ignored and their personal needs and viewpoints become more central.

Family and permanency planning are major concerns for the Latinas—These women rarely spoke of support they received by their partners and spouses in raising their family. In spite of being aware of the issues involved in providing for their family when they die, there appears to little information and few services to assist them in preparing for death.

HIV testing was a disaster for these women—Proper counseling was nonexistent and they had little or no support to confront their fears, denial and anger.

AREAS OF CONCERN

Substance use continues to be the primary HIV risk factor for Latinas, yet treatment slots continue to be limited and difficult for women to access—Women with children who are single-heads of households and are affected by substance use and HIV/AIDS have limited access to drug treatment facilities because such facilities are typically geared to men. Little accommodation has been made to address women's issues such as child care, and even less has been made to keep families together so that affected women may gain motivation to manage their drug problem for the sake of family cohesion. It is virtually impossible to find treatment slots for pregnant women.

Services for HIV-positive Latinas in prison does not match the need—With state budgetary cuts being proposed in many areas, HIV/AIDS-related programs which are just being fully established in women's prisons must be maintained and expanded to include such basic services as knowledgeable medical care, treatment information and access to needed permanency planning services. Infection rates for Latinas in New York State prisons remain the highest in the nation.

Conditions of poverty continue to act as barriers for Latinas in accessing needed HIV/AIDS services—Service providers to Latinas state categorically that you cannot reach Latinas in need without being prepared to address the complete range of problems women in poverty are forced to confront each day. HIV infection or AIDS is most typically one problem in a long list that includes substandard housing, drug addiction, marital abuse, the absence of child care, struggling with an increasingly restrictive social welfare system and much more. For example, while many service providers offer transportation or transportation reimbursement, less is provided in the way of adequate child care. Without such assistance, women are unable to access needed health care and social services.

Effective prevention education for women continues to elude public health authorities and many community-based organizations—Few Latinas report that their sex partners use condoms to prevent HIV infection. Condoms are worn to prevent pregnancy. Most of the HIV prevention messages target women as the decision maker in whether to use barrier protection. As a variant on the "just say no" approach, the expectation is that the women will have significant decision making authority before or at the moment of intercourse. For many Latinas this is not a viable alternative. At risk of being seen as promiscuous, Latinas often hesitate to raise the issue. In fact, studies have shown that sex workers in fact are more successful in insisting on the use of a condom during sex.

Latinas receive little information on treatment and disease progression—As was emphasized in the Commission's focus group results, discussed above, many of the participants expressed generalized fears of all medications and medical interventions. They also showed little knowledge of disease progression and possible points for helpful medical intervention. These findings were confirmed in conversations with several Latino service providers. There are virtually no treatment education or disease progression trainings targeting HIV-positive Latinas or their families.

Legislative representatives and government regulators appear to believe that women affected by HIV/AIDS lack judgment to make appropriate decisions about themselves and their offspring. Both at the state and national levels, legislators are introducing measures geared at reducing the rights of women with HIV/AIDS. Women affected by HIV/AIDS are overwhelmingly low-income and women of color. Federal prisoners constitute the only group that currently is mandatorily tested, yet legislators feel legislation is necessary to also force women to test themselves and their children for HIV. The eventual result of imposing restrictions or regulations on HIV-testing of newborns will have a number of other repercussions; 1) Latinas will be driven away from accessing services for fear of losing their children if they are found to be infected; 2) women who are immigrants will fear loss of their status in this country and deportation; and, 3) women will live in fear and anger of becoming the victims of domestic violence.

A newly adopted New York State Department of Health regulation directs doctors to determine whether a woman is "high risk" for HIV disease by using outdated methods of extremely broad risk factors which have been banned by institutions such as the Federal Centers for Disease Control and the American Medical Association. If the physician decides the mother is high risk, they can order the newborn's test without the mother's consent. Because all infants born to HIV-positive mothers initially test positive, and because 80% of those newborns will later convert to negative, the physician will actually be testing the mother. The regulation invites class- and race-based bias. To ask a medical professional from an upper-middle or upper-class economic bracket to sit and judge whether a woman has had "multiple sex

partners or extensive drug use" is to invite substituting racial and ethnic stereotypes for medical judgements.

The Federal Drug Administration has been lax in lifting barriers to women, especially Spanish-speaking women to clinical trials—Few clinical trials will deal with women with children or pregnant women. For Latinas, language barriers and less access to the "old boy's network" of medical personnel who refer individuals to clinical trials also impede their ability to get into the system.

As AIDS services provided under Medicaid move toward a managed care model, women affected by HIV/AIDS may find it difficult to reach skilled personnel—Many women seek medical attention for HIV infection only when they begin to manifest symptoms. This places a burden on the health care provider to be informed on HIV disease progression and symptoms in women. To date, many internists and gynecologists lack this expertise. As Medicaid moves into a managed care model, women will have fewer medical choices. It is critical that managed care plans ensure that their doctors are familiar with HIV-related diseases in women and that they don't stand in the way of accessing needed speciality services.

Sex workers need expanded prevention and peer education programs—Funding for HIV/AIDS prevention and care services specifically targeted to sex workers, as these women are at high risk of infection and are less likely to access care in mainstream facilities.

Insured and underinsured working women have limited access to needed services—Even with full-time jobs, working women who are insured or underinsured may find it difficult to access HIV/AIDS services. There are also working women who, even though they are employed, do not have access to health coverage because their employers do not provide it. These women do not qualify for Medicaid and must pay for medical services themselves. The result is lack of access to needed preventive care.

Violence against women may increase with the State's policies on HIV testing of women—There have already been reports of women being battered by their partners due to the partners fear and anger related to HIV status or risk. Similarly violence against women has also resulted from a woman's insistence in practicing safer sex, such as condom use, or the desire to abstain from having sex. Violence against women is not restricted to male/female relationships. Domestic violence related to HIV issues within lesbian relationships may go unnoticed or unidentified. Fear of homophobic reactions by service providers is as real and risky for lesbians as it is for gay men.

Rape and incest crisis centers must introduce HIV/AIDS-related issues to victims during the initial reporting process—Due to the nature and stigma of HIV/AIDS transmission and infection, all crisis center personnel must be trained on HIV/AIDS issues. Women and girls who have been traumatized by rape and/or incest will require additional attention and follow-up to ensure that they have understood the significance of their risk for exposure so they may make decisions relating to their situation.

Women over age 50 are in need of services targeted to their needs—Service providers and medical professionals must inform all women of HIV transmission risks, not just those of childbearing age as is now the case. The number of HIV-positive women over 50 has increased 2% in the last decade.[24]

Elimination of Health and Hospitals Corporation (HHC) facilities will have an adverse impact on Latinas—Services for poor women, among them many Latinas, will be severely limited, and will if the proposed privatization of many HHC facilities is implemented.

The undercount of homeless HIV-positive Latinas results in fewer services and targeted programs—It is not unusual to find homeless Latinas living in crowded conditions with other family members in order to avoid staying in shelters or living on the streets. This "doubling-up" solution creates significant burdens on the host family members, and for Latinas living with HIV/AIDS who may have HIV-positive children or a partner and inflicts high levels of stress on all the individuals involved.

CONFERENCE RECOMMENDATIONS

Mandate that all managed care systems guarantee Latinas with HIV/AIDS access to specialized HIV-related health care, including specific gynecological services—Coverage must also include adequate long-term care and home care services as needed by persons with HIV/AIDS-related conditions. Whether a women is in a special needs plan for the HIV-positive or with a general managed care Medicaid provider, critical specialist care must be easily available.

New York State must regulate religious-sponsored medicaid managed care programs to ensure that women are provided with all available information, services, and referrals which will guarantee full reproductive health options.

State DOH must mandate that managed care programs provide support to all levels of service providers in their networks with comprehensive ongoing training on HIV/AIDS issues.

Require bilingual HIV-related counseling in all pre-natal medical settings (private and public)—Early counseling can lead to necessary medical decision making. Primary care providers must provide counseling in a pre-natal setting in a culturally and linguistically competent manner.

24 NYC Department of Health Prevention Planning Group, *Workgroup Reports*, August 1995.

Hospitals which provide care to Latinas and other low-income, minority women must be regulated by the State Department of Health so that they include appropriate and full information.

Office of Substance Abuse and Alcoholism Services must set aside more funding specifically for drug treatment for pregnant women, women with families and all other women—Women with children and pregnant women are still being excluded from drug treatment system. Models with strong family preservation components during treatment should be replicated.

Private and public funders must support strong harm reduction and relapse prevention for women to make drug treatment more effective.

Funders must support CBO design and development of techniques to reach young women—Young women must also receive adequate and effective outreach and prevention services, and providers must make the extra effort to attract this population into services.

Funding is needed to support evaluation programs to assess the effectiveness of prevention education models currently in use to reach Latinas—These messages must be capable of reaching the diverse components of the Latina community, and should be behavior-based, and not generic.

Fund expansion of clinical drug trials available to Latinas with HIV/AIDS, and request the careful examination and analysis of existing trials as they relate to women's HIV/AIDS conditions and reactions to drugs—Enrollment of women is not enough. Though women have some access to trials since 1993, very little gender-specific analysis and information is being provided by researchers, who continue to focus on male responses. Little if anything is available on pregnant women and children, and drug effects on their AIDS-related conditions.

Federal government must mandate that information regarding drug trials should be provided in a culturally-competent manner—Further, the network of providers who have access to drug trials must be expanded to include health care personnel serving the Latino community.

Private and public funders must support programs that join HIV-negative and HIV-positive Latina peer led prevention and treatment education programs.

New York State legislators must explicitly reverse regulatory provisions issued by the Department of Heath that give a doctor the authority to direct an HIV test of a newborn when the mother has not decided whether to permit the test.

