Community Needs and the Future of Service Delivery for Latino MSM Living with HIV in the San Francisco EMA

SUMMARY REPORT

BACKGROUND AND METHODOLOGY

This needs assessment is a united effort by the Spanish-speaking Immigrant community, the Latino community at large, the Latino HIV Service providers and the SF HIV Health Services Planning Council. The content of this document offers context and factors to consider regarding the needs of Latino MSM living with HIV.

According to the most recent HIV Epidemiological Report "*Status of the HIV/AIDS Epidemic in San Francisco*", Latino/a PLWHA make up 17% of San Francisco's PLWHA population (N=15,849). This report also noted: Latino/a make up 15% of living HIV cases with history of jail (N=1,039); 12% were co-infected Hepatitis C; and an estimated 12% were not receiving care. In regards to San Mateo and Marin, the Epi Report noted that 25% of PLWHA are Latino/a in San Mateo and 15.6% in Marin.

According to the most recent ARIES Report "*An Analysis of San Francisco Eligible Metropolitan Area Ryan White Part A & B For the 2011-2012 Contract Period*", Latino/a PLWH make up 21% of San Francisco's PLWH population, 20.5% in Marin, and 39.3% in San Mateo. This report also noted that Latino/a make up 22.8% of Male PLWH, 22.2% of Female PLWH, and 31.9% of Transgender PLWH; 20.1% of New Clients (N=890); 15.5% of Clients Who Have Died (N=70); 61.8% lived at or below the Poverty Line; 65.3% of Latino/a HIV Exposure was from MSM contact; 34.3% had a "CDC-Defined AIDS" and 22.9% had a diagnosis of "Disabling AIDS"; 73.4% were currently on HAART; 51.5% has a Viral Load of less than 50 and 27.4% were between 50-399.

The Latino population is currently considered a targeted demographic within the San Francisco EMA HIV Health Services Planning Council's "Special Populations" Definition:

Special Populations

The Council recognizes special populations which have unique or disproportionate barriers to care. They need additional or unique services, or require a special level of expertise to maintain them in care. The following populations were identified, based on the data that has been presented to the Council:

• Communities with linguistic or cultural barriers to care. The Council includes undocumented individuals in this category, as well as monolingual Spanish speakers.

In 2011, the Consumer & Minority Affairs (CMA) Committee of the San Francisco EMA HIV Health Services Planning Council (HHSPC) discussed potential target populations for the 2012-2013 Needs Assessment. Factors for choosing a target population included target populations noted within the HHSPC's 2009-2013 Three-Year Comprehensive Plan, HIV disease burden within targeted populations, and amount of time since a targeted population has received a needs assessment. After deliberating on the topic over the course of two meetings, CMA determined that the 2012-2013 HHSPC Needs Assessment would target the Latino MSM population.

In March 2012, HHSPC Staff initiated the formation of the Latino MSM Needs Assessment Work Group (LMNA Work Group) by inviting a range of stakeholders, including providers and consumers of services associated with the following agencies:

- Clinica Esperanza, Mission Neighborhood Health Center
- Clinica Salud, San Francisco General Hospital Ward 86
- Edison Clinic, San Mateo DPH Community Clinic
- "El Ambiente", Aguilas
- Instituto Familiar de la Raza
- Marin AIDS Project
- San Francisco EMA HIV Health Services Planning Council

At the first meeting, the group decided to meet on a monthly basis, to operate by consensus, and to avoid the use of formal parliamentary procedure in order to better encourage participation by all of its members.

At its second meeting, the LMNA Work Group elected its Co-Chairs: Jorge Zepeda, San Francisco AIDS Foundation and Enrique Asis, HHSPC Staff. Discussion during that meeting and subsequent meetings determined that the LMNA Work Group would implement a series of focus groups: six to take place in San Francisco in the latter half of 2012 and one each in Marin and San Mateo in the first quarter of 2013.

The group also determined:

- Focus groups would take place in English and in Spanish
- Focus groups would take place in HIV service locations familiar to clients in order to better outreach to and recruit participants. Outreach also took place during community meetings for the Latino HIV+ positive;
- Structure of focus groups (described below);
- Members of the LMNA Work Group will also function as facilitators and note-takers for the focus groups. Attendance at a facilitator training (described below) was considered mandatory for all potential focus group facilitators;
- Attendance at focus groups would be incentivized (through \$30 gift certificates to Safeway and Walgreen's); lunch or dinner would also be provided.

Focus Group Structure

- 1) General facilitation and attendant interaction guidelines
- 2) Anonymous survey/questionnaire
- 3) Explanation of role and functions of HHSPC
- 4) Facilitated Discussion regarding utilization of services, access to services, barriers to care, and challenges/limitations in HIV service utilization
- 5) Description of Ryan White Part A HIV service categories
- 6) Service prioritization "dot exercise"
- 7) Participant evaluation of focus group session

Additionally, the LMNA Work Group created facilitator "scripts" in both English and Spanish to support facilitators during focus groups.

The CMA Committee reviewed and approved the Latino MSM Needs Assessment recruitment plan, focus group structure, facilitator scripts, and focus group dates and locations.

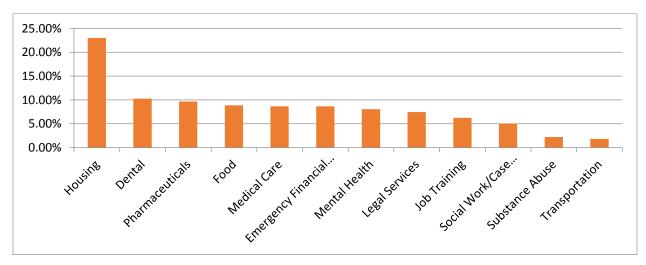
Facilitator & Note-Taker Training

As noted above, the LMNA Work Group determined that attendance at two-hour was mandatory for all facilitators and note-takers. Council Staff implemented this training, which included an overview of information collection methodology, demographics data input, HRSA directives regarding participant confidentiality, an overview of the "dot exercise", and a review of relevant HRSA service categories.

