WORKGROUPS FOR LATINO AIDS ACTION AGENDA PROCESS

Set out below are the proposed Workgroups for the Latino AIDS Action Agenda process. The points raised are simply an effort to promote discussion and interchange and should not be taken as the only issues or how the issues must be framed. Our hope is to stimulate discussion and collaboration for the Action Agenda we will develop over the summer for the September meeting in Washington DC. The listing contains a mixture of issues, questions, statements of fact and calls for legislative reform or agency funding. At some point the Workgroups will need to separate the categories in a more coherent way.

PREVENTION- Reporting of new HIV infections for Latinos by the CDC limited to 33 states that have had name based reporting for a specified period, new HIV cases among Latinos have averaged 18% between 2001 and 2005. There has been little variation in the number of new infections in the last five years for which there is data. With the exception that women account for a significant percentage of new cases, a changing trend among minority groups. This growing representation increases the emphasis in gender and culturally specific interventions. As well as, in the southern states there is a steady increase in prevalence among Latinos as a percentage of the statewide totals. [1]Fifty-seven percent of the Latinos reporting new HIV infections in 2004 went on to develop AIDS in less than 12 months. Latinos make up 14% of the United States population. The starting point for this work group is that new infections among Latinos have not changed over five most recent years for which any data is available. While there may be increases or decreases in infections among different risk transmission groups and in different areas of the country (Latinos in the Deep South are only an increasing epidemic) the national picture remains disturbingly static and disproportionate to number of Latinos in the general population.

- We need a profound commitment to lower the rate of new infections through funding initiatives that target Latinos and capacity building assistance provided by organizations with real roots and core competencies in the Latino community.
- Evidence Based Interventions (EBIs) adopted by the CDC have largely been tested on populations other than Latinos. Couples, Safe, Voices/Voces and MIP have been tested out with study populations greater than 50% Latino. There are no interventions where the study populations were 50% or more Latino for MSM. Naturally there are other interventions for all target populations that can be adapted for Latinos but we do not know if they will be effective with unacculturated and acculturated Latinos. There should be more interventions for Latino IVDU men and women, Latinas, Latino men who have sex with men and Latino young people.
- There are limited Spanish language materials developed by the CDC for HIV prevention on the www.cdcnpin.gov website except for VIH y SIDA: ¿Esta Usted en Peligro? [HIV and AIDS: Are You at Risk?] There are approximately 30 documents on the website with one or two page fact sheets in Spanish on a wide variety of topics prepared by the University of California at San Francisco.

[1] For example, the New Orleans SMA has shown an increase from 4% of overall prevalence up through 2005 to 8% of new reported infections in 2006.

- Few of the trainings on any the behavioral interventions are available in Spanish for target audiences that are Spanish speaking.
- We need social marketing tools available from the CDC that local groups can use in different testing, prevention, outreach or community education events that assist in addressing the stigma that surrounds AIDS.
- Federal support for needle exchange is especially critical for the Latino community. Latinos infected through use of HIV contaminated syringes accounts for a significant number of the AIDS cases in the Northeast and in Puerto Rico. Some states and localities have adopted limited needle exchange programs coupled with referral to services and drug treatment. Some states have legalized the purchases of a specific number of syringes over the counter without a prescription. With federal support these programs could even more dramatically reduce these infections.

ACCESS TO CARE – The death rate for Latinos with HIV/AIDS averaged about 15% of all persons dying from the disease over the period from 2001 to 2005. 23.3% of all persons living with AIDS in the United States and territories in 2005 are Latino. 20% of the AIDS diagnoses in 2005 were among Latinos. Set out below are some key policy and funding issues that contribute to poor health and death for Latinos living with AIDS.