LATINOS, PRISONS AND HIV/AIDS

PROFILE OF INCARCERATED LATINOS AND HIV/AIDS

Latinos in New York State prisons constitute the most affected group in a system ravaged by AIDS and HIV infection—Latino inmates make up about 30% of the more than 66,000 inmates currently incarcerated. Yet among prisoners with AIDS, Latinos constitute 47% (1501 of 3192) of the cumulative incarcerated AIDS population to date.[25] To constitute one-third of the State's inmates but one-half of its diagnosed cases of AIDS is distinction with implications for every aspect of the New York State prison system, the parole system and sentencing laws for repeated drug-related offenses.[26]

HIV seroprevalence surveys of men and women entering the New York State prison system have consistently shown that HIV infection in New York State prisons remains primarily a problem among Latinos. The New York State Department of Health conducts seroprevalence surveys every two years in the reception centers (Downstate, Ulster and Bedford), measuring HIV among new inmates.[27] While the number of identified HIV infections among newly arrived Latino inmates has been declining, the proportion of cases remains still remains high. For Latinas the rates have gone from 28.9% (1989) to 29% (1992) to 20% (1994). For Latino males the HIV seroprevalence rate dropped from 17% (1992) to 13% (1994). Of the 298 new inmate men testing positive for the virus, 141 (47%) were Latinos and 56 (40%) of the 140 of the women testing positive were Latinas.[28]

25 NYS Dept. of Health, *AIDS Surveillance Quarterly Update*, October 1995 at p. 17.

26 From 1983 to October 1995 the New York State Department of Health has reported a cumulative total of 3192 (4.8%) inmates officially diagnosed as having AIDS. New York State Department of Health's *AIDS Surveillance Quarterly Update*, September 1995. These figures are cumulative and have been reported since 1983.

27 Reception centers are the points where all new prisoners are processed before being sent to different facilities for completion of their sentences.

28 Since the first surveys in 1987, the rates of HIV infection among new male prisoners has been steadily decreasing—17.4% (1987), 14.9% (1990), 12.9% (1992) and 10% (1994). Among new women inmates the high levels of infection have been gradually decreasing—18.9% (1987), 19.6% (1992) and 16% (1994). 1994 data from AIDS Institute. Seroprevalence remains high in New York City detention facilities. A 1992 series of blind serosurveys conducted by the New York City Department of Health indicate that 25.9% of female and 12.3% of the male detainees are HIV positive. Based on New York Department of Health Bureau of Laboratories' seroprevalence studies 1992, and 1993. See also: Weisfuse, I.B. Greenberg, B.L., Back, S.D., et al. *HIV infection among New York City Inmates.* AIDS. 1991:5:1133–1138 Intravenous drug use is the risk factor for HIV transmission in over 90% of AIDS cases among New York City inmates.

New York State and City correctional institutions seroprevalence rates far exceed infection rates of other facilities in the United States. A national perspective enables us to see the unique tragedy unfolding behind New York State prison walls. In a Centers for Disease Control 1989-1992 national survey of nineteen metropolitan correctional facilities researchers found a median HIV seroprevalence rate of 1.7%—females at 1.8% and males at 1.2%.[29] Another national study of ten correctional systems found the average seroprevalence rate to be 4.8% for nonwhites and 2.5% for whites.[30] The percentages of cases with diagnosed AIDS in other prison systems are also instructive. The Federal Bureau of Prisons reports an average rate of seroprevalence of one percent.

Latino prisoner mortality rates are tragically high—With 47% of the cases of AIDS in New York State prisons it would be logical to expect Latinos to compromise about one-half of the prison deaths due to AIDS. But as with other measures, Latinos exceed the mortality expectations. In 1986, 1991, and 1992, **all** deaths among Latina prisoners in New York States were attributed to AIDS. Seventy-eight percent of the deaths among Latino prisoners in New York State were attributed to AIDS.[31] The medium survival rate after diagnosis is estimated to be 260 days with a much lower figure for African-American and Latino intravenous drug users.[32] In 1988 AIDS accounted for 70% of all inmate deaths in prison.[33] Each month about twenty inmates die of AIDS in a prison hospital shackled to a bed.[34]

New York State prisons have large numbers of Latinos with HIV and AIDS because of mandatory sentencing laws for drug-related offenses—The Rockefeller Drug Laws and the Second Felony Offender Law have resulted in the long term incarceration of thousands of Latinos with HIV infection. If the criminal justice system had more flexibility in sentencing for drug convictions this concentration of AIDS cases throughout New York State correctional facilities would not exist.

While mandatory sentencing laws maybe the cause of high levels of incarceration, the high levels of Latino HIV infection largely the result of drug use—Of the 23,548 inmates incarcerated in State correctional facilities for drug-related crimes as of July 1, 1995, 11,000 or 47% were Latinos. Every seroprevalence survey conducted in New York State prisons underscores the close relationship between prior drug use and HIV status. The rate of HIV infection has remained high among newly incarcerated female and male intravenous drug users—44.9% female/44.1% male in 1987, 46.7% male in 1990, 46% male/47.3% female (1992) and 46% male/33% females (1994). These continued high levels of HIV infection stand in contrast to the pronounced decrease in seroprevalence rates among entering inmates as a group.

For new female inmates, IVD use and sexual activity remain a significant avenue for infection. In the 1994 seroprevalence survey of Bedford Hills, 50% of the women testing positive reported a history of sex with an injecting drug user and 40% stated they had exchanged sex for money or drugs. Sexual activity between women may also be a factor in HIV transmission with 40% of the group testing positive reporting sex with another woman.

AREAS OF CONCERN

Absence of trained Spanish speaking personnel cuts off health care for prisoners with HIV/AIDS—The most profound barrier facing many Latino inmates with HIV/AIDS is the virtual absence of Spanish-speaking health professionals for inmates within the New York State correctional system. Because of the stigma associated with HIV infection in the prison setting, many prisoners are reluctant to reveal their status or seek medical attention. When they do decide to see a doctor, it is because their health has noticeably deteriorated. This unwillingness to seek treatment is made all the worse by the language barrier. A monolingual or Spanish-language dominant prisoner seeking medical treatment or HIV testing must often rely on a bilingual prisoner to communicate his or her needs to a DOCS health care provider. There are also occasions when bilingual Correctional Officers are used as interpreters.[35]

The use of unskilled or inappropriate translation services may violate an individual's rights to privacy and confidentiality and further result in stigmatization when interpreters carry this knowledge back to the rest of the prison population.

Education and prevention efforts geared toward the Spanish-speaking inmate are scarce—The failure to provide truly bilingual services tends to distance the inmate from the prevention message. Messages and programs that fail to take into account Latino inmate belief systems leads to lost educational opportunities.

Shortage of Spanish-language HIV-related educational materials developed for the Latino inmate—There is a scarcity of Spanish-language, HIV-related educational mate-

29 Withum DG Guerena-Burgueno, et al., *High HIV Prevalence Among Female and Male Prisoners in the United States (1989–1992): Implications for Prevention and Treatment Strategies.* Int. Conf. AIDS 1993 (Abstract No. PO-C21-3115).

30 Valhov D Brewer TF et al. *Prevalence of Antibody to HIV-1 Among Entrants to US Correctional Facilities*, JAMA 1991 Mar 6;265(9):1129–32. The study also found a 5.2% seroprevalence rate for women under 25 years old and 2.3% for men in the same age grouping.

31 Osborne Association, *AIDS In Prison Project*, Fact Sheet referencing New York State Department of Corrections Inmate Mortality Reports.

32 Mikl J, Kelly KF, et al., *Survival among New York State Prison Inmates with AIDS*, Int. Conf. AIDS 1991 (Abstract No. M.C.3124).

33 Morris D. Truman B. et al. *The Epidemiology of AIDS among New York State Prison Inmates.* Int. Conf. AIDS 1989 (Abstract No. Th.D.P.45).

34 Testimony of Dr. Marshall Trabout, Regional Medical Director, NYS Department of Correctional Services before A Joint Public Hearing of the New York State Assembly and Senate on Latino Inmates with HIV/AIDS (held July 6, 1995 in New York City).

35 See A Joint Public Hearing of the New York State Assembly and Senate on Latino Inmates with HIV/AIDS (held July 6, 1995 in New York City), pp 14–20.

rials within the State correctional system. Although both the New York State AIDS Institute and community-based organizations have made efforts in this regard, the demand for such educational materials remains largely unmet. In addition to being in Spanish, these materials are not developed for the Latino inmate. Such a deficiency results in lost opportunities for education. The absence of this material is not trivial for an inmate who wants to know about disease progression or medications. The lack of materials also means that life saving disease interventions and medications for Latino prisoners would be bypassed.

Shortage of Spanish-language peer and support group programs—Peer to peer programs such as PACE (Prisoners for AIDS Counseling and Education) and ACE (Bedford Hills peer program) are models for connecting HIV-positive prisoners to support services, empowering prisoners to become advocates for their own health care and educating about disease progression, nutrition and treatments. Very often, however, these support groups are unavailable to prisoners that speak Spanish. The result is that many Latino inmates are excluded from the only programmatic support structure meant to reach prisoners with HIV/AIDS.

HIV testing with pre- and post-test counseling is not available to prisoners on demand—Being tested for HIV infection is critical to any public health strategy designed to deal with AIDS. Testing is the core of prevention and treatment programs. In many State prison facilities, however, inmates reported that it is actually difficult to get access to the HIV test. It is also reportedly rare that prisoners will be provided pre- and post test counseling. Counseling is essential if the beneficial effects of testing are to be realized. It has been difficult to assess the extent of this problem because Department of Correctional Services and the AIDS Institute cannot seem to collaborate on a statewide reporting system for HIV testing in different facilities.

Location of state prisons makes it difficult to receive needed primary and specialized medical care for HIV-infected prisoners—Prisoners within the New York State correctional system have limited access to HIV-specialized medical care. Most Department of Correctional Services ("DOCS") facilities are located near hospitals and other medical facilities having little or no experience with HIV/AIDS. In many of these upstate counties, there is reluctance by local practitioners and hospitals to develop any kind of HIV expertise. DOCS is required to spend exorbitant sums to transport these prisoners to a medical care institution capable of treating AIDS related conditions. Rather than housing prisoners with HIV-related illness near an appropriate hospital care facility, DOCS continues to put prisoners in remote counties with little access to quality HIV care.

