# Latino Poverty and AIDS Prevention: The Over Spoken & Undeveloped Link

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by

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#### Introduction

The HIV epidemic is having devastating effects all over the world. The Latino community in the US continue to be impacted in high numbers. Professionals and community leaders have tried to explain the constant increase in Latino AIDS cases by different arguments, from lack of information and lack of resources for AIDS prevention programs to the lack of understanding of Latino behavior, in particular sex and drug use behavior, and the "cultural barriers" within the community. The explanations about the increase continue to grow and so does the number of AIDS cases among Latinos. The same can be said about the overall cases in women. Women is the fastest growing group in the AIDS epidemic. Some put sexism, racism and classism at the root causes to explain the effect of the epidemic among women, others again think that is more a problem of lack of information and access to condom or a chronic problem of drug use among a sector of minority women. The discussion continues and women continue to be dramatically affected by this epidemic. This paper does not expect to end this discussions nor it expects to become the "truth" in the debate. This paper expects to contribute to the understanding of HIV preventive behavior in a double jeopardized population group - Latina women in poor urban areas, and to make some recommendation in terms of intervention, advocacy and research.

In this paper, we will argue that the current social system: 1.) maintains minority women in living conditions of survival that contributes to a deterioration of their health and that places prevention priorities in such an order that HIV becomes the least of the problems, 2.) keeps a great sector of the Latino community uneducated which affects their ability to make informed decisions, 3.) maintains a status of affairs where inequality affects the spread of the HIV by maintaining women in a powerless position affecting their ability to prevent or make decisions that affect their health, 4.) keeps a great number of Latinos and Latinas under the poverty level and a. "working poor" without access to health care, that does not provide appropriate information and services that can assist these men and women in prevention or in making decisions that affect their health, and 5.) sets program priorities and resources in a way that is not consistent with the needs in these communities, encouraging descontextualized interventions separated from people's realities and communities.

The purpose of this paper is three fold. First, to discuss the negative influence that poverty has on the overall capability of Latina women and communities to prevent HIV. Second, to highlight and discuss the impact that socioeconomic status, and other societal structural elements, such as sexism, institutionalized racism and classism, have in increasing the relative risk for HIV infection among Latina women, as well as, in affecting their ability to prevent or make decisions that influence their health. Finally, to discuss the current "models of prevention" and to emphasize the main elements of a comprehensive strategy of prevention that address most of the causes of the problem.

### Background

Latinos represent 9% of the US population. In absolute numbers this means that 22.35 million Latinos live in the US. Latina women represent 49.2% of this amount. More than 10 million people in the U.S. are Latina women. (US Bureau of Census, 1990)

The Centers for Disease Control reported that by June 30, 1993 there were 315,390 cumulative cases of AIDS. Of them 53,616 - 17% - were in Latinos. As of June 1993 there have been 36,690 AIDS cases among women in the US. Seventy three percent (73%) of all female AIDS cases are in minority women. Fifty three percent (53%) of all female AIDS cases are in African American females, 20% in Latinas and 8.5% in Whites. In absolute numbers, as of June 1993, there has been 7,451 AIDS cases reported among Hispanic Females. (CDC, 1993) None of these numbers include those women that are infected with HIV and do not meet the AIDS surveillance definition. However, an analysis of AIDS trends among Latinos in the US (Diaz et al, 1993) shows that in 1991 Hispanics had an AIDS case rate 2.5 to 7.5 higher than the case rate for non-Hispanic Whites. The difference for women was the greatest among US born and Puerto Rican born Hispanic women. The predominant exposure category was injection drug use (47 %) and they had a significantly higher proportion of cases associated with sexual contact with an injection drug user (29%). IDU and Sex with IV drug user account for 76% of all AIDS cases among Latinas. (CDC, 1993)

The AIDS cases are still concentrated in large cities. The Hispanic AIDS cases are mainly concentrated in the North East, Florida, Puerto Rico and exceed the rate of cases in Whites in many states of the North Central region and the Midwest. In the West Coast and the Southwest although the rates do not exceed the cases in Whites, the absolute number of AIDS cases in Latinos is still high given the high concentration of Latinos in large cities affected by the HIV epidemic. (Diaz et al, 1993)

The geographic distribution of AIDS among all females places New York at the top followed by District of Columbia, Puerto Rico, Florida, New Jersey, Connecticut, Delaware, Maryland, Massachusetts, Rhode Island, Illinois, Georgia, Alabama, California, Nevada, and Texas. The AIDS surveillance system does not publish data on where the Latino female AIDS cases are concentrated.

#### Latino Poverty and the number of AIDS cases.

To understand what is the situation of poverty and female poverty in areas with high concentration of Latinos and high concentration of AIDS cases, we are going to present some facts about New York City and examine the situation at the Bronx. As well as in a few other cities in the US.

As of 1990 there were 1,737,927 persons of Hispanic origin in New York City. About thirty one percent (31%) of all Latino families in this city live below poverty level. (U.S. Bureau of Census, 1990) From all Hispanic families under poverty level, 71.3% were headed by a female. The major cause of deaths among women ages 15 to 44 in New York City are drug abuse, AIDS and homicide (Brown, 1992). Fifty percent of Hispanics in New York are Puerto Rican (Diaz et al, 1993). Forty percent of all AIDS cases among Latina women in the US are located in New York City. This city reported a total of 3,027 AIDS cases among Hispanic females. From those cases in Latinas in New York City, 60% were injecting drugs and 29% had sex with a partner at risk, mainly related to past or present drug behavior. (New York City AIDS Surveillance Report, 1993)

The distribution of AIDS cases in New York City shows that the concentration of AIDS cases among Latinos, follow the distribution of households under the poverty level. An excellent example to illustrate this situation can be given by examining the situation in the Bronx, New York City. The Bronx has a total of 1,185,796 inhabitants from which 518,207 (43.7%) are Latinos. In New York City, 8,933 AIDS cases are concentrated in the Bronx. In 1991, 37% of all pediatric AIDS cases in New York were among Latinos. Of this, 83% of all Latino Pediatric cases were in the Bronx. From 1991 to 1993, the prevalence rate of pediatric AIDS cases grew 61% from 80 per 100,000 children to 129 per 100,000. (New York City AIDS Surveillance Report, 1993; The Sourcebook of ZIP Code Demographics, 1990)

The City of New York reports number of AIDS cases by United Hospital Fund Neighborhood (UHFN). The Bronx is divided in seven UHFN with number of AIDS cases reported in each one. (See Tables 1 and 2).

UHFN #6 for example, is a low income neighborhood with a total population of 167,764 from which 85,109 are Hispanics (50.7%). There are 43,383 families in UHFN #6. On the average, 58.64% of the households in this area are headed by a female. The median family income is \$12, 375 per year and 54.21% of the families living in this area live with an annual income less than \$15,000. As it pertains to AIDS cases, this UHFN reported 2,003 AIDS cases which means 1,702 cases per 100,000 adults in the area. This case rate means that 43,383 families, mainly Latino families, live in a three ZIP code areas of the Bronx where 2 in 100 adults have AIDS. Over a period of two years the cases of AIDS have increased by almost 90%

Similarly, UHFN #7 is another low income neighborhood with a total population of 107,559 from which 77,27 are Hispanics (71.8%). There are 24,599 families in UHFN #7. On the average, 57.08% of the households in this area are headed by a female. The median family income is \$13,730 per year and 50.9% of the families living in this area live with an annual income less than \$15,000. The UHFN #7 reported 1,235 AIDS cases among adults which means 1,754 cases per 100,000 adults in the area. This case rate means that 24,599 families, mainly Latino families, live in a four ZIP code area of the Bronx where 2 in 100 adults have AIDS. Over a period of two years the cases of AIDS have increased by almost 80%. (New York City Office of HIV/AIDS Surveillance June 1993 and The Sourcebook of ZIP Code Demographics, 1990)

The pattern of poverty and high prevalence of AIDS continues in those areas of the Bronx with high concentration of Latinos. See Tables 1 & 2.

By way of comparison, the area with the highest prevalence of AIDS cases among Caucasians - the area of Chelsea, Clinton in Manhattan - shows a demographic radically different: UHFN #6 is with a total population of 123,109 from which 23,628 are Hispanics (19.19%). On the average, 21.6% of the households in this area are headed by a female. The median family income is \$31,283 per year and 14.2% of the families living in this area live with an annual income less than \$15,000. The UHFN #6 reported 3,429 AIDS cases among adults which means 2,767 cases per 100,000 adults in the area. This case rate means that 18,966 families, mainly Caucasian families, live in a six ZIP code area of the Bronx where 3 in 100 adults have AIDS. Over a period of two years the cases of AIDS have increased by almost 30%.