- With increasing restrictions on Latino undocumented immigrants accessing care except on an emergency basis, more Latinos are showing up with an AIDS defining condition at the same time they are learning their HIV status. Some of these "late arrivals" may be persons who felt they were infected but delayed testing because of stigma and immigration concerns. In some states the percentage of Latinos learning their status at this late disease state is as much as 48%. What can be done to change this paradigm and increase testing and access to care sooner?
- There is a shortage of Spanish language and culturally responsive medical care especially in areas where there are moderate to low numbers of Latinos like the South and Midwest. .
- Treatment education in Spanish enables Spanish language dominant Latinos to become participants in their health care decisions. Many states do not support such education as part of their Ryan White granting process. Such information is essential.
- Puerto Rico is in crisis mode in delivering health care services under Title II. Patients and official documents an unreliable and inconsistent access to medical care. HRSA needs to commission an audit on patient care in Puerto Rico and urge the San Juan EMA and Commonwealth Health Departments to contract with third party vendors with experience to handle the funds. A congressional oversight hearing is essential to call HRSA to account, to call the governmental entities to account and hear the advocates concerns
- The current situation with ADAP is that states can decide their own access rules. While no state to this point has specifically excluded undocumented immigrants, to some immigration advocates it is only a matter of time. There are many, many obstacles to care for the undocumented aside from an outright prohibition. Ryan White must be changed to specifically allow ADAP coverage for Latino immigrants regardless of documentation.
- Early Treatment for HIV Act (ETHA) and Medicaid must be amended to include all immigrants with HIV/AIDS. Currently, undocumented immigrants with AIDS can only access hospital care for an AIDS related illness on an emergency basis. This is because immigrants without documentation are excluded from Medicaid and, if it passes, ETHA.

This exclusion is bad health and poor human rights policy. The change in the Medicaid law to enable pregnant women to get prenatal care without residency status is a step in this direction.

- In states with larger numbers of Latinos infected through intravenous drug use, most of the available data indicates that most of the Latinos dying of AIDS are from this segment population. With appropriate consent, there needs to be a review of a representative sample of the cases to determine intervention points that were missed in enabling such patients to remain healthy for longer periods.
- There must be special outreach to migrant Latinos at risk for infection and who are infected move from state to state. A comprehensive care system to enable such cases to be tracked with confidentiality guaranteed will raise the likelihood that such migrants will remain connected to care.

IMMIGRATION – Being an immigrant with HIV/AIDS is probably the most precarious healthcare position facing any person with HIV/AIDS today. There is enormous stigma facing immigrant Latinos with this disease that makes accessing and sustaining healthcare a real barrier. Some health providers refuse to even serve the undocumented. Undocumented immigrants with AIDS connected to ADAP live with the constant fear of being deported thus severing links with medical care and other services.

- President Bush announced on World AIDS Day this past year that he would order the Department of Homeland Security to implement a "categorical waiver" for HIV-positive non-citizens seeking short-term visits. The regulations for such a change have not been forthcoming. Such a change would do nothing to stabilize the lives of immigrants with HIV/AIDS who will remain in effect “outside the law” and may in fact do more to target this population depending on how the initiative is implemented.
- For many immigrants the enforcement of the legal bar against naturalization for those who are HIV infected presents a risk of being sent back to a country with different medical resources. While the impact of such a fear has not been quantified, it is commonsense that it would lead to delayed access to medical care and low levels of response to HIV prevention services.
- The anti-immigrant waive is making it more difficult for Latinos immigrants to obtain asylum based on sexual orientation or HIV status. And it is pushing them further and further away from health services in general so that they are less and less likely to get timely testing and early intervention.
- For immigrants who are becoming legalized through normal channels, the HIV waiver provision of the immigration law is being enforced more narrowly extended. This waiver is the only way that an immigrant can normalize their status outside of marriage and asylum.
- Immigration reform proposals must include a road to legalization for the HIV infected undocumented persons.

EPIDEMIOLOGY – Access to data concerning Latinos and AIDS from the CDC is extremely limited. Accurate data is important for funding and planning purposes. We need state data to be available by HIV risk classification, race/ethnicity, age and gender. To require that advocates and policy makers gather such data from each state is ill-advised given that many states do not report the data publicly or such data would lack the statistical “leveling” role CDC has in subjecting data to a common set of criteria. Further many states and territories underreport Latinos with HIV/AIDS and localities are in need of technical assistance to improve the quality

of the data received by the CDC and to address the acknowledged problem of undercounting Latinos. Furthermore, Latinos present culturally specific risk behaviors and outcomes, none of these are recognized by CDC among contributing factors to HIV risk, therefore ignored through data gathering methods, analyses and recognition of preventive intervention. This information was profiled through a short period in the proposed PEMS systems and shortly dropped without explanation.