DOCS medical facilities are not certified by the New York State Department of Health—Prisoners are sentenced to serve time for a particular crime. Most sentences do not include a condition stating that if you become ill you will receive medical treatment in a facility not licensed by New York State Health authorities. Why is it then that none of the clinics, infirmaries or hospitals run by DOCS are required to meet the same minimum health care standards and inspections of any other medical facility in the State of New York? Although DOCS states it conforms to nationally accepted prison health guidelines, the reality is prison health care does not meet basic Department of Health certification guidelines.

Lack of coordination between DOCS medical personnel and outside medical providers—Medications and nutritional programs prescribed by "outside" medical providers are reportedly frequently unavailable to prisoners on their return to the prison.

Medical parole does not reach intended groups—When Medical Parole was passed into law in 1992, legislators, advocates, prison officials and prisoners all hoped it would enable New York State prisoners with terminal illnesses to obtain an early release to their families, a nursing home, or hospice. Sadly, the dream of medical parole has not lived up to its promise. Since its inception in 1992, over one-third of the prisoners with AIDS who applied for Medical Parole died while their applications were being processed.

Cumbersome and bureaucratic application process causes unnecessary delays. Information required is repetitive, with some forms going to DOCS, others to the State Department of Health and still more to the federal Social Security Administration.

Inadequate staffing by DOCS to process the applications is a problem. As of this writing there is only one staff position dedicated to moving these applications.

Failure to distribute information regarding Medical Parole eligibility throughout the state prisons. Prisoners obtain information by going to the prison law library or most often through acquaintances. Monolingual or Spanish-language dominant prisoners are unlikely to receive information on Medical Parole until they are experiencing end stage HIV disease.

Untrained prison personnel are said to be a frequent source of delay in processing Medical Parole applications.

Failure to include inmates with AIDS awaiting transfer to a State facility from a county jail and to permit medical parole once an inmate has passed his or her parole eligibility date is contrary to the express intentions of State legislators.

Too many barriers to family interactions during serious illness/final stages of the disease—With the majority of New York State prisons situated in upstate rural areas, it is extremely difficult for New York City Latino families to visit

their sick and/or dying loved ones. Given the central role in Latino culture of the family, this deprives well-intentioned prison officials and inmates of a potential resource for developing positive social networks on discharge.

HIV infection during incarceration is an unacknowledged reality—Virtually all we know about the extent of HIV transmission during incarceration is from prisoner and prison staff anecdotes and the sporadic reports from journalists and community-based organizations. Taken together these sources form the basis for a real concern that many prisoners may become infected with HIV while under the care and custody of the New York States Department of Correctional Services.

The New York State Correctional Association's AIDS In Prison Project reported that former State inmates participating in a focus group acknowledged that "[h]igh risk consensual and non-consensual sex between inmates and inmates and staff was commonplace." These same former State inmates claimed that "...IV drug use with syringes as well as pieces of pens and light bulbs."[36]

Several witnesses during the Assembly/Senate Joint Hearing on Latino Inmates with HIV/AIDS made repeated references to active drug use and needle sharing in State facilities as well as unprotected sex between inmates.[37] A series of articles in the *New York Times* reported numerous anecdotes and reports of the use of drugs in New York State prisons. One article featured an extensive discussion of the death of Frederick Matthews, an inmate at Great Meadow Prison, who died of a cocaine overdose with a syringe still in his hand at the time of death.[38]

Outbreaks of HIV infections have been documented in countries that conduct ongoing blind seroprevalence surveys after incarceration. In Glasgow, Scotland carefully collected seroprevalence information was able to detect eight new HIV infections in prison because of sharing contaminated needles. In Mexico health officials have officially documented that 4.33% of the inmates share needles and that 10.3% of the prisoners engage in high risk sex in prison.[39] While the available information is sparse and anecdotal the mere existence of such high levels of HIV infections among Latinos and African-American prisoners should give rise to serious prevention concerns.

Lack of condoms guarantees infection of more prisoners—While the New York City correctional system has issued condoms to inmates for some time now, the state prison system remains steadfast in its refusal to do so.

Discharge planning for prisoners with HIV/AIDS is inadequate—Pre-release discharge planning is especially critical for HIV-positive and prisoners with AIDS. For New York City's Latino communities, this planning takes on a special urgency because most former Latino inmates typically return to their neighborhoods.[40]

Prisoners who are simply released with the standard Department of Parole discharge planning typically relapse in drug use with no connection to harm reduction programs. One study found that prisoners released to substandard housing, limited social support, and who are not participating in a relapse prevention program are more likely to experience drug relapses.[41]

HIV-positive prisoners are also at risk for losing medical and social services and resuming dysfunctional sexual behavior on release. Unless the planning for entitlements and needed services is initiated prior to release, the former inmate's life expectancy can be reduced. An innovative program initiated by New York State Department of Health Commissioner Barbara DuBuono when she was Director of the Rhode Island Department of Health underscored the importance of comprehensive pre-release planning. By bridging the gap to community-based services coupled with ongoing case management there was a successful reintegration into the community and the reduction of high-risk behaviors.[42]

Less than ten percent of New York State prisons provide comprehensive discharge planning to HIV-positive inmates about to be released. The facilities where such services are offered are all close to New York City even though many prisoners from New York are serving time in remote upstate facilities.

CONFERENCE RECOMMENDATIONS

Legislators must require that all medical, peer, support group, education, treatment and prevention services be available in Spanish for monolingual and bilingual prisoners—DOCS must confront the reality that one-half of the inmates with AIDS are Latino. Most of these inmates either speak only Spanish or are bilingual with a lesser capacity for English. With a disease as serious as AIDS, it should not be acceptable to rely on untrained staff, prisoners or guards to do critical translations.

Governor Pataki and Department of Correction Services must make changes in how medical parole law is administered—Only a fraction of potentially eligible prisoners are applying for medical parole. DOCS must simplify the application process and provide adequate staffing for administration. There must be wider dissemination of information (Spanish and English) regarding medical parole among prisoners and training on the law's requirements.

36 Mahon N. *Let's Talk About Sex and Drugs: HIV Transmission and Prevention Behind Bars.* Int. Conf. AIDS 1994 (Abstract No. PD0521).

37 See testimony of Dr. Nereida Ferran, former inmate Eddie Lavezzary and others. *A Joint Public Hearing of the New York State Assembly and Senate on Latino Inmates with HIV/AIDS* (held July 6, 1995 in New York City).

38 Matthew Purdy, *Bars Don't Stop the Flow of Drugs Into Prison*, NYT, July 2, 1995, p. 1.

39 Taylor A., Goldberg D. et al., *Outbreak of HIV in a Scottish Prison.* Int. Conf. AIDS 1994 (Abstract No. 463C) and Magis C, Del Rio A, et al., *HIV Infection in Prison in Mexico.* Int. Conf. AIDS 1994 (Abstract No. 467C).

40 New York Times, *Ex-Inmates Urge Return to Areas of Crime to Help* (December 23, 1992).

41 Mayer J, Kane, D, et al *Drug Relapse Among Recently Paroled HIV+ Individuals.* Int. Conf. AIDS 1993 Jun 6–11(Abstract No. PO-D12-3693).

42 DeCiantis ML, DeBuono BA and Carpenter C, *Post-release Program for HIV Positive Inmates.* Int. Conf. AIDS (Abstract No. PoD 5055).

State legislators need to amend medical parole law—Re-enact an improved version of the Medical Parole Law (which expired March 31, 1996) for three years as opposed to the current year-by-year renewal. In addition, the law must be amended to cover "state-ready" inmates awaiting transfer to State facilities and inmates whose parole eligibility date has expired.

Oppose Governor Pataki's proposals to cut the Alcohol and Substance Abuse Treatment (ASAT) program in prisons—Given the extent to which drug use is the primary source of infection in the Latino community, it is remarkable that Governor Pataki has proposed the elimination of 40 critical positions from the Department of Corrections ASAT programs. ASAT has also been critical to exposing injecting drug users to information on HIV/AIDS. The result of the cut will only ensure that more Latinos will reenter the correctional system with a greater and greater likelihood of being HIV-positive.

Pass legislation requiring DOCS to bring medical care facilities up to New York State Department of Health standards for clinics and hospitals—Just because a prisoner has AIDS in a prison setting is no reason for offering a different standard of medical care. Prison medical facilities should meet the same standards as similar facilities outside the prison with the same expectation of regular inspections and certification.

Expand health services for HIV-infected women and their children—DOCS should be able to provide gynecological care such as Pap smears, mammograms, and breast exams to all HIV-positive incarcerated women, and pre- and post-natal care to all pregnant inmates. Pediatric care over and above emergency services must be available to infants kept with their mothers in prison.

Make HIV testing available on request—Voluntary and confidential HIV testing with pre- and post-test counseling must be affirmatively promoted and made more available throughout the State prison system. Once requested, testing should be made available within seven days and results provided within two weeks. This will enable testing to occur in more reception facilities and other facilities with a rapidly changing prisoner population.

Fund comprehensive discharge planning by community-based organizations for prisoners with HIV/AIDS in all state prisons—By some estimates comprehensive discharge planning for prisoners with AIDS exists in only ten percent of DOCS facilities. Such planning must be done by community-based organizations with case management follow-up capacity in the areas prisoners return. Turning prisoners with AIDS into the streets of any city without proper pre-discharge planning guarantees an expensive disaster at the community level.

DOCS and the Division of Parole should mandate that medical discharge planning include the preparation of all required medical paperwork and documentation, and provide coordination as needed with the NYS Department of Health, NYC Human Resources Administration/Division of AIDS Services, and community-based organizations providing case management and housing services.

Fund peer education programs for HIV-infected prisoners in all facilities and provide adequate space/time for programs—Provide funding to CBOs to expand peer education programs within State prisons. In order that these programs be effective in changing and reducing behaviors which lead to the spread of HIV, DOCS, the Division of Parole, and associated health care organizations should provide the necessary support of peer education efforts, including adequate space and equipment for the provision of services to persons living with HIV/AIDS. In addition, CBOs operating within the prison system should offer incentives to prisoners to become peer educators. For example, completion of an HIV education curriculum could be rewarded by certification, which could be used by the individual after release to assist in finding employment.