#### Table 1

## General Demographic Characteristics

	Borough of Bronx, 1990								
UHFN #1	Total Population	gini	% Caucasian	%	Average Family	Total Families	% Female House-	Median Household	% families <\$15,000
	90,775	21,263	60.63%	37.27%	Size		holders	Income	415,000
Kingsbridge, Riverdale UHFN #2			00.00 /2	31.21%	2.88	22,756	24.04%	\$30,390	15
NE Bronx	166,805	42,038	24.05%	25.20%	20,220			\$50,390	15.01%
UHFN #3			24.00%	25.20%	3.25	36,220	25.63%	\$27,116	
Fordham, Bronx Park	222,171	103,344	74 4494	46.52%	120000			*27,110	16.88%
UHFN #4			~ 1. 14 /0	40.52%	3.31	52,797	38.72%	\$18,316	
Pelham, Throgs Neck	259,309	97,036	38.03%	27 42.00	2000.00			410,310	34.41%
UHFN #5			00.00 /8	37.42%	3.23	66,245	~ 31.33%	\$23,503	
Crotona, Tremont	181,054	105,855	3.69%	50 4744				\$23,503	22.92%
UHFN #6		100000000000000	0.05%	58.47%	3.58	42,602	54.08%	*12.000	
	107,559	77,001	1 4 2 94	71.59%				\$13,330	51.02%
High-Bridge, Morrisania UHFN #7		1241201	1.42.70	/1.59%	3.65	24,599	58.64%	\$10 ATE	
	167,764	85,109 2.0	2 078	.07% 50.73%			00.04 /0	\$12,375	54.21%
Hunts Point, Mott Haven	- I al a series a series		2.07%	50.73%	3.58	43,383	57.08%	****	
TOTAL	1,195,437	E21 640		_			01.00 %	\$13,730	50.09%
	1.00,407	531,646	20.11%	44.47%	3 36 2	88 602	10.000		

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3.36 288,602 40.18% \$19.954 34.54%

#### Table 2

#### AIDS Prevalence.

	199	ı 1	199	%	
	AIDS	Rate	AIDS	Rate	Change
UHFN #1	127	178	213	260	5 <u>1</u> 1 1 1 1 1 1 1 1 1
Kingsbridge, Riverdale			•		
UHFN #2	320	201	590	399	84.38%
NE Bronx					
UHFN #3	875	518	1483	892	69.49%
Fordham, Bronx Park					
UHFN #4	764	328	1341	589	75.52%
Peiham, Throgs Neck					
UHFN #5	920	881	1718	1556	86.74%
Crotona, Tremont					
UHFN #6	1069	965	2003	1702	87.37%
High-Bridge, Morrisania					
UHFN #7	691	1292	1235	1754	78.73%
Hunts Point, Mott Haven				1 Miles	NAMES OF STREET, NO.
TOTAL	4,766		8,583		

Borough of Bronx, 1990 & 1993



General Demographic Characteristics.

Chelsea-Clinton Area. Borough of Manhattan, 1990

	Total Population	Hispanic Origin	% Caucasian	% Hispanic	Average Family Size				% families <\$15,000
UHFN #6 Chelsea, Clinton	123,109	23,628	67.21%	19.19%	1.64	18,966	21.6%	\$31,283	

#### Table 4

AIDS I	Prevalence.
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Chelsea-Clinton Area. Borough of Manhattan, 1990 & 1993

	1991		19	%	
	AIDS	Rate /100,000	AIDS	Rate /100,000	Change
UHFN #6 Chelsea, Clinton	2,719	2,194	3,429	2,767	26.11%

#### Other Areas

In Illinois, data from the Chicago Department of Health Community Area Health Inventory shows how community areas such as Logan Square, Humboldt Park and West Town are among those with very high concentration of AIDS cases (more than 250 and less than 499 per area). Those happen to be also among the poorest community areas in the State and are known as the Puerto Rican neighborhoods. (Chicago Department of Health Community Area Health Inventory, 1990 & 1993; Midwest Hispanic AIDS Coalition, 1993) (See Figure 1 and 2) In Texas, the majority of Latina female AIDS cases are concentrated in inner city metropolitan areas (Houston, Dallas and San Antonio) and the border counties Cameron, Hidalgo, Webb and the City of El

Paso, which is the 4th poorest city in the US. (Texas Department of Health June 1993 and El Paso City-County and Environmental District Preventive Health Services, June 1993).

As of June 1993, there were 313 AIDS cases in Latina females. Los Angeles county data is compiled by health district. 48.2% of all cases in Latina women are concentrated in the poorest areas of the city (See figures 3, 4)

# Poverty among Latinos with special emphasis in Latina women and HIV mode of transmission.

73% of all female cases in the US are in minority women. Intravenous drug use and sex with an intravenous drug user are the risky behaviors reported by 56% of all AIDS cases among minority women and 76% of all AIDS cases among Latinas. Intravenous drug use and sex with intravenous drug users are more prevalent in poorer areas of large cities where the majority of cases are reported among minority women. (CDC, 1993).

Eighty percent of poor people in the US are women and children with an over representation of women of color. (McKenzie, Bilofsky and Lerner, 1992) Puerto Rican women and those Hispanic born in the US constitute the majority of Latino female AIDS cases. Among Latinos, Puerto Rican families are the most likely to be poor (NCLR 1992). Thirty percent of Puerto Rican families were living below poverty line in 1991 in comparison with 25% for other Hispanic families and 9.5 for non Hispanic families. Hispanic female headed families have the highest poverty rate of all family types. In 1991 one in two Hispanic female-headed households was poor. Puerto Rican families have the highest rate of female-headed household. 64.4% of those families were living in poverty by 1990. (NCLR 1992 and NCLR 1993)

#### The Impact of Poverty

How poverty is affecting the spread of HIV and the HIV prevention capabilities of Latina women living in poverty areas?. We argue that poverty increases the vulnerability for HIV infection and decreases the capability of prevention among individuals, and in particular among Latina women. The majority of female cases occur in large cities with overall high number of AIDS cases. (CDC, 1993) Since a great number of women living in poverty are from minority groups, poverty should be examined not only as a mean of finding the explanation to the continuous increase in AIDS cases in these communities but also as the basis for designing the overall preventive strategies for these communities. The needed strategy has to take into consideration confronting "Poverty itself" for the intervention thus moving the HIV preventive strategy beyond only diffusion of information and condom distribution. The fact that HIV could infect anyone does not mean that every body is at the same risk. The statement made very often that "AIDS is an equal opportunity disease" reflects a poor analysis of how the epidemic is affecting different sectors of our society and is profoundly misleading in terms of the burden that HIV has become for poor minority communities in the US.

The majority of people living in poverty in the US are people of color and women of color (NCLR, 1993). Institutionalized racism and sexism, more than individual prejudice, is greatly responsible for this situation. Women and children represent 80% of poor people in this country. In 1990, 32.7% of all African Americans and 28.7% of Hispanics were poor in comparison with 11.3% among Whites (NCLR, 1993)

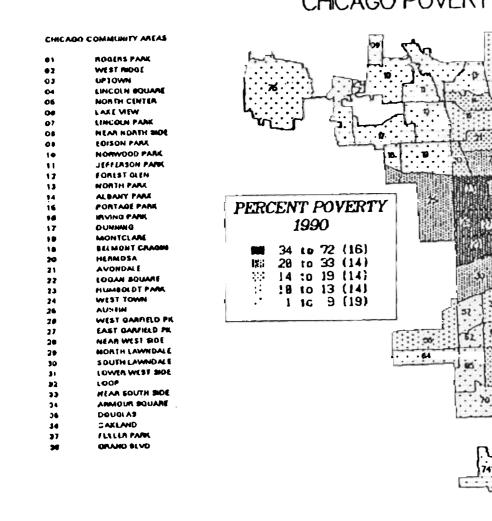
Institutionalized racism refers to:

<sup>&</sup>quot;...the established, customary, and respected ways in which society operates to keep the minority in a subordinate position......These social arrangements and accepted ways of doing things may consciously or unconsciously disadvantage some social categories while benefiting others." [Emphasis added] (Bacca Zinn, 1989)

Figure 1

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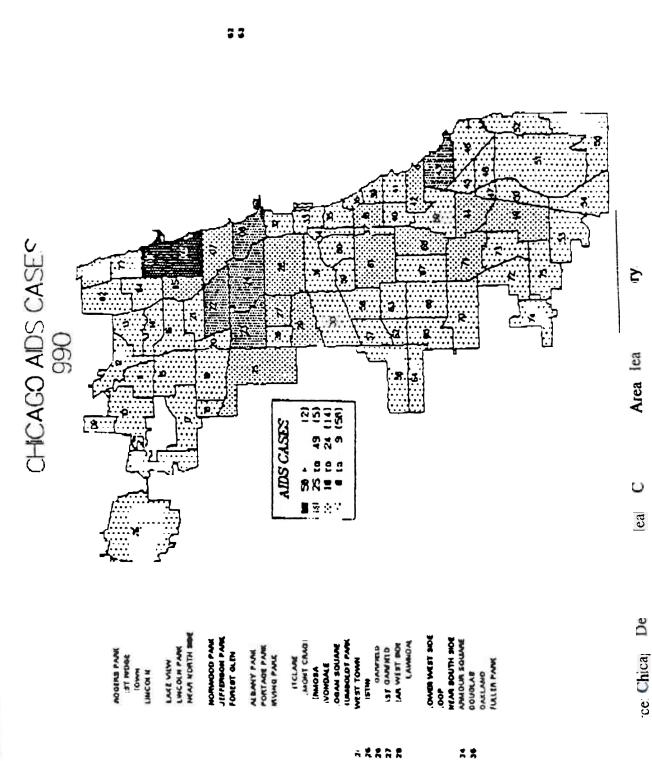


CHICAGO	POV	<b>ERTY</b>	1990
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30	XENW000
40	WASHINGTON PE
41	HYDL PAAK
42	WOODLAWN
43	SOUTH SHORE
44	CHATHAM
46	AVAL ON PARK
48	SOUTH CHICAGO
47	BURNSIDE
46	CALUMET HEIGHTS
48	NOSCIAND
60	PULLMAN
61	SOUTH DEENING
82	EAST SOE
53	WEST PULLMAN
64	RIVERDALE
66	HEGEWASCH
60	GARFIELD MOGE
67	ARCHER HEIGHTS
6.0	BRIGHTON PARK
60	MCKINLEY PARK
80	BADGEPORT
	NEW CITY
62	WEST LLEDON
83	GAGE PARK
84	CLEARING
86	WEST LAWN
00	CHICAGO LAWN
<b>e</b> 7	WEST ENGLEWOOD
41	ENOLEWOOD
	GREATER GRAND CR
70	ASHEUM
21	AUBURN GRESHAM
72	BEVENLY
73	WASHINGTON MOTS
74	NOUNT GREENWOOD
16	MORDAN PARK
74	O'HARE
77	EDGEWATER