FUNDING AND RESOURCES – There has never been a single RFP from the CDC that has been targeted to Latinos while there have been at least dozens targeting exclusively African Americans. Obviously given the pandemic sweeping Black communities there should be even more funding available for Black community. The problem, however, is the failure of the CDC to focus in on the Latino community for specific problems in particular populations. With 23% of the population living with AIDS, the risk of transmission to sexual partners is real.

- We need CDC directly funded RFPs focusing on the two groups where we are seeing the fastest growth of new infections – Latino men who have sex with men and Latinas. First, while no evidence based interventions have been "adopted" for Latino MSMs which used study populations of 50% or more Latinos, existing interventions could be adapted. The need is critical among Latino gay and bisexual men who face "prevention fatigue" and a sexual ecology in their communities that leads to higher levels of HIV exposure. The southern immigrant population is not experiencing prevention fatigue but rather lack of any prevention interventions and education. They haven't been around for the previous ones, so they aren't fatigued, but ignorant. Second, Latinas in the Northeast and Puerto Rico are experiencing rapid rises in new infections, at levels not seen elsewhere in the country. Often the source of infection is men who were or are intravenous drug users or whom are behaviorally bisexual. Often these are women for whom the notion of "risk group" is itself a negative attribute which they reject.
- In 2008 the CDC should fund providers for Capacity Building Assistance that have a real track record of involvement with the Latino community and Latino community leadership. Capacity building is not merely a matter of hiring a group of Latinos and setting up shop. There needs to be community roots in place and a clear demonstration of cultural competence.
- The CDC in partnership with NIH needs to dramatically increase funding for research described below that will be critical in responding the HIV epidemic in the Latino community.

RESEARCH – Research of relevance to Latinos and HIV/AIDS is needed to effectively promote prevention and access to care. Set out below is a sampling of some topics that we believe should be considered. The CDC should convene a group of Latino behavioral scientists to assist it in planning research directions for the Latino community.

- There is incredibly little literature on how to mitigate stigma that impacts accessing prevention and care in the Latino community. While there is growing data on the experience of the stigmatized, research has yielded few tools that can be put to use to address the stigma. While social marketing is the most common approach to this mitigation, there is little study on the impact of such marketing. Are there interventions other than social marketing?
- We do not truly understand why so many Latinos engage in risk behavior. We have not been successful in producing research that contextualizes the risk.

- Everyone talks about the ethnic differences between different Latinos populations but there is little research on how these differences impact on risk taking. Different Latino groups may have different food preferences and words for objects but how does the background impact on the behavior that leads to HIV infection?
- In Europe, Central Asia and the former Soviet Union there has been growing research on the impact of migration on the spread of HIV. How do mobile Latino populations in the United States impact on HIV exposure? Anecdotes abound of sexual practices where sex workers are supplied by growers or other employers.
- Greater research is needed on the unique situation facing rural Latino workers and families, where accessing HIV information or care can be such stigmatizing interactions. What are the vectors of transmission for migrants (and even suburban migrant populations) and HIV infection?
- Acculturation is almost never taken into account when studying Latinos and AIDS yet most would agree it is a significant factor. But what does it mean? How do different stages of acculturation impact on risk taking and health care decisions?
- The CDC and NIH need to set aside more funding for emerging scholars who can be introduced to the large needs for research in the Latino community.

LEADERSHIP – Changes and adoption of policies or strategies seldom occur without the presence of representatives of the targeted population in decision-making positions. It is clear that Latino representation in federal upper management positions is clearly under represented. Project officers often lack the sensitivity to understand emerging trends, values, culture and linguistic significance of programmatic activities in Latino projects, resulting in a continued struggle to prove the evidence or validity of an intervention. There has been limited leadership from the CDC, HRSA, SAMHSA or the Office of the Secretary of HHS to raise public awareness of the epidemic in Latino communities. The Latino community is often treated like an afterthought in the services and efforts of these agencies. Even though we have more than our proportion of the population that is HIV infected (in some areas the rates of infection far exceed whites), the CDC does not reach out to our diverse business community, media or other organizations (or such outreach is invisible to us). There have been no special publications, webcasts, or anything similar to raise public awareness.