Repeal mandatory sentencing laws—Repeal mandatory sentencing laws that require prison terms for non-violent offenders, including the Second Felony Offender Law and the Rockefeller Drug Law.

LATINO FAMILIES AND CHILDREN AND HIV/AIDS

PROFILE OF LATINO FAMILIES AND CHILDREN AND HIV/AIDS

Latino "Orphans" of the AIDS epidemic

While the actual number of children and adolescents whose parents have died from HIV disease has never been collected, all estimates point to an unfolding tragedy. Carol Levine and associates from the Orphan Project have estimated that approximately 4,800 children and 4,500 adolescents had been "orphaned" by HIV/AIDS.[43] In 1994, the estimated numbers of orphans was set at 7,000 children and 6,700 adolescents by the New York City Department of Health Prevention Planing Group. The Centers for Disease Control has estimated that between 93,000 and 112,000 uninfected children will be born to mothers who die of HIV/AIDS between 1992 and the year 2000.

Traditional patterns of care have changed as children come home to die. HIV/AIDS has promoted a redefinition of "family" to include diverse social networks and family structures, including gay and lesbian families. Although there are differences within Latino groups, maintaining close relationships with the extended family is expected and highly valued.[44] In many instances, HIV/AIDS has disrupted these patterns of interactions, while on other occasions it has brought together family members and families of choice. Co-parenting by the extended family system, i.e., grandparents, parental siblings, godparents, or even friends who are like "familia," is accepted and legitimate.

The devastating impact of HIV/AIDS in the Latino community is multi-generational, as evidenced by the experience of multiple losses of both parents or of HIV-positive parents with an HIV-positive child—Grandparents, aunts, and other family members of choice are taking the roles of new caretakers or guardians. The impact of the disease is not limited to the diagnosed child/adult, but has consequences for the entire family network. For example, when a whole generation is missing, what are the implications for the family members and their social support network?

Many women with substance abuse histories do not live in traditional family settings and do not have the support of extended family members or partners. Their supportive networks are "chosen" family members. Service providers have not traditionally recognized the central importance of chosen family members in the planning and delivery of services as well as custody planning.[45]

The governmental and social service responses to the AIDS epidemic in the Latino community have not been grounded in the socio-political and cultural realities of Latinos in New York City—Providers have not reconceptualized the discussion of the so-called "orphans" of the AIDS epidemic within the cultural reality of *compadrazo* and *familialismo*. The fact that Latinos move back to their respective countries, as well as to Puerto Rico, raises several concerns pertaining to custody planning and options available to parents living in New York or in a Latin American country. For example, the law recognizes stand-by guardianships in New York State but arrangements made pursuant to that law may not be honored out of state. Consequently, there is a need to systematize the access of information, i.e., birth certificates, home studies, translations, and clearance forms for child abuse and neglect.

Even though new programs and laws are in place to address the multiple needs of parents and children with HIV, service providers continue to assume that all families need the same services without considering their cultural beliefs and values. This is especially true in the context of custody planning and anticipatory grief and/or bereavement counseling. The surviving child has often had to face a number of losses and a cycle of repeated rejections before the actual death of the parent. The cycle of foster care, moving from one relative to another, and watching the deterioration of family life are familiar experiences for many of these children. In some families, the experience of rejection has often been intensified by acts of violence, including domestic violence and child abuse.[46]

Because research on AIDS and Latino families is so limited, there are no findings that really address the needs of Latino "orphaned" children—Service providers are left to construct their own service delivery models, which are often based on cultural misconceptions and misunderstandings of the socio-economic context in which Latino families strive to survive. Consequently, the resulting service provision may lack cultural sensitivity to Spanish-speaking clients, may disregard immigration/migration patterns of family members to the United States, or may mishandle sensitive information regarding sex, drug use, violence, custody planning, and/or disclosure.

43 Michaels & Levine, *The Youngest Survivor: Estimates of the Number of Motherless Youth Orphaned by AIDS in New York City*, from Orphans of the HIV Epidemic (United Hospital Fund 1993).

44 Chachkes, E., & Jennings, R. (1994) *Latino Communities: Coping with Death.* In Dane, B. O., & Levine C. (Eds.) *AIDS and the New Orphans.* Connecticut: Auburn House and Bor, R., & Elford J. (Eds.) (1994) *The Family and HIV.* New York: Cassell.

45 Woodruf, G., & Sterzin, E. D. (1993) *Family Support Service for Drug- and AIDS-Affected Families.* In Barth, R. P., et. al. (Eds.) *Families Living with Drugs and HIV: Intervention and Treatment Strategies.* New York: The Guildford Press.

46 Chachkes, E., & Jennings, R. (1994) *Latino Communities: Coping with Death.* In Dane, B. O., & Levine C. (Eds.) *AIDS and the New Orphans.* Connecticut: Auburn House.

Managing various social service systems becomes a major stressor for the adult or the family affected by HIV/AIDS—Inner-city families have to deal with a wide variety of agencies within the school, child welfare, judicial, public entitlements, and medical systems. Among the multiple levels of systems interventions, there are duplication of efforts, lack of clarity regarding boundaries, case manager insensitivity, intrusive behavior from foster care/voluntary agencies, and allegations of child abuse and neglect without an adequate assessment of the family.

Another area that has been neglected in the discussion of children and AIDS is the number of HIV-negative children with incarcerated parents who may be HIV-positive or already have AIDS—Many of these parents are powerless in the areas of parental decision-making and parent-child contact. Research findings have suggested that termination of parental rights may occur disproportionately among incarcerated parents, especially among those whose children entered foster care.

Latino Children with HIV/AIDS

Over 40% (591) of all the Latino infants with AIDS in the United States have been in New York City—The Bronx and Brooklyn account for 29% and 33%, respectively, of pediatric AIDS cases in New York City. This geographic distribution of pediatric AIDS cases parallels that of women with AIDS.

Delivery of services to HIV-infected children and adolescents is a complex and multifaceted process. Pediatric AIDS occurs disproportionately in poor, inner-city populations with high rates of drug use and STDs. Vastly over-represented are racial-ethnic groups and the poor.[47] The majority of pediatric AIDS cases have occurred at the extreme ends of the pediatric age spectrum, i.e., birth to two years and adolescents.

One of the misperceptions regarding HIV infection and AIDS in children is that these children are doomed to brief lives of nothing but pain, suffering, and early death.[48] The reality is that because the course of the disease is variable, long-term survivors until adolescence and beyond are more and more common.[49]

In many Latino families, one or both parents may be HIV-positive, and it is difficult for them to provide care and attention to their HIV-positive child—These parents may be doubly hindered, psychologically and physically, in their capacity to meet the child's needs. The child welfare system, specifically foster care, may play a role in servicing these children. The continuum of services and care for HIV-positive children within the child welfare system has not been challenged so that it responds to the needs of Latino families and children.

Support services for HIV-positive parents and their positive children are needed within the context of drug-using and AIDS-affected families—The roles of the different components within the child welfare system, i.e., voluntary agencies, legal, medical, social, etc., need to be clarified, as well as their interactions when they come in contact with a family. These components, traditionally, have worked independently of each other and with a single-problem, client-focused approach, which has not been effective with families of multiple needs. On the contrary, this may lead to the provision of isolated services which inadvertently perpetuate a family's problems.

The cost and inaccessibility of treatment, the scarcity of clinical trials, as well as the failure to recognize that many children with AIDS are born to poor, drug- using parents, are all impediments to the treatment of Latino children with HIV infection—Latino families faced with this reality also encounter a lack of community support. For example, unlike children with other diseases, such as cancer or diabetes, children with AIDS face the added obstacles of isolation and discrimination. On the other hand, children contracting HIV through perinatal transmission are seen as the victims, while their drug-using parent (usually the mother) is not seen in this manner.

AREAS OF CONCERN

Few programs are responsive to the needs of Latino families—Most providers have not adapted to the needs of HIV/AIDS-affected families, and few are responsive to the cultural perspective of Latinos. Many continue to use a "cookie-cutter" approach and try to fit families into the services they provide, rather than provide flexible services that best serve their clients.

Lack of coordination between HIV case managers causes stress to Latino families—HIV-positive parents suffer stress overload as they maneuver between case management services because HIV case managers have not learned to coordinate with each other, and have not established boundaries between themselves.

AIDS Institute funded permanency planning services are inadequate—Current permanency planning services are comprised of two components: social services to help families make difficult choices about disclosure and to select potential care givers, and legal services to help families turn their plans into legal realities. At current funding levels, upstate cities, including Albany, Syracuse, Buffalo and Rochester receive funding for only one component of ser-

47 Bim, A., Santelli, J., & Burwell LW. G. (1994) *Pediatric AIDS in the United States: Epidemiological Reality Versus Government Policy.* In Krieger, N., & Margo, G. (Eds.) *AIDS: The Politics of Survival.* New York: Baywood Publishing Company, Inc.

48 Mayers, A. (1994) *Natural History of congenital HIV infection.* Journal of School Health. January.

49 Boland, M. G., & Leske, J. (1995) *The Health Care Needs of Infants and Children: An Epidemiological Perspective.* In Boyd-Franklin, Nancy, et.al. (Eds.) *Children, Families, and HIV/AIDS: Psychological and Therapeutic Issues.* New York: The Guildford Press.

vices, which limits the effectiveness of programs. In addition, virtually all service providers in the New York City area are providing services well above projected capacity and are in need of expansion. These City providers are frequently required to limit outreach and triage intake, accepting only emergencies for direct representation and handling.[50]

Many children end up in foster care because the parent has not been provided with the resources to ensure a successful placement—The legal and social work aspects of permanency planning are intertwined. For successful placement planning to start the family needs to have both services involved from the outset. To date, these services have been separate, resulting in outcomes that often run contrary to the benefit of parents, care givers and/or child. There are no services models that combine planning and then offer targeted services and assistance following the death of a parent.