Source: Chicago Department of Health Community Area Health Inventory, 1990

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NUTNDALE HEOTMBCH GAATIFLD NIBBE AACHEN HEIDH"B

SOUTH CHICAGO

VALON PARK

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DE FAM

CALUMET HEIGH

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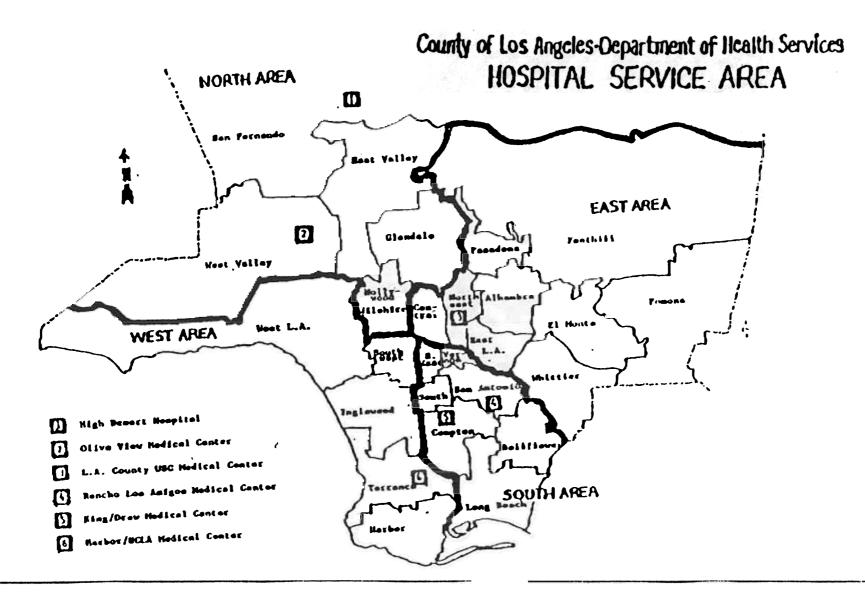
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FULMAN SOUTH DEEMNO LAST SOE WEST PULLMAN CHICADU LANN WES THOLENDOS ENOLENDOO OAEATEN QAAND -Ashburni Auburn - Aebhan

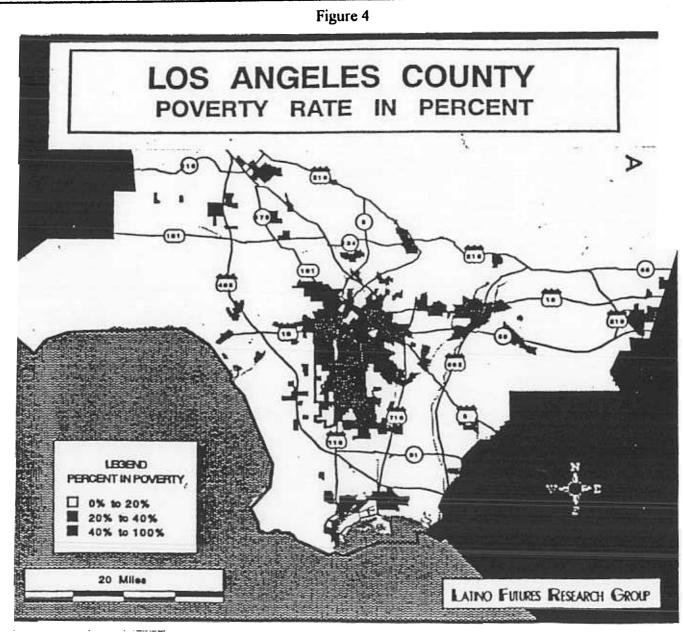
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MOUNT OREMWOOD MONAA PANK HANE DQFWAT





Source: Los Angeles County Department of Health Services, 1993



Source: Latino Futures Research Group, 1993

This society discriminates not only for what the system do but also for what the system ignores. According to McKenzie et al (McKenzie, Bilofsky, 1992), between 1980 and 1990 poor women have suffered reductions in federal funding that amount to:

- 14% cut in maternal health benefits
- 40% cut in community clinics
- 35% cut in health benefits to children and the elderly
- 67% decrease in employment assistance
- 74% decrease in housing assistance
- 66% cut in title X funds (contraceptive services for 83% poor women)

All these cuts have negatively impacted even more the few services that were available for poor women and children.

Minorities in general are affected by Institutionalized racism. But if we think in many of those neighborhoods where Latinos live in poverty, particularly we will realize how they have been victims of the indifference, lack of education and lack of opportunities, among other things.

In the words of Knowles and Prewitt:

"The institutions of society have great power to reward and penalize. They reward by providing career opportunities for some people and foreclosing them for others. They reward as well by the way social goods and services are distributed-by deciding who receives training and skills, medical care, formal education, political influence, moral support and self-respect, productive employment, fair treatment by the law, decent housing, self-confidence and the promise of a secure future for self and children" (Knowles and Prewitt, 1965)

#### **Poverty and Health**

Poverty, unemployment and child poverty rates among Hispanic families are on the rise. Hispanic married couple and families continue to face economic hardship, even when both adults work (NCLR, 1993a). Poverty rates are highest among Puerto Rican families and lowest among Cuban families. 33% of all Hispanic families were headed by a single parent, the great majority 29% headed by a woman. Puerto Rican families have the highest proportion of families maintained by women. In 1990 almost two-thirds (64.4%) of female headed Puerto Rican Families lived in poverty. Hispanic women are less likely to have health insurance, to receive prenatal care than their White counterpart. (NCLR, 1993b)

The association between Poverty and Health has been demonstrated in several opportunities. "People of low Socio-economic status experience higher incidence of chronic diseases, higher mortality rates and poorer survival rates" (Haan et al, 1987; DHHS, 1985; DHHS, 1990; DHHS, 1991; Woolhandler et al, 1985; Miller, 1987; Cooper et al, 1981). The disparity in health status between Hispanics and Whites has been called the "reflection of the Socio-economic disparity between Hispanics and Whites" (NCLR, 1992)

The discussion still exists regarding the reasons why it affects health. However, it is known that poverty influences health because among other things, individuals living under these conditions usually lack access to health care, have low level of education, live in neighborhoods where there is high consumption of alcohol, tobacco and drugs, high levels of criminality, face many environmental contaminants, poor housing and lack individual and community awareness, power and resources to change that situation. Poverty is a major influence in the production of disease and creates numerous barriers to prevention.

It is very important to clarify that in every poverty area there are stories of "success". People that overcame many barriers and "made it". Unfortunately this is the minority of cases and we cannot depend on the exceptions to formulate health programs or policies.

## **HIV Primary Prevention and Poverty**

Primary prevention is defined as "an intervention implemented before there is evidence of disease or injury. This strategy can reduce or eliminate causative risk factors (Risk Reduction)" (Teutsch, 1992)

The high risk behaviors for contracting HIV that are more prevalent among minority women are: needle sharing among intravenous drug users and unprotected sex mainly with intravenous drug users. These behaviors need to change. However, this high risk behaviors are the ultimate set of behaviors that come as a result of many variables associated with the individual, the family and the community. There are many other behaviors that preceded the specific one that is placing this person at risk of infection.

Although some public health professionals agree that behavior will not change if knowledge and attitudes do not change (Becker & Joseph, 1988) several behaviors need to change first in order for these ultimate behaviors to change, and the context where these ultimate behaviors are occurring need to be changed in the process of individual change.

Lets illustrate this idea with some real cases from our experience. Rosa, is a Mexican American Latina IVDU. She and her partner who is also IVDU used to run a shooting gallery in Detroit. She knew about our AIDS project through another friend. She was visited by us upon her request to take a look to her legs. They were swallow and infected. Rosa thinks that what really make the legs get infected is the "bad stuff" meaning drug is not very pure. Rosa did not want to go to the Hospital for fear that they could take her kids from her. Rosa perceived that she was not damaging the kids because they were left with the grandmother whenever Rosa was using drugs. Rosa preferred to lose her legs than to lose her kids. Rosa was sexually molested by two uncles when she was a little girl. She dropped out from school when she was in 7th grade, started using drugs when shr was 16, intravenous drugs when she was 19. Rosa shared needles and the rest of the injection equipment. Rosa is HIV negative and is aware of the way HIV is transmitted. Running this business allow her to make a little amount of money while assuring drugs for her. She have tried to quit drugs 4 times but has gone back to drugs. One time in methadone, one in outpatient treatment and two "cold turkey" (by herself).

What is the behavior that is putting Rosa at risk? Obviously, the ultimate behavior is "needle sharing". Why is Rosa sharing needles, why is she using drugs? If we start this simple process of reflection as Freire says (Freire), we will find a set of situations linked to another. If primary prevention has to do with "reducing or eliminating the risks for contracting a disease", what is the risk in the above situation? In the traditional model the risk is "the infected blood in the needle". Indeed this is the ultimate risk but what about the social and economical environment? What about the absence of effective, competent drug treatment and relapse prevention programs for women? What about other economic opportunities? Does the environment in which Rosa lives facilitate ultimate risks such as sharing needles and having unprotected sex can occur? If the answer is YES, then primary prevention is extremely difficult to occur if the environment remain the same and the only possible intervention is giving more AIDS information, condoms, and bleach.