Parents who cannot identify a person to be legal guardian are often unable to plan for the future care of their children by arranging for voluntary foster care while retaining custody until the time of death or incapacity—Many parents are unable to identify a guardian but want to be satisfied about the appropriateness of foster care parents. They also want to retain custody of the child until their death. Current Social Service Law allows parents to place their children in foster care but the transfer of custody to the authorized agency must occur immediately. That is, parents must surrender control and care to the foster parents even though they can still take care of them. This results in a failure to make foster care placements until the last minute when the family is least able to carefully consider alternatives.

Financial support is grossly inadequate for new or second families—The loss of HIV-specific benefits, which typically expire on the ill parent's death is devastating to many children and their new families. Guardianships receive no financial support from New York State. This placement option, therefore, is more difficult for the low income families that predominate in the community affected by AIDS. This burden could be eased if the public assistance benefits owed to the child were provided in a timely manner. As things stand now there are delays of several months before the guardian can count on this assistance for the child. In addition, the State does not treat the child as a separate public assistance household. This means public assistance benefits for a new child to a family already on benefits will reduce overall benefits to the family.

Most agencies providing permanency planning services know little about Latino families and have very few Latinos in senior policy positions—As is true of most AIDS service providers, there are virtually no Latinos involved in policy making positions except at the intake/case manager level. Policy regarding placement issues is being made with minimal input from the involved communities. The classic middle class social worker approach to many of these difficult questions is sowing structural problems that will take years to undo.

Basic information needed for permanency planning is difficult to obtain—There is a need to systematize the access of information regarding issues that affect Latino caretakers and guardians, as well as provide supportive services which assist these clients with the planning process, in order to facilitate transfer procedures. Birth certificates, home study, translations, clearance forms for child abuse and neglect, are all elements of the process which are at times hard to access.

Caseworker attitudes toward and prejudices against HIV-positive Latino parents or potential foster parents hinder the home certification process—Even though a range of legal options are available, HIV-positive Latino parents often encounter barriers to implementing their choices because of prejudices and culturally-insensitive practices. Limitations exist in the Child Welfare Administration's Early Permanency Planning program based on lack of recognition of the cultural needs and preferences of the affected Latino population. Latino parents often find their choices are not respected and their decisions disregarded.

Drug treatment programs do not consider the special needs of Latino families affected by drug use/HIV/AIDS—HIV-positive Latinas and their children have special needs that drug treatment programs do not address. A number of programs deal with the client's drug issues based on an individual-treatment model, but do very little to address her HIV/AIDS issues. Few programs look at the entire family unit, its service needs around HIV/AIDS, as well as the substance use issues affecting the family.

CONFERENCE RECOMMENDATIONS

Mandate agencies providing permanency planning services to Latinos be culturally/linguistically competent and familiar with the Latino community affected by AIDS.

Mandate that the New York City Child Welfare Administration's Early Permanency Planning (EPP) Program develop a specialized unit of trained bilingual/bicultural staff—The staff of this unit must be trained in bereavement issues, as well as in issues related to Latino clients' cultural behaviors and views, which can favorably or unfavorably affect the ability of biological and prospective foster parents to accept the guardianship process.

Fund demonstration projects that provide legal and social welfare counseling as part of one program for parents with children—Services to assist children who will lose a parent to HIV/AIDS begin with support for the parent while she or he is alive. This support must provide opportunities for

50 See *Interim Recommendations, The Working Committee on HIV, Children & Families* (March 14, 1996) for full discussion of these issues.

planning and parental involvement. Equally important are transitional services to assist children and new care givers after the parent's death, when financial and emotional needs can be overwhelming.

Amend social services law to enable parents who have not found a guardian to retain custody while putting voluntary foster care in place prior to death or incapacity—If parents are forced to rely on foster care for their children, they should be able to identify voluntary foster care parents and transfer their children without losing custody. Why should a parent be required to surrender care while they are still capacitated in order to gain an acceptable foster care placement?

Governor Pataki and New York State Legislators must amend social service laws to enable new and second families maximum financial support and continued benefits to children orphaned by the death of a parent—The legislature must ensure continuity of benefits to children after the head of the household has died by requiring the local social service districts to develop procedures that avoid unnecessary bureaucratic delays. In addition, guardians should receive some form of direct financial assistance to enable them to provide for the child.

Expand qualifications for voluntary foster parents to best meet the needs of the child and the parent.

New York City Child Welfare Agency ("CWA") must provide "new" families with all the legal options available—CWA should recommend that "new" parents consider several options, not just adoption or custody. Sometimes there is a push for adoption within kinship foster care which, in many cases, may not be culturally appropriate. (For instance, grandparents who may be the "new" family may not wish legally to become their grandchild's "parent," out of respect for their deceased son or daughter.)

As the Child Welfare Agency and its foster care programs move into a managed care model, early permanency planning and agencies contracted to implement EPP programs must redefine their policies regarding "the best interest of the child" to deal with the best interest of the family—At a practical level, there is an opportunity for positive changes toward family-centered practice.

Child Welfare Agency must assure that foster parents, as well as new caretakers and guardians, are provided supportive services—Specifically, agencies contracting with CWA to provide foster care services must assure the provision of individual and family counseling, bereavement counseling, and support groups for the family. CWA must also assure that "new" families are helped to navigate the complicated and changing entitlements systems in order to assure that children will continue to receive benefits.

The Child Welfare Agency should use widely available resources like the New York Public Library Data System to create broad access to information on community resources for both families and the agencies which provide services—With current budget cuts, this would allow low-cost solutions to coordinating services, and make information of importance available to foster care and other families, providing them a step toward self-determination.

The Board of Education should assure that the school system provide comprehensive and consistent HIV/AIDS prevention and education efforts—The Board must work with parents through Parent Teacher Associations, and with community-based organizations, to develop multi-level programs which constantly reinforce prevention efforts.

Teachers and other school staff must receive HIV/AIDS training that is culturally sensitive, and includes training on issues of confidentiality/disclosure and bereavement for students who have lost parents or other loved ones.

For those children who are HIV-positive and are long-term survivors, the school system must respond with comprehensive programming, such as support groups, counseling, and other integrated support services.

Community-based organizations serving the Latino community must address long-existing barriers to services, that limit opportunities for providing services to Latino families and children—These barriers include restrictive views on gay and lesbian adoptive parents, lack of acknowledgment of Latino diversity by nationality and migration patterns, and negative associations regarding "machismo." Passivity or acceptance of existing barriers serve to maintain high levels of HIV infection in the community. Community-based organizations must also aggressively address the family as a service unit, and move away from serving clients as individuals. In the Latino community, extended families and support systems are the cultural norm, and, when addressed, can lead to more effective family intervention and outreach strategies.

The New York State Department of Health and the AIDS Institute must create an information flow between New York City and upstate service providers who have little access to the services provided at the epicenter.

The New York State Department of Mental Health and the New York City Department of Mental Health, Mental Retardation and Alcoholism Services must respond to the recommendations made over the last ten years of the epidemic to mandate that bilingual and bicultural professionals provide mental health services to Latina/os with HIV/AIDS.

LATINO IMMIGRANTS AND HIV/AIDS

PROFILE OF LATINO IMMIGRANTS AND HIV/AIDS

Immigrants are an integral part of national life and the fabric of New York City—On a national level immigrants pay more than $70 billion in taxes—about $25 billion more than they use in services. About 95% of foreign-born laborers survive without any form of public assistance, which is comparable to the amount received by native-born persons.[51] Almost 30% of New York City's residents were born outside of the United States. Further, the Immigration and Naturalization Service estimates 15% of all undocumented immigrants in the United States reside in New York City.[52] According to the 1990 Census, 41% of New Yorkers speak a language other than English at home. Generally speaking support for immigrants has always been strong among New Yorkers. A 1995 public opinion survey by the Hispanic Federation of New York revealed that 62% of the City's Latinos oppose any legislation making undocumented immigrants ineligible for public social and health services or for attendance in City schools.[53]

According to the New York City Department of Health there have been about 5,565 reported cases of AIDS among persons where the reported country of origin is other than the United States.

Almost 50% of the male and 30% of the female immigrant AIDS cases are from Spanish speaking countries in South America and the Caribbean—Within this group, most male immigrant cases come from Cuba, the Dominican Republic, Columbia, Ecuador and Mexico (in that order) with the primary mode of transmission being sex between men. For female immigrants almost one-half of the cases reported from a Spanish speaking country are from the Dominican Republic with transmission primarily through sex with a man. Among all the countries of origin, immigrants and refugees from Haiti have the highest rates of HIV/AIDS.

Epidemiologists express little confidence in the reported figures of AIDS among immigrants—First, data is not routinely collected from the health care or social service system on an individual's country of origin. Therefore, reports of countries of origin in clinics and hospitals are extremely episodic. Second, undocumented immigrants access health and social care systems infrequently because of fear of harassment and deportation. This leaves a large group of potential cases that are routinely bypassed in collecting epidemiological data. Third, many legal immigrants with HIV/AIDS are increasingly reluctant to access needed services because of a growing anti-immigrant trend that places their security at issue. Finally, the barriers of culture and language keep many immigrants from social service interactions where they might be reported to the Immigration and Naturalization Service.

Like many other Latino immigrants, immigrants with HIV/AIDS typically reside in economically depressed areas of the City, hold low-paying blue collar jobs, lack any form of health insurance, lack an understanding of the health and social services systems, and lack fluency in the English language—The enormous challenges immigrants normally face are compounded, however, for immigrants with HIV/AIDS, who must manage the ravages of their illness and support themselves and their families in a society that is increasingly hostile to all immigrants.

The future of health care and life-saving social services have been put at risk by recently enacted legislation—Congress recently passed welfare reform legislation that would remove important elements of this modest safety net by limiting immigrants' access to the types of programs, benefits, and services immigrants with HIV/AIDS so desperately need. The legislation would preclude most immigrants, including legal permanent residents, undocumented immigrants, and even naturalized citizens, from accessing many of the programs that they rely on to meet their most basic needs.

Other provisions of the legislation subject ***future*** legal permanent residents to a five-year prospective bar on all federal means-tested benefits. After the initial five-year bar, immigrants will continue to be subject to deeming, which means that the agency must assume that the income of the immigrant's sponsor is available to the immigrant for purposes of determining his/her financial eligibility for the desired entitlement. The legislation would extend applicability of the deeming period for most programs until the immigrant becomes a citizen.

The legislation would also give states the option to bar current legal permanent residents from Medicaid, social services block grants, and Temporary Assistance for Needy Families (formerly Aid to Families with Dependent Children), as well as the option to bar ***future*** immigrants from these programs ***after*** the five-year, federal bar.[54]

51 *Welfare Reform: An Analysis of the Issues.* Urban Institute 1995.

52 *1994 Report of the New York State Department of Health Prevention Planning Group.*

53 Hispanic Federation of New York, *Hispanic New Yorkers on Nueva York, Third Annual Survey,* September 1995.

54 A safety net comprised of federal, state, and local programs has thus far made it possible for immigrants with HIV/AIDS to receive the basic benefits and services required to survive. The federal government's Supplemental Security Income (SSI) program guarantees a minimum monthly income to persons disabled by HIV/AIDS, while cash benefits and rental assistance available through New York City's Division of AIDS Services (DAS) make it possible for immigrants with HIV/AIDS to receive proper nutrition and to avoid homelessness. Programs such as ADAP Plus and Medicaid (funded through a combination of federal and state funds) also ensures that immigrants with HIV/AIDS

The legislation would not bar future legal permanent residents or undocumented immigrants from participation in emergency Medicaid, immunizations, and testing and treatment of "communicable" diseases. It is unclear, however, whether treatment of HIV/AIDS will be considered a communicable disease for purposes of this exception to the bar. Congress did make clear, however, in its conference report that the communicable disease exception is intended to be "very narrow . . . [applicable] only where absolutely necessary to prevent the spread of such diseases."

AREAS OF CONCERN

Many immigrants access available services only after experiencing a HIV-related medical crisis—Many immigrants with HIV/AIDS are uninformed and/or misinformed with respect to the medical, social, and legal services to which they may be entitled, while others fail to seek out services available through governmental and non-governmental sources because they fear that their HIV status may negatively impact their immigration status. Consequently, many immigrants with HIV/AIDS do not receive preventive health care to help them stay well longer.

Case managers serving people with HIV/AIDS are often unfamiliar with immigrants' rights—Community-based organizations receive funding to provide case management services to people with HIV/AIDS. Many case managers, however, are not familiar with the rights of immigrants with HIV/AIDS nor are they aware of the services and benefits to which they are entitled. As a result, many case management functions are referred to legal services providers, who are not funded to provide case management services. A more efficient use of available resources would result if case managers were trained on these issues.

Because of funding limitations, ADAP, ADAP Plus and a handful of clinics are the only services available to meet the medical needs of immigrants with HIV/AIDS—The costs of repeated hospitalizations can be contained if immigrants with HIV/AIDS are assured quality primary care on a regular basis. For this reason, it is essential to assess the quality of care provided to immigrants whose primary care is through ADAP Plus. There are a limited number of clinics which accept ADAP Plus, and even fewer still which treat a primarily immigrant population.

Few legal services for immigrants with HIV/AIDS—The availability of legal services for immigrants with HIV is crucial since the ability to access needed benefits and services is so closely tied to an individual's immigration status. The need for increased advocacy will be even greater if the new federal legislation forces sweeping changes in eligibility programs. Increased numbers of immigrants will seek legal advice concerning the programs in which they may participate. In addition, increased advocacy funding to assist immigrants in becoming naturalized citizens ensures that legal permanent residents with HIV/AIDS become eligible for programs otherwise barred to them by the new Federal legislation. By doing so, the cost for providing benefits such as SSI would shift again to the federal government.

Deportation of incarcerated immigrants with HIV/AIDS is cruel—An important policy issue has emerged with the State of New York's recent decision to pursue aggressively the deportation of incarcerated immigrants. Incarcerated immigrants with HIV/AIDS would in most instances be deported to countries of origin where treatment for HIV/AIDS is either unavailable or woefully inadequate. Deportation would interrupt the individual's treatment regimen in the United States and would virtually assure a rapid decline in health. For humanitarian reasons, an incarcerated immigrant with HIV/AIDS should be permitted to remain in the country to receive treatment, particularly if the individual has paid a debt to society by completing the prison term imposed. Incarcerated immigrants are often unable to defend themselves against deportation because they cannot access legal services, resulting in deportations that might otherwise be avoided.

More aggressive outreach to immigrants with HIV/AIDS is required in regard to the availability of permanency planning—Many immigrants, particularly nonlegal permanent residents, are reluctant to make such arrangements, resulting in the placement of surviving children into the foster care system.

Lack of data on immigrants leads to underfunding of immigrant-specific prevention programs—The dearth of immigrant-specific prevention programs is partly attributable to the lack of epidemiological data concerning immigrants. Funding sources in the prevention area, such as the Centers for Disease Control, base funding on the number of reported AIDS cases in a given community. Because data concerning immigrants with HIV/AIDS is not collected in a systematic manner, the information needed to justify funding of prevention programs specifically for immigrants is not available. Until funders are able to implement more accurate data collection systems, they should be encouraged to relax their criteria for the funding of immigrant-specific prevention programs.

CONFERENCE RECOMMENDATIONS

Secure commitments from New York State and New York City to continue providing current types and levels of benefits and services to immigrants with HIV/AIDS, despite anticipated federal welfare reform legislation.

are able to receive adequate, ongoing medical treatment and home care to help prolong life. These programs provide a bare minimum of what is required to sustain a person affected by HIV/AIDS. Any reduction in the benefits and services made available through these programs will have a devastating effect on the lives of all immigrants with HIV/AIDS.

Secure commitment from New York State government to continue current types of medications and levels of services to immigrants with HIV/AIDS through the AIDS Drugs Assistance Program (ADAP) and ADAP Plus.

Expand advocacy services for immigrants with HIV/AIDS in anticipation of Federal legislation affecting immigrants' eligibility for a wide variety of benefits and services—Funding to establish a network of pro bono counsel would be a cost-effective means of meeting the increased demand for advocacy services.

Fund community-based, naturalization clinics that allow CBOs to conduct group processing sessions for legal permanent residents who wish to become naturalized citizens—Because Federal legislation will bar even legal permanent residents from receiving certain benefits, i.e., SSI and food stamps, it is critical to assist eligible persons in becoming naturalized citizens as soon as possible. CBOs funded for this purpose should encourage legal permanent residents to apply for naturalization immediately after diagnosis, so that they can become citizens and avoid the bar to benefits they may need when they become ill.

Expand early permanency planning services for immigrant families affected by HIV/AIDS—Increased advocacy services and outreach are required to ensure immigrant families engage in **permanency planning**. Such services must take into account the entire family, including all surviving children and partners. Additional services are needed specifically for surviving children who are undocumented. CBOs should receive funding to establish an enhanced case management model to assist immigrant families with **permanency planning** and related matters.

Increase services to incarcerated immigrants with HIV/AIDS in light of recent New York State actions to expedite deportation—To help minimize the possibility of deportation, the criminal defense bar should receive comprehensive training with respect to the immigration consequences of certain plea bargains. Once placed in deportation proceedings, immigrants should have access to information within the prison system regarding their rights and available legal assistance. Increased coordination between prison discharge planners and CBO case management for released prisoners is required.

Increase outreach to immigrant communities by funding culturally-sensitive community-based organizations to educate immigrants with respect to the rights of and services available to immigrants with HIV/AIDS—These expanded outreach efforts must therefore be multi-cultural and multi-lingual to maximize the impact on the targeted communities. Exorbitant costs associated with emergency hospitalizations would be significantly reduced if immigrants with HIV/AIDS accessed health care and social services shortly after diagnosis.

Train hospital personnel, particularly hospital-based social workers, with respect to immigrants' eligibility for benefits and services, so they can advise immigrants with HIV/AIDS—On-site, hospital-based programs would best serve this function.

Train post-testing counselors, community-based case managers, and other service providers regarding the services and benefits available to immigrants with HIV/AIDS. This function will be particularly crucial in light of impending federal legislation which will force changes in immigrants' eligibility for a wide variety of benefit programs and services.

Increase funding for peer education prevention models (both primary and secondary) to educate the immigrant population on HIV/AIDS—Government agencies should provide funding to Latino-based CBOs to develop special prevention strategies to reach migrants, who have to date not been the target of concerted prevention and education efforts.

Fund increased outreach, prevention, and direct services to immigrant seniors with HIV/AIDS, a difficult-to-reach group which is growing in numbers but has been largely ignored.

Require State and local Departments of Health to design data collection modalities that will generate statistical information needed to justify increased funding of direct and prevention services for immigrants with HIV/AIDS—These government agencies must design data collection systems which can overcome immigrants' reluctance to provide information regarding their immigration status.

CBOs should undertake a large-scale voter registration and mobilization drive within the immigrant community, and should provide instruction to new registrants regarding the workings of the political system—Latino-operated CBOs should expand participation in voter registration efforts conducted in conjunction with swearing-in ceremonies for newly-naturalized citizens.

HIV/AIDS AND LATINO GAY, BISEXUAL, TRANSGENDERED AND OTHER MEN WHO HAVE SEX WITH MEN

PROFILE OF LATINO GAY, BISEXUAL, TRANSGENDERED AND OTHER MEN WHO HAVE SEX WITH MEN AND HIV/AIDS

The issue of identity among men who have sex with men (MSM) is critical whether they are white, African-American, or Latino men—It affects prevention, treatment, and all other programs designed to reduce the incidence of HIV infection and extend help to those infected with the virus. Like MSM of other races or ethnicities, most Latino men who have contracted HIV through having sex with other men self-identify as gay. There are also Latino MSM who self-identify as bisexual, transgendered, or heterosexual. Whatever the identity, however, one thing is clear: Latino MSM have been ignored in virtually all primary and secondary prevention efforts and suffer indifference and rejection by most service providers.