A second case is Teresa. She is Puerto Rican. Single mother of three kids. She works during the night in a local factory. During the day she sleeps and take care of the kids and the house. On Saturdays she clean two houses in the suburbs. Sundays she cleans her house and take the kids to the park or to visit around. Officially she is under the poverty line. Teresa is the classic example of the working poor, without health insurance. Her house is small, and she only can afford the neighborhood where the house is located. Is not a very good neighborhood but at least she knows many people that assist her with the kids and other needs that may arise. Teresa main concern is that her kids do not get involve in drugs and gangs. In one opportunity, our women group from our local AIDS project met in her house. During the meeting (none infected with HIV), some women including Teresa admitted that they were reluctant to use condoms because they thought they would become lodged inside

their vaginas. Teresa also admitted that she very rarely had sex with a man so she defined herself as "not sexually active". When she has intercourse she does not think in condoms but she takes the pill.

What is putting Teresa at risk for HIV? Obviously, the ultimate risky behavior is unprotected sex. However, what about her lack of knowledge about her body, her lack of time to learn and discuss about her "so many priorities" that places HIV in a very insignificant position? What is primary prevention in the case of Teresa? What risks should be reduced and eliminated? How effective can a strategy be with Teresa if the only thing that is addressed is condom use?

Multiple problems create numerous barriers to prevention.

"...by virtue of their social environment, financial status, or other characteristics, people experience an overwhelming number of barrier to the translation of intentions into behaviors... individuals tend to respond to problems on a day-to-day basis..long term treatment regime is difficult or impossible." (in DiMatteo, 1982)

Even if the individual thinks that it is important to follow the advice, "the demands of everyday life focus the patient's attention not on getting ahead but simply in getting by" (DiMatteo, 1982)

If it is accepted that the "risks" of getting the HIV infection are not only behavioral but social, economical and psychological then Primary Prevention is negatively affected in poor urban areas where many Latina women live.

Opportunities to prevent HIV are minimal for a large segment of the Latino population. 48.3% of all Latino female-headed household were poor by 1990. Among Puerto Rican female-headed household the poverty level increase to 64.4%. Poverty among Latino children reaches dramatic proportions. 38.4% of all Latino children live in poverty and 56.7% of all Puerto Rican children in comparison with 15.9% among White children. Since Latino women represent a large sector among Latinos in poverty together with their children, we must recognize that this sector of the Latino community is the least prepared to deal with the HIV epidemic.

Primary HIV prevention for Latinas in poverty is affected by many factors; among them, their living conditions, under education, the lack of knowledge and information about their bodies, AIDS, and many other topics, lack of services including drug services, the negligence in the treatment of women in the AIDS epidemic, the portrayal of the Latino culture as responsible for the increase in AIDS cases, the limited educational and preventive activities and the health conditions and lack of access to health care for Latinas before the epidemic.

<u>Living Conditions</u>. Poverty keeps them in living conditions that deteriorates their health and place them at higher risk. Poor housing is one of the main characteristics of poverty areas and represents a key priority in the daily living of this women. To this it is necessary to add the living conditions of women in shelters, shantytowns, the streets or crack houses.

The neighborhoods where the AIDS epidemic has affected more individuals are urban settings. Geographic areas where there are high number of AIDS cases in Latinas are also areas of high number of cases of other diseases. HIV prevalence is high in the geographic areas where they live and the opportunities of dating men from that same neighborhood who may be infected are high. (Diaz et al, 1993)

The drug problem in many of these cities i.e. New York, has been endemic since many years before the HIV epidemic. The possibility for individuals engaging in high risk behavior of getting infected in these neighborhoods is higher than in a low-HIV and low drug prevalence areas including poor rural areas. Violence is not uncommon inside and outside their homes, stories of incest, child molestation or rape are part of the daily living and part of the history of many of these women affecting the self-esteem in a very negative form. Low self-esteem has been linked to low preventive behavior which in turn affect HIV primary prevention. (Medina, 1988; Bandura, 1987)

#### Under education Welfare Dependence and Lack of Job Opportunities.

"Latinos remain the nation's most undereducated group" (NCLR, 1993a). Latina women are specially affected by low level of education, low labor participation and low wages. They cannot afford health insurance and quality child care. Hispanics are more likely than non Hispanics to attend overcrowded, segregated and poorly funded schools, to be enrolled below grade level and be placed in non-academic tracks. 90% of Hispanics students attend urban school and face the problems of inner city: crime, drugs, deteriorating infrastructure and persistent poverty. There are many well documented reasons why Hispanics remain less educated and why they confront high drop-out rates (NCLR, 1993a; NCLR, 1990). Latina women have high rates of school drop-out which continue feeding the cycle of poverty.

Latina in welfare have expressed that self-sufficiency have many obstacles such as family responsibilities, lack of basic skills and relevant job training, the costs and logistics of transportation and housing costs. Many of these women cannot afford to work because they will lose health coverage. AFDC regulation account partially for keeping these women in dependency (NCLR, 1993a).

Under education also affect the opportunity of these women to make informed decisions including those that affect their health. An individual with higher education and better economic position has more options in terms of individual choice and consequently, he or she is more likely to have and to use the information about prevention. Various studies have shown that within high income white gay communities, which are relatively organized and in general posses an educational and socioeconomic advantage, the increase in knowledge as well the change in behavior is facilitated by the social and economic conditions present in those communities. (Becker & Joseph, 1988; Cooper, 1981)

<u>Health Status</u>. Latina women living in these poverty areas confront many other circumstances that affect their health. Hispanics are more likely to be uninsured than Whites and African Americans. In addition, Hispanics receive less preventive health care than Whites (NCLR, 1992; NCLR, 1993b; COSSMHO, 1992) Eating habits are not very healthy with high consumption of fats. Healthy food is scarce or absent from the local markets. Preventive services and health education programs are minimal or absent. (DHHS, 1985) Treatment and prevention programs for tobacco, alcohol and drug use is minimal or non existent for women. Tuberculosis has been prevalent in high proportions in poverty areas before the HIV epidemic but were never confronted with the necessary strategies. (COSSMHO, 1990; Haan, 1987)

<u>Knowledge and Services</u>. Information and services that could assist these women in prevention or in making decisions that affect their health have been minimal and in many cases absent. Information about HIV in low income neighborhoods started after three to four years into the epidemic (Santee, 1989). Then, it was prevalent in these communities the notion and perception that HIV was a "White gay issue" since the media and the health institutions were mainly presenting the HIV information with emphasis in the White gay cases. Information about women was for many years non-existent. Bilingual HIV information was during several years of poor quality, with poor translations, without a program that could outreach and follow up with this women. Information has been given about HIV without taking into consideration other informational needs that this women may have i.e information about their own anatomy and biology. The readiness for giving information of HIV is not assessed. i.e. maybe a woman needs to discuss about rape or marital relationships before being ready to process information about condom, negotiation and the like. In addition more often than not, women will have a myriad of needs including mental health, child care, transportation etc. that are not considered in this programs jeopardizing in this way the participation of women and the impact of the message.

<u>Drug Abuse Services</u>. The services more needed and more absent for women have been those related to drug treatment. The problem of drug use among women in general and Latinas in particular have been ignored or timidly addressed by the system's institutions before and during the HIV epidemic. Although the system for drug

treatment and post treatment for low income individuals is minimal and not very effective, services for women with a different culture and language are extremely scarce and more so than for men. The situation of lack of drug services have been specially devastating in the HIV epidemic. The major cause of deaths among women ages 15 to 44 in New York City are drug abuse, AIDS and homicide (Brown, 1992). 50% of Hispanics in New York are Puerto Rican. In 1990 almost two-thirds (64.4%) of female headed Puerto Rican Families lived in poverty. Drug Abuse is the predominant HIV exposure category for US-born and Puerto Rican born Hispanic women which represent the majority of AIDS cases among Latinas. (Diaz et al, 19930 The number of addicted women continue to increase. In New York, for example "there was an estimated of 10,000 drug addicted mothers in 1991, a more than threefold increase since 1988. The number of women in prison New York State increased 59% form 1988 to 1989 largely as a result of drug abuse" (Brown, 1992; NYSDSAS, 1989). In Texas, a state with a very different Hispanic population, Hispanics reported 27% increase in AIDS cases between 1988 and 1989. During that same period of time, there were larger percentage increases in the number of cases among Females (24% increase). The Texas Health Department reports an increase of 80% of cases in women due to sex and/or IV drug use compared to an increase of 27% in male to male sex. 58% of the women who transmitted the HIV to their children in Texas became HIV infected as a result of either personal drug use (43%) or IV drug use by their sex partner (15%). (TDH, 1991; TDH, 1993) The numbers of Latinas infected with HIV with drug related cause continue to increase before the indifference or slow response of the health and social system

<u>Culture and Gender</u>. The reasons why some Latinas may be at risk has been shaped by philosophical dissertations of Latino and Non-Latino researchers that bring their own values and expectations to what a Latina should be and how she should respond to her partner demands. In this way, Latinas were further stereotyped as individuals at risk as being infected because a learned "cultural" role of passiveness and dependence in front of a "macho" Latino man that do not want to use condoms.(Worth, 1987) Latinas were portrayed as attached to traditional values were sex is not discussed. Those analysis that center the problem in the culture have been criticized in various opportunities for ignoring the impact of the socio-economic context in which the culture occur and because they perceive the culture with many deficits (De la Cancela, 1989) instead of using the strengths to design effective interventions. Furthermore, studies have shown that when controlling for socieconomic variables, there is no difference in condom use among partners of women of color as compared to partners of white women, suggesting that poverty and not culture or race alone need to be addressed to increase condom use and preventive behavior (Kost, 1992; Roper, 1993, Catania, 1992)

Although this common portrayal holds many real situations, it further stereotyped Latinas placing the blame and the responsibility for the HIV infection in the culture and in the Latino men. This analysis does not consider that passiveness in the relationship with men, economic dependence, lack of control in one's sexual life and machismo is a fact of life in many cultures not only in the Latino culture and that all this roles and situations are rooted in societies that force those roles among women and men. Domestic violence is also a fact across classes and cultures and not a characteristic of Latino culture. It is well known that even for middle and upper class women with formal education it is very problematic to end violent relationships. For Latinas in poverty, economic dependence means lack of opportunities sometimes for generations regarding access to education and jobs. Many of these women depend on men who also received a very low wage and are also victims of a system of inequalities. When violence occur in these low income neighborhoods, the situation is extremely complicated. Women here face all the psychological difficulties of women everywhere plus lack of money, shelters or a place to go, lack of knowledge about rights, many times they do not speak English, etc. In addition, regardless of those cases there are difference among Latinas. Although women in better economic and educational position also face issues of inequalities and they are also getting infected with HIV, it is less problematic for a Latina with formal education, economic security living in a relatively safe, low HIV seroprevalence community, without drugs all over the neighborhood, without a problem of chemical dependency to analyze the situation of preventing HIV and take some action. However, the particular difficult situation of low income Latinas needs to be highlighted and brought into context. For low income Latinas survival comes first.

## **HIV Secondary Prevention and Poverty**

In addition to primary prevention, secondary prevention is also affected by poverty. Secondary prevention is "an intervention implemented after a disease has begun but before it is symptomatic (screening and treatment)." (Teutsch, 1992). The prevention strategy for this level is "early intervention". In the case of HIV, the early intervention has been defined to include regular medical check- ups, immunizations, treatment of other infections (e.g. venereal), possible Tuberculosis profilaxis, psychological support, risk reduction education, etc (Valenti, 1992)

It has been recognized that many women do not know that they are infected until they develop opportunistic diseases or until they have a baby with HIV antibodies. (Santee, 1989; Stuntzner-Gibson, 1991) There are many reasons that could explain why many HIV infected women are not receiving the benefits of the early intervention. Our latest example of Teresa is a typical case of a woman that have so many problems in her life that HIV does not make to the list of priorities. If Teresa becomes infected she probably will ignore it for long time. She understands the HIV information but that alone is not helping. She does not have enough basic education, not even about her body. Teresa does not have a health insurance and when she feels sick she waits until it passes. She is the bread winner of her family and does not have time for herself. If secondary prevention is affected by situations that interfere with HIV early intervention strategies, then poverty affects negatively the opportunities for secondary prevention among Latina women by creating numerous barriers to access to the overall strategy of early intervention.

The HIV epidemic has entered these communities where the living conditions are sub-standard and found a very vulnerable target. In that sense the number of AIDS cases among Latino women and the rapid increase in those numbers should not be a surprise for anyone. Latinas with HIV and those at risk have been victims of a system that forgot about them. Poverty, sexism, institutionalized racism and classism are associated with high risk for infection with HIV among Latinas (Stuntzner-Gibson, 1991; IWGWA, 1988).

The portrayal and treatment of women in the HIV epidemic. The perception of women in this HIV epidemic has had devastating effects for them. Women were perceived as vectors of the disease. The message was more directed to women as potential mothers than as individuals. The AIDS surveillance definition was created based on the male body of White gay males. Women infected with the virus started presenting higher rates of cervical cancer, vaginal candidiasis that were not responding to treatment, pelvic inflammatory disease and many others related to women's reproductive system. However since women's reproductive system were not part of the CDC Surveillance definition, many women were excluded from being diagnosed on time and receiving services. The same situation was happening with Intravenous drug users, who where having a particular set of diseases that were not being recognized as associated with HIV. Many women even died without knowing they were infected with HIV or the HIV diagnosis was not considered as part of the post morten report. (Buehler, 1992; Diaz et al, 1993, Stuntzner-Gibson, 1989)<sup>1</sup>

Access to research and experimental treatment has not been easy for women in general which add to the reasons why we cannot be more effective in defining the natural history of HIV in women. (Stuntzner-Gibson, 1989; IWGWAA, 1988; Santee, 1989; Moss, 1989) This has hampered the development of adequate early intervention program to address the HIV specific needs of women infected with HIV.

<sup>&</sup>lt;sup>1</sup> The CDC surveillance definition was changed in January, 1993.

## **HIV Tertiary Prevention and Poverty**

Poverty also creates barriers for tertiary prevention. Tertiary prevention is "an intervention implemented after a disease or injury is established. This strategy can prevent sequelae" (Teutsch, 1992). This is the level of coping with complications, rehabilitation, maintenance of the highest level possible of quality of life. The tertiary level of prevention for HIV infection has to do with the management of opportunistic diseases, with the tremendous need for support services and care. This is the stage through which many women in poverty do not have resources and usually even in sickness, have to work and take care of her own kids. The burden for these women is extreme. Not only they have to face the many AIDS related diseases and their complications but for the ones with children, they have to go through all this process knowing that their kids face the risk of losing their only economical and affective support. For other women, the burden is to handle their addiction and HIV related diseases simultaneously such in the case of Laura, another client and friend from the Detroit AIDS project. Laura found out she was infected with HIV in the prison. She went in probation when she already was having some opportunistic diseases. Laura was very motivated to stay clean but her strongest support network was among her friends, all drug users. Laura got an apartment and invited her teenager kids to live with her. The two boys were dealing crack and Laura found the opportunity of using it for free. After that, crack gave Laura again the opportunity of being part of a social network. Laura had tried in the past to stop using drugs and she decided to tried again. Detroit lacks residential drug treatment for Latinas. The only one in existence during that time was located in Grand Rapids and they were not apt to treat individuals who had AIDS. Laura went to Grand Rapids and during her time there she became very sick and had to go to the Hospital. A hospital that was not ready to handle individuals with addictions. After leaving the Hospital she went into crack houses from which she never came out until she was in terminal stages and died. What are the opportunities of these women in poverty of dealing with medical complications and trying to keep a minimum quality of life? Poor communities rely in community Hospitals and although case management models have been implemented in many communities, still there are many challenges for those systems in neighborhoods overburdened with high prevalence of AIDS cases and drug use and lacking the necessary services thus jeopardizing the provision and quality of services these women can receive.

#### **Current Strategies For HIV Prevention**

#### Diffusion of Information: Defining the Message & Framing Interventions

The strategy for HIV prevention have been based on the diffusion of information. The first message has to do with the sex-virus connection. The content of this message reflects the development and maintenance of faithful relationships. The former Surgeon General Everett Koop also offered an alternative for those who engage in casual intercourse: "use a condom". Abstinence and condom use have been the two key messages regarding HIV-sex. The second set of messages has to do with drugs and HIV. Within this message the information has to be structured in such a way that the first recommendation has to be to seek help for stop using drugs. The alternative recommendation which follows for those who continue to use drugs is: "do not share needles". Many local health department and community programs recommends a third alternative: "Clean paraphernalia with bleach".

The major AIDS prevention programs so far have been designed to spread this information. The strategies are being studied carefully to ensure that the message is sent to the whole population. In this campaign, the Public Health Field has joined forces with the marketing field to apply marketing techniques to influence behavior change through information. i.e. studies of knowledge and attitudes regarding AIDS; prevention measures for targeting specific barriers; studies of culture and language for appropriateness of the message; the use of role models and peers for sending the message and "hitting" the audience: African Americans sender- African American receiver, Hispanics sender -Hispanics receiver. In accordance with this strategy, community based organizations are the obvious places for the design of a loca' intervention plan and the development of activities consistent with that plan. This effort at the local level, together with national efforts are crucial for the diffusion of AIDS prevention information.

The fact that the majority of funding channeled to low income communities is public money has forced local programs to request this money based on what the funding source wants to accomplish and not in what needs to be done. Through this funding "game" Grant makers and Grant seekers have been creating programs based in diffusion of information, distribution of condoms and bleach, counseling and testing. These interventions have value. Awareness in many communities has been possible thanks to the outreach workers and educators that work at the local level. What seems not to be happening is the "action" needed for prevention. The majority of preventive interventions are not more than "educational interventions" with clear objectives to reach. Under this provider-centered approach to education, the providers own the "word, the thinking process and the action". There are root causes of inequality that are serving as the best culture broth for the spread of the HIV. Reflection and Action on the part of the community and the women will not happen by maintaining them as "recipients of information" in a powerless position that is affecting their ability to prevent or make decisions that affect their health.

#### Prevention I: A Medical Model of Prevention

The only known form of avoiding the HIV infection is by not engaging in the high risk behaviors associated with the infection. How the individuals act to prevent a disease have been subject of numerous debates

In a recent CDC publication " A Framework for Assessing the effectiveness of Disease and Injury prevention" (Teutsch, 1992), the author express:

"Public health professionals and policy makers at the state, national and local levels make judgments about public health priorities, select prevention strategies and allocate resources...information about the efficacy, effectiveness and costs provides a basis for optimal utilization of techniques".

This article talks about targeting Preventive interventions within two approaches:

(1) "Delivery of Prevention Technologies" and (2) Targeting intervention by Stage of Disease or Injury. In order to discuss this same framework in relation to HIV prevention, we will provide a brief summary of Teustch's framework, using his examples from the original article.

(1) Delivery of Prevention Technologies. This approach include:

- (a) clinical prevention strategies. Described as" the traditional medical model requiring individual efforts to obtain services." offers: screening, vaccination and diagnosis and early treatment.
- (b) Behavioral Prevention strategies. Described as the "health promotion model requiring individual action to effect behavior change" encouraging life style change based on individual behavior modification". ie. healthful diets, exercise.
- (c) Environmental prevention strategies. Described as the "health protection model requiring little or no action on the part of the beneficiary" include measures such as water fluoridation and seat-belts.