The New York City Department of Health reports that as of October 1995, 21% (5,849 of 28,250) of all cases of MSM AIDS cases were Latino—On a national level, the CDC reports 23% of all cases of Latino MSM transmissions were New York City Latino males.

Latino gay men have shown significantly higher seroprevelence rates than white gay men year after year[55]—From 1988 to 1993, seroprevalence rates among MSM using New York City Sexually Transmitted Disease Clinics declined from 53% to 34%. The rate for Latino MSM remained high at 40% and, in fact, increased among Latino MSM in their 20s.[56] This changing reality is beginning to show up in new cases of AIDS among men who have sex with men. According to the New York City Department of Health's AIDS Surveillance Updates for 1994, the number of Latino gay men diagnosed with AIDS increased thirty percent more than new AIDS cases among white gay men.[57]

Prevention programs for Latino and African-American MSM have been an absolute failure—In a recent report, the Centers for Disease Control (CDC) reviewed the incidence of new AIDS cases over the past five years among MSM. The CDC found that new cases have been steadily increasing among African-Americans and Latinos but decreasing among white gay men. The implication of the report is that men of color were becoming infected in large numbers during the middle to late 1980s. The New York City Prevention Planning Group Committee on MSM noted that between 1986 and 1993, the number of Latino AIDS cases among MSM in New York City increased from 436 to 812, a 46% increase.

An examination of the press accounts and programs initiated during this time period support the conclusion that the broader society thought gay men in general had brought new infections under control through safer sex practices. The feeling among many well-intentioned health educators in the gay male community was that the "war" had been won. In the last three years, however, there was renewed interest in and funding for prevention programs because new infections in the white gay male community began to rise. The press and AIDS services organizations declared that there was a "second wave" of HIV infection in the gay male community. The sad reality was that there was no second wave in the Latino community—only one sustained rise of infections.

The epidemiological category of MSM, which was created to trace the course of the epidemic among those men who do not identify as gay has been improperly used by many AIDS services providers to conclude that somehow this is a phenomenon primarily seen in communities of color—The result has been that gay Latinos have been made virtually invisible in the AIDS world, and the nebulous messages of the prevention campaigns for MSM, expected to speak to them as well, never worked. The term MSM does not equal Latino gay men.

In the view of many, the term MSM seeks to deny history—Latino gay men, lesbians, and transvestites were at the center of the Stonewall rebellion of 1969, which marked the beginning of the modern lesbian and gay rights movement. Since then, Latino lesbian and gay organizations have existed to fight for recognition in the larger Latino community. Since the 1970s, Latino gay men and lesbians have organized to participate in the Puerto Rican Day Parade, the largest parade of its kind in the city. Currently, there are

55 See Easterbrook P.J., Chmiel J.S., et al., *Racial and Ethnic Differences in Human Immunodeficiency Virus Type I Seroprevelence Among Homosexual and Bisexual Men*, American Journal of Epidemiology 1993;138(6) 415–429 and Dean L. and Meyer L., HIV Prevalence and Sexual Behavior in a Cohort of New York City Gay Men (Aged 18–24), Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology 1995;8:208–211.

56 Torian, Weifuse, et al. *HIV Seroprevalence Trends in MSM Attending New York City Sexually Transmitted Disease Clinics 1988–1993*. Natl. Conf. Hum. Retroviruses Relat Infect. (2d Conference 1995).

57 Latino gay men engaging in anal sex fail to use a condom almost forty percent of the time. Carballo-Dieguez, A. *Need for Virucide Gel As Alternative to Condoms for Minority Men Who Have Sex With Men*, unpublished abstract and Morris, M. supra at n. 4. While this is not much lower than condum use among white gay men, Latino gay men as a group report a higher incidence of receptive anal intercourse, anonymous sexual partners and a greater prevalence of sexually transmitted disease histories See Easterbrook P.J., Chimiel J.S. et al., supra. and Dean, L. *Patterns of Sex Behavior and Risk Taking Among Young New York City Gay Men 1995*, unpublished manuscript. In one study of gay Puerto Rican men the critical role of anal intercourse to the "completion" of the sex act was emphasized by the vast majority of those interviewed. Fellatio was considered foreplay but not "real" sex which gay Latino men equated with anal penetration. Carballo-Dieguez A. and Dozlezal, C., *Contrasting Types of Puerto Rican Men Who Have Sex with Men (MSM)*, Journal of Psychology & Human Sexuality 1994 6(4):41–67.

eight organizations, one radio show, and two television shows by and for lesbian and gay Latinos in New York.

Since the beginning of the AIDS crisis, HIV-prevention strategies have failed properly to address the needs of gay Latino men—These efforts have been dominated by a fear of alienating the larger Latino community by dealing with gay Latinos openly and candidly. Also, the Latino community has always been incorrectly perceived as being disproportionately more homophobic than other cultures, when the truth is that homophobia is "equal opportunity hatred," equally found in most communities.

Latino providers have been reluctant to welcome Latino gay men to their programs—The same has been true of straight and gay-identified programs in the non-Latino community. Most organizations have refused to initiate special outreach efforts or to openly accommodate Latino gays. There are virtually no Latinos in executive level positions at many gay groups receiving funds for prevention and treatment. It seems as though people identify "gays" as white men and "Latino gay men" as something else. Latino services providers have exhibited the same discouraging homophobia by refusing to recognize the need to openly welcome Latino gay men and encourage their empowerment.

There is little understanding of bisexual Latino men and of bisexuality in general—Most often it is included in research as a substitute or synonymous term for "gay." The work that has been done underscores the need for targeted prevention programs to this population. One study of seroprevalence among MSM attending a New York City Sexually Transmitted Disease Clinic found that 22% of the men identified as bisexual. Bisexual men had a seroprevalence of 37% as compared to 43% for the overall MSM sample.[58] These lower rates of seroprevalence may be due to different sexual behaviors. A recent study of the sexual behaviors of bisexual men found that bisexual men were half as likely as gay men to have anal sex. The study also found that bisexual men were three times as likely to have unprotected sex with their female partner as their male partner.[59]

There is virtually no outreach targeted to Latino men who call themselves bisexual. Case managers and health educators have no information that enables them to design intervention or service programs for this population. Bisexual Latinos often have serious identity issues which must be addressed before they are able to access needed safer sex services.

The transgendered or transvestite population in the Latino community is probably the most underserved segment of the Latino MSM population. The problems of drug use and prostitution that affect some, but not all, of this population make the need for treatment and prevention information even more clear. With the exception of a couple of street outreach programs there are no "safe spaces" in the Bronx or Brooklyn where transgendered men can safely gather or participate in support groups. There is no prevention literature directed at the Latino transgendered population. AIDS service providers know next-to-nothing about the population. Transgendered Latinos face serious problems in accessing medical care and obtaining needed housing.

Men who have sex with men but do not see themselves as gay, bisexual or transgendered are difficult to reach—One of the challenges in providing treatment and prevention services in the Latino community has been the difficulty of reaching men who self-identify as heterosexual but have sex with other men. As with bisexual men, this is a very difficult population to identify and bring into supportive services, in part because of provider insensitivity. According to the Centers for Disease Control, MSM who do not identify as homosexual "are not adopting behaviors to reduce the risk for HIV infection with the same frequency as men who self-identify as homosexual or bisexual."

Persons born outside the U.S. account for one in seven MSM AIDS cases in NYC, and MSM account for approximately two-thirds of all of New York's immigrant cases.[60] Studies have documented fairly substantial numbers of such men among Latino immigrants from countries where concepts of "gay" or even "bisexual" have not permeated the popular culture. In many of these cultures, concepts of sexuality evolve from male/female roles in which the receptive sexual partner is the homosexual but the insertive male is still considered a straight man. These social constructs are decisive in determining where such men go for services.

Infection through the use of contaminated needles is a major source of HIV transmission for MSM and heterosexual Latino males—As of October 1995, the New York City Department of Health reports that Latinos make up 31.1% of MSM with a history of injection drug use and have been diagnosed with AIDS.

AREAS OF CONCERN

Lack of appropriate and effective prevention materials and service models—AIDS outreach and prevention to Latino populations continues to use concepts, models, and messages developed for communities outside the Latino community.

Too little funding for Latino MSM prevention by Latino CBOs in community settings—Many Latino MSM never make it to lower Manhattan for prevention programming funded by the New York City Department of Health, the Centers for Disease Control or the AIDS Institute. Yet Man-

58 Torian, Wehrle, E. et al. *HIV Seroprevalence Trends in MSM Attending New York City Sexually Transmitted Disease Clinics 1988–1993.* Natl. Conf. Hum. Retroviruses Relat. Infect. 3d Conference 1995.

59 Wold, CM, Seage, GR, et al. *Unsafe Sex Among Men Who Have Sex With Men and Women,* AIDS, February.

60 New York City Department of Health, Prevention Planning Group, Subcommittee on Gay Men.

hattan is where the vast majority of private and public prevention money goes to support efforts directed at Latino MSM. Latino community-based providers are a resource that governmental funders have often chosen to ignore on the assumption they are homophobic or unskilled at dealing with MSM. While it may be true that these programs have not historically targeted Latino MSM, it is critical that they be offered the opportunity to develop programs with the necessary technical assistance. Quite obviously, the past funding patterns and programs have failed to reduce the level of HIV infections among Latino gay men. A different approach seems merited.

Prevention messages directed at young Latino MSM must be developed with the awareness that explicitly gay information may be a barrier to access—Consistent, frequent, and strong messages are need to be developed for Latino adolescents and young men. These must be focused on attaining the right comfort level for messages on staying HIV-negative, and be bundled with other youth issues like teen pregnancy, S.T.D. prevention, etc. Peer models may be the most effective for this population. Locations where young people gather, such as night clubs and bars in Manhattan, offer opportunities to provide prevention education messages to men. Messages containing information on MSM should not be overt if presented in mixed settings like these. Gay identification on materials may present a barrier to access by some of the targeted population, while for others, the gay identification may facilitate access. Messages must have variety, and be presented in different "packages."