(2) Targeting intervention by Stage of Disease or Injury. This framework offers different intervention for Primary, Secondary and Tertiary Prevention. "Primary prevention, which should reduce or eliminate the risk factors i.e. sex education to eliminate sexually transmitted diseases. Secondary Prevention with early detection and treatment such as mammographies and Tertiary Prevention providing supportive and rehabilitative services."

From the perspective of this article Prevention is some sort of technique used by a health professional that requires or not individual effort or social cooperation. The participation of individuals in identifying their health

priorities is overlooked. These frameworks are consistent with the resistance in the Public Health structure to confront the complexities of the root causes of diseases. A public health structure that want to solve the problem of sexually transmitted disease with sex education without confronting the human and social dynamics of these diseases, that wants to confront cavities with water fluoridation resting importance to appropriate nutrition or access to dental care. These frameworks ignore the relationship of human beings with their environment and the influence of one in the other. It ignores the group effect in individuals and communities. If we examine the application of this frameworks within the poverty areas / inner city where many Latinas are becoming infected with HIV, we may be able to explain why it is so complicated to avoid diseases and their sequela is so difficult. We still have a Public Health system more worried about finding magic bullets that on confronting situations which have been associated with poor health . It is like looking for the miraculous effects of sanitation in public health in industrialized countries long time ago. As Ellen Bilofsky says:

"the decision not to attack the root causes of public health emergencies, the factors that encourage the spread of a disease is a very political one ....the medicalization of urban chaos, poverty and inequality and the technologization of prevention will have a very limited medical, technical effect in the most needed communities". (Bilofsky, 1992)

In first place the clinical prevention strategies, presupposes some effort on the part of the individual to access and utilize services. Access to services requires more than individual effort. There are many determinants to access to health care and many barrier access faced by individuals in these communities. (Giachello, 1985). It is important to highlight that the presence of services in this communities when provided in a competent way, and after removing as many barriers for their use as possible, make a difference in people's use of them. (MMWR, 1991). However, this clinical strategies together with the "intervention by stage of disease", approach prevention from the medical point of view only. Therefore, does not consider other social, economic and psychological problems as elements influencing health and does include the provision of services to overcome these other problems. The environmental prevention strategies, do not include the community in which people live as "environment". Does not discuss housing, contaminants, criminality and many other elements that influence negatively individual and community health. (Hahn, 1989).

#### Prevention II: A Behavioral Model of Prevention

There are many theories to explain compliance and preventive behavior (Becker, 1986; Becker, 1974; Kirscht, 1983, Bandura, 1977) One of the most accepted theoretical framework to explain preventive behaviors and compliance is the Health Belief Model (HBM) (Becker, 1974) which serve as the basis for the "behavioral prevention strategies". I have selected the HBM as a separate discussion not only because is the most comprehensive behavioral theory for preventive behavior but also because it has provided the theoretical framework for most of the AIDS Preventive strategies nationwide.

The HBM states that people prevent only under some circumstances. Under this model people need a minimal amount of knowledge about the condition, as well as, some interest, concern and motivation to health; she has to perceive herself as vulnerable and susceptible, must want to avoid the consequences of the condition, must perceive the preventive behavior as worthy and doable, most be convinced that by performing the behavior she will be able to prevent the condition, and that the cost of engaging in this behavior in terms of energy, money, time etc. do not exceed the benefits. These are summarized as the: beliefs in susceptibility, severity, efficacy and cost.

"an individual will seek to comply with preventive and rehabilitative health regimens as long as the relief from or prevention of disease is seen as more positive than the difficulties encountered and the effort required to attain prevention or cur. Of course, the individual also must feel threatened by the disease and must feel that he or she has some power to overcome it. ..In order for people to engage in preventive care people make decisions". (Becker, 1974)

Within the HBM there are modifying and enabling factors. These include among others: access to care, patient perception of the health system, social support, family support and complexity of the expected behavior. To

complete the model, there are the "cues to action" which consist of symptoms, media or educational presentations and personal contact with significant others that have or talk about the problem.

Although the HBM is very useful in helping understand some aspects of individual preventive behavior, it does not take into consideration the influence of past and present interaction of individuals with other people and the world in the generation of those beliefs. The HBM focus on individual preventive behavior, things that the individual does, for his own benefit. It does not consider behavior in group or community action as preventive behavior. Preventive behavior within this model is related to a perception of "health" as absence of "disease" rather that "the complete physical, mental and social well-being " as the World Health Organization defines health. This model does not consider the individual immerse in a community where there are many threats to health and life itself. Communities where problems are so many that individuals become masters in the prioritazation of problems in order to address the most urgent ones; where individuals make decisions at all times in a constant juggling with the few resources that they have to address the many needs of daily living. Communities with a variety of social, economical, psychological, political problems that affect health outcomes independently in some instances of individual behavior. Where preventive behavior is negatively impacted by issues beyond individual's beliefs. So it is not only to perceive oneself as vulnerable but what to do when one perceives oneself vulnerable to many things simultaneously. In the same order of ideas, how can one feel that a single behavior is going to keep one healthy when one is facing multiple threats. If several behaviors need to happen, how do people design multiple interventions to prevention. The HBM express that in order for a person to engage in a preventive behavior he or she has to feel some power over it. But what are the determinants of that power?. Power is not an imaginary feeling but rather a very real relationship than one establish with the outside world. Power has to do with knowledge, skills, resources, support as individual and as a community. Therefore when we talk about preventive behavior related to power it is not just up to the individual to "feel" powerful but it requires the inclusion of other elements to achieve this power. The HBM does not provide an answer to how to influence the elements of the preventive behavior to assist individuals and communities in acting toward prevention.

Preventive strategies, inspired by the marketing strategies and the belief system, use research findings constantly about attitudes, beliefs and behaviors of individuals so the professional intervention can be more effective; thus, expecting a change in the individual behavior without the development of the "awareness" or "consciousness" about such a process within his/her own reality. The expected change will be outside from its own context, disconnected from the daily reality and if there is a change it becomes very difficult to maintain overtime.

From the Social Learning theory (Bandura, 1977), for an individual to change he or she will need not only information and explanations on why to change but he/she needs to be provided with means and resources for that change. "Circumstances" in which problems occur are critical for people to exercise coping skills". We do not know what exactly was Bandura meaning with the words "circumstance or means or resources". However, for individuals at the level of HIV program planning and funding allocation and for many HIV educators, the only circumstances that need to change are in the "classroom", the only resources are condoms and bleach and the only means are the ones suggested by the educator based on the objectives he/she has to meet to get the grant renewed. The family and community environment are not included in preventive strategies when discussing "change of circumstances". Human and material resources are much needed in the lives of women in low income urban neighborhoods but this is not discussed.

In another aspect of his theory, Bandura also explains that people have to be convinced about their own capability to control their lives, people need to feel powerful in front of the situation, belief that they can control it. "When people lack a sense of self-efficacy, they do not manage situations effectively even though they know what to do. Self-esteem and perceived self-efficacy are critical for preventive behavior." (Bandura, 1987)

The Social Learning Theory is the one from which the concept of "self-efficacy" derives. The HBM includes this concept of "efficacy" as part of its principles. We prefer to discuss "self efficacy" together with "the cognitive functions in expectancy learning", two pivotal ideas in the Social Learning Theory of Albert Bandura. The "cognitive functions in expectancy learning", is a basic idea in Bandura's theory; this principle is extracted from the fact that individuals learn more from an event if they have information about what is going to happen, how it is going to happen and what are they going to do while the event is happening. Bandura expresses this principle by saying that "...awareness of the correlation among events will lead to learn from those events....individuals must be informed of the conditions in which it will happen in order to allow them to be prepared for the experience...". (Bandura, 1977)

The concept of preparation is based on the capability of humans to imagine situations provoking in themselves a sequence of reactions at the cognitive and emotional level, that enable them to deal with a given situation in an anticipated way. In Social learning theory this capability is called "self-arousal function" and it is viewed as fundamental in the facilitation of the learning process. This aspect of his theory has inspired the educational sessions based on learning answers to resist peer pressure or teaching women how to handle a discussion when they want a man to use a condom.

It has been shown that the "cognitive process" acts as an intermediary in the change of behavior when is triggered off by "cognitive events", the most interesting assumption here is that this cognitive events, in order to contribute in a positive way to the modification or creation of the desired behavior, must be induced by successful performances of the desired behavior by the target individual. Although, the author gives a crucial role to the success in the cognitive process and subsequently in the behavior change, this success is not enough to complete the process of behavior change but also is necessary the individual's conviction on the possibility of reaching the desired outcomes using those just-learned performances. As recapitulation, we will say that once the possibility of performing that behavior, he/she will go through the process of adquicision of knowledge and skills related to the specific task. After that, he/she will proof his/her knowledge and skills performing the required activity and if he/she succeeds, this individual will ask to himself/herself about the reliability of reaching the outcomes he/she is waiting for, as a result of the performance of a given behavior (outcomes expectation). In fact if behavior is going to change, at the end of this complex process the individual must feel that the performance of that specific behavior will be in such a successful way, that the outcomes will be feasible ("efficacy expectation").

In our opinion, self-efficacy constitutes a key component of the empowerment process. However, current preventive strategies provide the information, show people how to use condoms and clean paraphernalia and provide a list of possible answers to say "no" or to make your partner use condoms. The process of individual reflection is denied and people are expected to change without being influenced by the outside world and without influencing such a world. Bandura, in fact, does not talk about the relationship of individuals with their world. If a human characteristic is common in low income communities, that is the lack of control over many aspects of one's life. It is very improbable that as a result of growing up with economic limitations, having low educational attainment, having a partner that uses drugs or being single mother in an poor urban community a person will be able to develop a high level of self-efficacy without interacting and changing this outside reality.