Special prevention programs must be aimed at immigrant MSMs Currently, in New York City, 20% of the documented population was born outside of the U.S.—For immigrant men, arriving alone or with little social supports, unaware of or unable to understand AIDS prevention messages, unprotected MSM sexual behavior becomes high risk. Consistent messages and outreach needs to be provided to this population.

Service providers are typically unaware of their biases toward gay Latinos—Latino men seeking services within their community very often experience discrimination if they identify their risk behavior as oral sex or anal intercourse. If they move out of their community for services, and access services run by the white gay community, they may also experience discrimination, this time based on race/ethnicity. If they do not experience the homophobia or racism, it is still rare that they will encounter a service provider who is fully understanding of their needs. Though their intention is to serve people from their community, they are unaware of the special needs of men who are reluctant to discuss sexual behaviors that have placed them at risk. Even after more than a decade of the epidemic, this is still a major problem.

Clinical interventions are not directed and relevant to each distinct community—Most programs are generic in nature, with very little targeting toward specific populations within the population of men who have sex with men. This lack of focus makes these programs ineffective in their outreach to provide services.

Effectiveness of hotlines hampered by rigidity of models and limited access—Hotlines are one of the most effective means of distributing information on HIV/AIDS, but these are very limited in access. Waiting time to talk to a service provider, if he or she is even available, is counterproductive to getting the right information out. Spanish hotlines are rare, and are hampered by mimicking hotlines established by and for the white gay community.

CONFERENCE RECOMMENDATIONS

Set aside funding for Latino MSM prevention programming for Latino-run, community-based organizations—The precedent for such directed funding would be the AIDS Institute's MSA programs. Each funded agency is community-based in a targeted area and reflects the population it serves. Set asides for community-based organizations would expand resources for targeting clinical interventions which address distinct communities within the MSM population. In particular, peer education models should be implemented to contact hard-to-reach populations such as transgendered individuals.

Mandate training for service providers on minority MSM—Organizations are typically unfamiliar with the diversity in the MSM population. Labels don't always work. They must become aware of their biases toward gay, bisexual, transgendered and men who have sex with men, and must understand the negative effect such biases have on the Latino community at large. Funders should support a continuum of in-service training to be provided to medical staff, social workers, technical assistants, and others who come in contact with these populations in order that they may "unlearn" their homophobia.

Repurpose existing prevention messages and programs to target all segments of the Latino MSM population—The New York City Department of Health and the New York AIDS Institute must require existing prevention contractors to dedicate resources to developing programs aimed specifically at Latino gay, bisexual, transgendered and other Latino men who have sex with men. If they are unable to do so they should be required to subcontract with other organizations that can provide the service. General messages urging large groups to behave a different way have rarely, if ever, been effective. For the Latino MSM population this message bears special urgency.

Fund Spanish/English media education efforts directly addressing homophobia, AIDS-phobia, and heterosexism—Homophobia and heterosexism have been identified as a primary cause in the spread of HIV among gay

men. The barriers created by bigotry have resulted in to all segments

Fund pilot program to monitor service delivery to Latino MSM and other Latinos with HIV—The Latino as consumer is a potent force for both improving service delivery and for building community involvement in local programs.

Initiate prevention programs directed at Latino men who have sex with men and women—Bisexuality is a reality that has unaddressed within the Latino community. None of the existing service paradigms and prevention messages reach this group.

Develop Latino community-based support and prevention programs for Latino gay men who inject drugs—There is wealth of experience among Latino CBOs in the area of drug treatment and HIV prevention. These programs should be given the opportunity to provide such services.

Open up the State and City prevention planning process to include more Latino consumers and organizations.

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HUNTER

Appendix A

Dennis de Leon
Latino Commission on AIDS
80 Fifth Avenue, Suite 1501
New York, NY 10011

December 18, 1995

Dear Dennis,

It was a pleasure to attend the Conference on Latinos and HIV/AIDS held on November 9. The conference was extremely well organized and covered issues of ultimate importance. In addition, the level of expertise and commitment of participants was evident in the production of the initial draft of the workbook as well as throughout the issue group discussions.

As Latino professionals conducting research on and evaluation of HIV prevention programs throughout New York City, we were concerned with the minimal attention given to documenting and evaluating existing programs as well as researching new models of intervention targeting the Latino community. The systematic examination of the strengths and challenges of specific interventions for the Latino community would greatly inform and contribute to the persuasive power of any advocacy effort.

In an effort to provide the Commission with recommendations with regard to program evaluation and research for each one of the topic areas discussed in the workbook, we have drafted the enclosed document 'Evaluation and Research recommendations for the agenda on HIV/AIDS in the Latino community.' In this document, we have detailed some general evaluation and research needs followed by issue-specific recommendations that we believe should be included in any policy effort put forth.

Please feel free to contact us at (212) 481-7672, if you have any questions or comments.

Sincerely,

Ana Motta, M.A.
Project Director
Community-Based Evaluation Program

Lucia Orellana, B.A.
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Evaluation and Research Recommendations for the Agenda on HIV/AIDS in the Latino Community
Prepared by
The Community-Based Evaluation Program of
Hunter College Center on AIDS, Drugs and Community Health

Overall Need for Research and Evaluation

- Further research is necessary to evaluate the efficacy of prevention/education models specifically targeting the Latino community
- Evaluation of existing models of service provision is critical to inform program planners, policy makers and funders
- Evaluation strategies and methodologies must be "user-friendly"
- Standardized documentation of program implementation will inform and facilitate replication of efficacious intervention models
- Research and evaluation of prevention/education models need to be funded separately and not at the expense of the program
- Evaluation findings must be accessible and disseminated to the different stakeholders, i.e., community, providers, policy makers and funders

Issue-specific Evaluation and Research Recommendations

Criminal Justice:

- Documentation of the current HIV/AIDS prevention/education interventions within the criminal justice system
  - What models are being used?
  - How is recruitment and engagement conducted?
  - What format, languages, styles and materials are used?
  - What are the space, time and privacy limitations?
  - What and how are the linkages as well as continuity of care established?
  - How can prevention strategies be developed for gang-oriented individuals?

- Conceptualization and design of culturally sensitive and competent intervention models based on research of norms, traditions, and practices of Latinos (e.g., role of family, gender roles, fatalism)

- Investigation of the impact of existing programs
  - Definition of success measures (recidivism, IV drug use, unsafe sexual behaviors)
  - Tracking mechanisms
  - Effectiveness of interventions in achieving objectives

Families and Children:

- Formative evaluation to help identify and document needs of "orphaned" Latino children (e.g., parental substance use, gender roles, domestic violence, immigration status, the extended family and related familial attitudes)
- Conceptualization and design of culturally sensitive and competent intervention models based on field research of norms, beliefs, traditions and practices of Latinos (e.g., role of family, gender roles, fatalism)
- Impact evaluation of current models (individual-oriented versus family-centered)

Gay, Bisexual, Transgender and MSM:

- Specifically targeted research to identify, locate and include gay, bisexual, transgender and MSM in prevention/education efforts (design and implementation of programs)
- Documentation of specific needs
- Description of current models used
- Documentation of current recruitment and engagement strategies
- Comparison of the models targeting a homogeneous gay community (white-middle class) versus a heterogenous Latino gay community

Immigration:

- Develop strategies to identify the needs of Latino immigrant populations
- Documentation of needs and resources of specific sub-groups (e.g., HIV positive individuals and families)
- Description of implementation of current models (including recruitment strategies, intervention format, setting, language)
- Outcome evaluation of models currently used (e.g., peer education models)
- Identify barriers to providing services and care to immigrant Latino populations

Substance Users:

- Documentation of differences in needs within Latino community (i.e., family involvement, child care provision, gender roles)
- Specification of objectives of current programs targeting behavior change (i.e., realistic, time specific)
- Description of current models used (risk reduction, harm reduction, outreach, peer driven, empowerment)
- Description of program implementation (including setting, community response, police intervention)
- Outcome evaluation of current models to assess efficacy of intervention models within Latino community

THE LATINO COMMISSION ON AIDS

The Latino Commission on AIDS is a nonprofit membership organization dedicated to improving and expanding AIDS prevention, research, treatment and other services in the Latino community through organizing, education, program support and training. Founded in March 1990 the Commission started as a group of committed and influential leaders who came together in response to the devastating impact of AIDS in the Latino community. The Commission began the process of becoming a membership organization in December 1994 while initiating a number of projects.

As a membership organization the Commission is able to respond to the reality of AIDS in the Latino community. More Latino elected leaders have been assuming greater leadership on AIDS issues. There are more Latinos working in AIDS and more Latinos with AIDS playing greater roles in advocacy. The Commission is dedicated to bringing these forces for change and concern together.

The objective of all Commission programs is the same - HIV/AIDS prevention and education for the Latino community. The current Commission projects are: promoting the availability of needle exchange sites in the Latino community; organizing leadership around Latino prisoner health issues; developing community-based AIDS Advisory Committees for each of the Latino elected officials; expanding information on prevention and treatment opportunities to Spanish-speaking New Yorkers; meeting the HIV prevention needs in the Latino gay male and lesbian community; assisting service providers in meeting the challenge of managed care; enhancing services available for Latinas; and developing traditional Latino clergy leadership on AIDS. In addition, the Commission, together with several other service providers, organizes an annual conference to develop a strategic plan for legislators, private and public funders and Latino community leaders on addressing HIV/AIDS in the Latino community.

The Commission is committed to using every opportunity in the English and Spanish language media to highlight the reality of HIV/AIDS in the Latino community. In addition to ongoing radio, television and newspaper educational outreach, the Commission publishes a weekly column in El Diario La Prensa (the largest Spanish language daily in New York City) and distributes an educational biweekly newsletter on HIV/AIDS in Spanish and English.

HISPANIC
FEDERATION
OF NEW YORK CITY

The Hispanic Federation of New York City was founded in 1990 as a service-oriented membership organization of Hispanic health and human-service agencies. The Federation's mission is to strengthen Hispanic social welfare agencies, enabling them to better meet the growing needs of New York City's Hispanic community. As the 21st century approaches, the Hispanic Federation of New York City continues to move forward expanding its network as it works to improve the quality of life for New York City's two million Hispanics.