To change means different things to different people. The "change" has to be defined by the people affected by the problem not by the "AIDS program educator". The educator may provide needed information for the preventive strategy but from there on, the educator should facilitate the process of empowerment and adquicision of this important feeling of self-efficacy. Maybe for a person with certain level of readiness and many basics in life solved, the perception of self-efficacy can be develop in a rapid manner. Unfortunately, life gets much more complicated in low income minority communities. It is even more unfortunate because in the learning and changing process, many people get the HIV infection. Maybe the process of change will start in or with the church, or through a women group, or through a job training program or by getting a better job and solving many survival problems that hold back people's potential change and advancement.

#### Prevention III: A Participatory Model of Prevention

As discussed in our paper about education with Hispanic families (Bracho-de-Carpio, 1989) and with Hispanic drug users (Carpio-Cedraro, 1990), participatory research and participatory education have emerged as an alternative approach for those who work at the community level. Participatory approaches constitute alternatives for practitioners that believe culturally specific interventions and community empowerment are two essential elements in the development of preventive health behavior in low-income Hispanic communities and therefore in AIDS prevention. (De la Cancela, 1989; Amaro, 1988; Marin, 1989; Freudenberg, 1989; Freire, 1970; Hall, Gillette & Tandom, 1982).

This approach is based on the combination "of community participation in decision making with methods of social investigation" (Hall, Gillette & Tandom, 1982). It involves the target population in the program from the needs assessment stage until the evaluation. It is based on the concept that the audience will learn by reflecting and acting on their reality while attempting to change it. This process of reflection and action will assist the individual in developing a critical consciousness (Freire, 1970; Minkler & Cox, 1980). By means of this approach, "both process and results can be of immediate and direct benefit to the community". (Hall, Gillette & Tandom, 1982.). The main role of the staff is merely as "facilitator" (Kassam & Mustafa, 1982).

Minkler and Cox, as well as, Bracho-de-Carpio, outline the Frierian concept of conscientization in health education practice as a transformative process of: a) reflecting upon aspects of their reality e.g. problems of poor health, housing, etc., b) looking behind these immediate problems to their root causes, c) examining the implications and consequences of these issues, and finally, d) developing a plan of action to deal with the problems collectively identified. (Minkler and Cox 1980; Bracho-de-Carpio, 1989; Carpio-Cedraro, 1990). Critical consciousness relates directly to self-efficacy and in turn empowerment. Simply stated, people who understand their relationship to the structures of power in society and believe they can change are more likely to make an effort to transcend the negative conditions in their lives.

In addition to the participatory approach, the Social Network approach is widely used in health education programs. It demonstrates that social factors play an important role in the production of disease and therefore, in the preservation of health. Social Network is defined as "that set of personal contacts through which the individual maintains his social identity and receives emotional support, material aid, services, information and new social contacts." This definition is not complete unless we add that "the characteristics of those linkages among persons are useful for understanding the behavior of the persons involved". The analysis of groups or individual social networks contribute to the design of education and prevention strategies (Cwikel, 1985; Israel, 1987)

## **Redefining Prevention Strategies**

The Wisconsin Prevention Network defines prevention as "a process which promotes health by empowering people with resources necessary to confront complex, stressful life conditions and by enabling individuals to lead personally satisfying, enriching lives." (Wisconsin Prevention Network, 1983)

This concept suggest two elements in the approach to prevention:

<sup>&</sup>quot; A deliberate and constructive process designed to promote growth of individuals toward their full human potential and the counteraction of harmful circumstances such as health and safety hazards, family stresses, job pressures, isolation, violence, economic hardship and inadequate housing, medical services or child care." [emphasis added] Wisconsin Network, 1983.

In this concept there is a process that promotes empowerment. This process belong to the individual, no one can empower another person but herself. However, assistance and facilitation in the empowerment process is critical for any prevention strategy. This is particularly necessary when working with social groups that have been largely oppressed such as women, minorities and people living in poverty areas. The process of empowerment is vital in a HIV prevention strategy working with low income Latinas.

The former Surgeon General, Dr. Novello referring to Latinas expressed

"...how can we expect women to take care of themselves if the system is unfriendly, the services are not amenable or are unavailable, the data on women is incomplete, the research is narrow and the findings are irrelevant to women's social needs and the state of their disease". [Novello, 1993]

In thinking on Latinas at risk in relation to "power" many questions arise. What type of power can you have when you use drugs, when you do not know your body and you do not know about STDs, cancer and many other health issues, when there are no drug treatment centers where you can go without losing your kids, when you cannot afford private drug treatment, when your self-esteem is low, when you feel alone, when you are economically dependent on your partner, when you have been sexually molested or abused, when you cannot establish a productive conversation about sexuality with your partner?

Many people agree that empowerment needs to happen. For some empowerment is to give information, for others is to tell people what to do and let them do it, for a sector is to teach them how to comply with the professionals or the system recommendation.

"Empowerment is a process not a product which has several levels. The first level is the realization that one deserves to have one's needs met and that one is capable of making decisions in order to fulfill one's needs. The second level is knowing when and how to use this newly discovered voice, and the third is using the voice and wielding power. Thus, there must be an evolution of personal empowerment first before political Empowerment can be developed. But, we should not overlook that the converse is also true. Powerlessness does not occur without structures of oppression" [Emphasis added](Mertzel, 1991 p. 5)

In addition, the empowerment process should be moved beyond the individual to include the family, social networks, the community and organizations. (Zinn, 1989). Theorists such as Julian Rappaport (Rappaport, 1987) call empowerment the promotion of "healthful living environments" as opposed to prevention; while Katz describes it similarly, as "expanding the communities healing resources". (Katz, 1984)

The development of critical consciousness is intertwined with the process of empowerment. Most of the empowerment literature and the literature on consciousness-raising relates specifically to the concept of critical consciousness developed by Paulo Freire and his Brazilian colleagues [Freire, 1970]. They proposed that by reflecting in their own reality they learn to critically examine their lives in relationship with the larger socio-economic-politic-health environment.

The empowerment perspective emphasizes the process of increasing the power of individuals that facilitate behavior change, rather than simply providing information and resources. Power is the capacity to influence, for one's own benefit, the forces that affect one's life space (Salomon, 1976). Empowering individuals alone would be nearly impossible if we neglected their environments which can influence their empowerment.

If we want to apply this approach to health prevention targeting women, HIV preventive strategies should be more than passing out pamphlets, bleach and condoms and instructing people how to use risk reduction methods. It has to involve talking about their bodies, their health, their sexuality, their children's and family's health, their dreams, their souls and minds. Their past and present. It is also reflecting about racial and sexual oppression. This approach has to include skill building to deal with relevant situations, support and resources throughout the process. Much of this support and resources can be found in the process itself. Moreover, this approach works in facilitating the development of critical consciousness by developing sessions in which women can, for example: a.) reflect upon their reality (drug user partner, poor housing, etc.), b.) look behind these immediate problems for



root causes, c) examine the implications and consequences of these issues, and d) developing a plan of action t deal with the problem. (Zinn, 1989; Minkler & Cox, 1980, Freire, 1970; Bracho-de-Carpio, 1990; Carpio-Cedraro, 1991) As part of this whole process, these women must be connected with agencies that can assist them to improve their overall living conditions. HIV and AIDS prevention can only be a part of the list of priorities of these women if and only if the overall lives of these women become a priority for organizations working in HIV prevention. This approach to practice has also to consider the specific cultural characteristics of the Latina group it is targeting since Latinas are not all the same, come from different geographies, religions, backgrounds etc.

Action is the spirit of prevention because it is by acting upon one's reality that one can change it. Behavior modification, community change and any other change has to be achieved through action at the individual, family or community level. However, as Freire says, "action without reflection is mere activism and reflection without action is mere verbalism" (Freire, 1970). As individuals interested in facilitating a change in those communities that could assist Latinos in HIV Prevention, we need to explore what are the determinants of the "action" and how do we engage in a process of reflection with people living in these communities. Each individual and each community must have the opportunity to become part of the dialogue of HIV prevention. The word of prevention needs to be spoken by the community. Individuals have to be able to separate themselves from their reality through sessions of problem posing and investigate their own reality. They need to discuss their beliefs and attitudes regarding HIV within the context of their neighborhoods and families. They have to decide what to change and how. Human and material resources should be made available to them to facilitate this strategy. Each of them have to design and act in their individual and community strategies for HIV Prevention. Programs on HIV Prevention should consider this premises and facilitate this process.

This does not mean that we can cannot design preventive strategies within a poverty situation. It does not mean either that we have to stop talking about condoms. It means simply that for an strategy to work it has to include those elements that are creating a situation of risk for the people. Those elements, have to be identified by the people in conjunction with the educators. Programs on HIV prevention should consider this premises and facilitate this process. But for programs on HIV prevention to act in a real "competent" way, they must assist individuals in the resolution of their problems and in regaining the power and control that is critical to be able to change community situations as well as individual behavior.

During the AIDS epidemic, the most innovative, creative and relevant programs have come from community based groups and organizations. This is true for Whites or people of color, gays, lesbians and addicts or sexual partners, children, adolescent and adults.

White gays in San Francisco went beyond the public health recommendation of "avoiding sex or use condom" and discussed with people other alternatives such as reduction of number of partners and safer sex practices. For many of this White gays themselves came up with ways of modifying their sexual practices to avoid the HIV infection. It is important to highlight that those groups were behavior modification was demonstrated were white collar middle and upper class White Gays. This fact is important for future comparison with intervention in poor communities and is not intended to take the merit away from these successful stories. The value of the interventions of the Gay community remains across the nation. They got organized, challenged the system's indifference, poured money into what they thought should be the strategies, got into streets, bars, universities to outreach "their community" and have continuously advocated for resources, research and changes in policies.

In another front, people working with minorities have taken the streets of their communities with commitment and creativity. Reaching "their people" in markets, houses, Laundromats, bars, schools and so on ( De la Cancela, 1989, Health PAC, 1988; Bracho-de-Carpio, 1990; Carpio-Cedraro, 1991). A great number of Community Based Organizations were overwhelmed with the many needs of their communities even before the AIDS epidemic and now are even more. Many are in the situation of giving the message on AIDS prevention, giving information, providing everything they can and feeling that the problem is very big for such a limited intervention. Rev. Carl Bean was quoted saying "We're dealing with mothers who have to grease the crib legs and place them in cans of oil to keep the rats off" (Health PAC, 1988).

Women have been targeted with few but special efforts by community organization. The Latina AIDS Action Plan and Resource guide, (HDI 1990) contain some examples of HIV programs targeted to Latina and other women. One of those programs deserves special attention, The Women and AIDS Resource Network. This program recognizes the impact of the epidemic in economically disadvantaged women and works in advocacy, public policy, education. Their funding is private and as many of this programs, the demand is greater than what they can offer.

People working with intravenous drug users have been participating in a variety of innovative programs such as the "needle exchange program" in New York. ADAPT is one of those community organization recognized as a leader in going beyond what public health recommends in order to be more effective with people using intravenous drugs. In 1980, ADAPT initiated its services for addicts seeking treatment. In 1985 it started going into shooting galleries to reach and teach intravenous drug users about AIDS and the need of not sharing or cleaning needles. "In 1988 ADAPT's Board of Directors voted unanimously to add needle exchange to its education efforts, thereby risking its tax-exempt status and public funding." After many threats ADAPT initiative forced the City of New York to look more into the issue of needle exchange which became legal in November, 1988. (Sorge, 1990)

Educational strategies have been fed with innovation as well. There has been an effort in some programs to frame a message in a way that can invite people to reflect in their own situation and act in a way they consider appropriate with their values and resources. From story telling, to involve parents in educating their kids (Bracho-de-Carpio, 1990), to the use of poems, art, participatory theater and many others. There is even a pioneer effort on the part of a group of researchers to demonstrate the effectiveness of participatory education in assisting with the creation and development of HIV preventive strategies (Magaña, 1993)

#### Highlights of a Comprehensive Intervention

The efforts are ongoing, the creativity is there, the will to challenge the recommendations that are not appropriate is there, the community based organizations are getting progressively more and more involved and the people in the community have more information about AIDS. Then what is the problem?

The problem is that the number of AIDS cases in minority communities continue to increase, cases among females are in the rise and just in the Bronx, AIDS pediatric cases doubled in two years. The problem is that as the presence of vaccines did not stop many measles epidemics in poor neighborhoods, and TB tests and treatment did not stop the high prevalence of TB in poor neighborhoods, isolated local efforts even in the hands of committed competent workers and leaders can not have the needed impact in poor communities where a vast majority of Latina women AIDS cases are concentrated.

The problem is that we need a comprehensive preventive strategy where we can use many of these innovations accompanied by more resources that can allow these community based organizations to address the sociodemographics risks (education, income, lack of drug treatment services, etc) of this epidemic and not only the direct behavioral (sharing needles) or biological risk (infected blood).

A comprehensive prevention strategy will be more effective in the long run because many other disparities will be affected when individual and community power, decision making ability and poverty are addressed in the plan. A real cultural competent HIV prevention program for Latino women in poor urban settings only can be done through a comprehensive prevention strategy. A cultural competent program will benefit if the educators speak

Spanish, know the culture and are also Latina women, but an Ethnic Competent intervention knows, appreciate and can utilize the culture of a group in assisting with the resolution of a human problem. This is done in a way that is congruent with the behavior and expectations that members of a distinctive culture recognize as appropriate among themselves. (Green, 1981)

A competent comprehensive HIV Prevention strategy for Latina women in poor urban settings should include the following:

1.- An educational component where people are not recipients of information but active participants of the educational process. Where this participants generate themes that are important to their health, survival and safety and these themes are main core of the activities where AIDS information is going to be immerse. An educational approach that respect the fact that people in those neglected communities are MASTERS of survival and daily decision making. Experts in making priorities and planning on a daily basis. Artists of the negotiation to get today's food or this month's rent. Courage, strength, sacrifice, and patience characterize a large sector of individuals in this community who in spite of their own needs take time and resources to work in powerful networks of support for each other. We are dealing in this communities with individuals of great initiative that have to take time, sit, and think in how to use those same strengths and skills for changing other set of situations related with their community, their behavior, their health and HIV.

The information about HIV needs to be given (or in many programs continue to be given) in a simple, sensitive, relevant ,appropriate way. Simple words, sensitive to the culture, the gender, their reality, relevant to other needs and particular situations e.g. pregnancy, fear for children safety, economic need, addiction, violence, illiteracy or low level of general education; as well as, appropriate, e.g. not expecting to do condom demonstrations in the church and criticizing the church if they do no accept.

Skill building is another key element of the education process. Skills to use condoms, to resist situations, to find information, to take charge of your community, to press your leaders, to participate and so on. Skill building within a process of empowerment "whereby persons who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skill in the exercise of interpersonal influence and the performance of valued social roles". (Salomon, 1976)

Adult education, literacy projects and health education programs should be implemented to improve the educational level of many of these women in this neighborhoods. e.g. UHFN # 7 in the Bronx, one with a very high number of AIDS cases, high concentration of Latino population and female-headed house holders (Table 1), has 30% people with less than 9th grade education. In addition women need to learn about their bodies and their health to be able to understand better the HIV information

2.- Programs of economic development should by brought to these urban poor Latino neighborhoods and assure that women get the training to get decent jobs, better pay and health coverage

3.- Access to Services need to improve. Medical services need to be available in these areas including those directed to detect diseases at early stages. Drug treatment programs specific for Latina women should be implemented and or expanded. Barriers such as cost, transportation, child care, language and others should be addressed.

4.- Environmental problems should be confronted. Housing, toxic substances in the environment, garbage disposal and the likely.

5.- Personal Safety. Crime and violence should be part of the strategy in places like New York where homicides is among the first causes of death among women 15 to 44 years old. Domestic Violence should be addressed with resources, education and law enforcement. Reduction of crime in the streets need to be a priority.

6.- Mental Health and Recreation. Programs to address issues related with self-esteem, traumas and depression are of critical importance. In addition, alternatives to use the time in a healthy constructive manner is a must.

<u>The role of CBOs</u>. Community Based organizations need to cooperate in this strategy and is not realistic to expect all this intervention from one single agency. Staff need to be recruited and trained to become competent in the conduction of his/her portion of the strategy. Human and financial resources have to be made available for these CBOs.

<u>The role of the Federal Government</u>. The Department of Health and Human Services need to redefine the preventive strategy and improve cooperation with other federal agencies. i.e. for years now, The Centers for Disease Control have supported the development of AIDS programs at the community level. It is time for CDC to redefine the prevention strategy. We cannot repeat more of the same while women continue dying in inner city. The Request for proposals must reflect the invitation for a more comprehensive HIV prevention strategy.

CDC have requested lately more cooperation among agencies to avoid duplication of services. It is time that Latinos demand that CDC cooperates with other Federal Agencies to include education, economic development, mental health services and other elements in the AIDS Prevention strategies for poor minority communities.

The role of the Latino Leadership. The leaders of the Latino community have to include this strategy is their agendas. i.e. The NCLR have launched the Anti-poverty agenda which hopefully will have effect at the policy level. Organizations such as the NCLR, COSSMHO and others, should take the leadership to channel private funding to implement pilot projects on HIV comprehensive prevention strategies. At the local level all people interested must act as leaders in changing what is not working and advocating for more effective programs.

#### Implications for Research.

Researchers interested in Latino and women issues have numerous roles to reduce the impact of the HIV epidemic among Latina Women. Among others researchers should:

a.- Work with other sectors of the community to design and evaluate a comprehensive HIV preventive strategy.

b.- Involve individuals from the community, lay individuals, in participatory research projects and evaluation with participants. Design with these individual simple tools to collect information and investigate problems in the community, simple mechanisms to assess the success of failure of an intervention.

c.- Involve lay individuals in interpretation of findings of qualitative and quantitative research, inviting them in this way to explain their behaviors and their community issues.

d.- Release research results in a simple way to those professionals working with community based organizations that could transform those results in proposals to request funding for programs. Assist those professionals in grant writing.

e.- Investigate in depth the role of socio-demographic risks in behavior change.

f.- Investigate the role of those so called "co-factors" (nutrition, STDs, pregnancy, drug use, stress and others) in the progression of the HIV infection toward AIDS.

g.- Investigate the drug abuse and sexual behavior of Latino women.

h.- Advocate for more human and financial resources for research with Latinos and in particular Latina Women.

i.- Assist Latino Organizations in investigating situations that should be highlighted in order to develop position papers that could impact policy making as it relates to HIV and Latinos.

## CONCLUSION

After 12 years into the HIV epidemic the AIDS cases continue to increase in minority poor communities. Latina women living in urban poor neighborhoods have been dramatically affected and confront the most serious risk of all Latinas. Latino families living in these neighborhoods of high prevalence of AIDS cases confront a much higher risk than other families in neighborhoods of low AIDS prevalence. The official institutions and the Latino professional community cannot continue endorsing a limited view of what a HIV preventive strategy should be after witnessing 12 years of neglect and failure of traditional strategies in these communities. Successful approaches with individuals of different gender, class and /or culture cannot be transferred to communities with high level of socio-demographic complexities and disadvantages. A change in how preventive programs are conceived and developed is urgent. A comprehensive approach that view the individual in his/her wholeness is critical. While we continue our discussion many more Latinas are getting infected with HIV and dying of AIDS.

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