- > 66 attendees participated in the six focus groups taking place in San Francisco
- > 9 attendees participated in the San Mateo focus group
- 9 attendees participated in the Marin focus group
- > 84 questionnaires were completed by focus group participants

FINDINGS

Prioritization Exercise Results



1. Immigration, Poverty & Language Barriers

Immigration

The HIV+ Latino MSM population in the SF EMA includes many Spanish-speaking immigrants. Only a small portion of this group were born in the US, with a majority immigrating from Mexico and other Latin American countries.

- Only 9.6% of the Latino MSM needs assessment participants were born in the US.
- Over 90% of needs assessment participants were immigrants.
- The majority (50.6%) of immigrants that participated in the focus groups are from Mexico.
- The next largest groups were immigrants from El Salvador (10%), Guatemala (7.2%), and other Latin American countries including Nicaragua, Peru & Cuba.
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- These neighboring countries (Mexico, Guatemala, & El Salvador) have a history of transient immigration
- Participants noted challenges with integrating within American culture and finding their sense of belonging.

Poverty

- Comparing the data with other specific groups in previous Needs Assessments (aging, transgender), the majority of Latino MSM who participated in the needs assessment demonstrate the lowest level of poverty.
- Close to 90% of participants report having either 'only enough money to survive' or 'not enough money to live on'.
- Over 73% of participants reported an annual income of less than \$10,000 (for reference: Ryan White eligibility defines low income as an annual income equal to or less than 400% of the Federal Poverty Level, which for 2013 is \$45,960 for one person)

Native Spanish-speaking immigrants

- Less than a quarter of participants reported being fluent in English, with nearly 15% reporting that they didn't understand or speak English
- Less than 10% of participants were born in the US.

A New Dimension of Severe Need

The focus group participants are a "special population" that encounter cumulative barriers on several different levels: severe poverty, linguistic challenges, cultural difference, and issues around legal status barriers. This creates a series of systematic and structural barriers and challenges.

2. <u>Homelessness & Financial Hardship</u>

Homelessness

- More than 40% of participants reported having been homeless or marginally housed at some point in the US.
- Of this group, over 28% reported being homeless or marginally housed within the last year.
- Housing was the number one priority in each focus group.

Financial Hardship

- Over 45% of participants reported relying on Disability (26.2%) or General Assistance (19%) as their primary source of income.
- More than 40% reported not having enough money to live on.
- Less than a quarter of participants have a steady employment situation.
- More than 50% of participants receive between 0 and \$500/month including all of their sources of income.

3. The Immigrant Experience in the SF EMA System of Care

- Each focus group included participants who expressed concerns about the final implementation of the Affordable Care Act in that it does not cover undocumented residents.
- Service Points of Entry and Eligibility were considered confusing or unknown for some focus group participants.
- Focus group participants were often reticent to discuss barriers and challenges to care instead expressing feelings of gratitude, appreciation, and even guilt at the services they receive.
- Many focus group participants from Marin and San Mateo Counties were unaware of legal and support services for which they are eligible.
- The challenges and language limitations of this immigrant group plus HIV stigma aggravate an extreme situation of cultural and social isolation.

4. Non-Medical Service Needs

- Housing was the number one priority in the service categories prioritization exercise within each of the 8 focus groups.
- Housing, Dental, Medications and Food are the four top priorities for all focus groups during the aggregated prioritization exercise.
- The prioritization exercise, as well as consistent comments within all focus groups, indicate a clear need for non-medical support services.
- All data about services priorities illustrates the importance of evaluating the San Francisco Model of Care and its outcomes as a continuum, with significant strides to be made towards addressing the social and economic determinants of health – including poverty, homelessness, and the unique linguistic and cultural challenges faced by Latino immigrants in the US.

5. <u>A Unique Cascade</u>

- Overall, Latino MSM surveyed in this needs assessment demonstrated stronger health outcomes than those reported both locally and on a national level within the Gardner Cascade. For example, regarding viral suppression: 95% of focus group participants self-reported an undetected viral load vs. 50% (San Francisco overall) vs. 19% (national).
- 100% of participants in Latino MSM focus groups self-reported taking HIV medication.
- Many of the focus group participants are long term survivors with high levels of adherence and a long history of medical treatment.
- Over 95% of participants reported a great success of having achieved an undetectable viral load.
- While the high rates of viral suppression and treatment adherence indicate positive health outcomes, these outcomes exist within a setting of severe indigence, indicating a set of clearly unmet needs.

QUOTES FROM PARTICIPANTS

"Se convierte en algo facil cumplir con tu tratamiento (tomar los medicamentos) cuando tienes casa y comida, por lo que no puedo decir que es mas importante."

It becomes easy to comply with your treatment (take your medications) when you have a home and food, because I can't say what is more important.

"La dificultad de los programas de vivienda, son complejos de por si y para los latinos se convierten de una pesadilla tormentosa."

The difficulty of the housing programs are complex and for Latinos they become a turbulent nightmare.

"Las listas de espera son tan largas... Hay dos tipos de clientes: los que entraron en el Sistema cuando habia casas...y los que en los ultimos anios nos pusieron en listas de espera."

The wait lists are so long... there are two types of clients: those that entered the system when there were houses and those in the last couple years that have to wait on the wait list.

"Creia que exageraban cuando escuchaba que se quejaban de los dentistas...hasta que me toco a mi"

I thought that they were exaggerating when I heard them complain about the dentists.... Until they got their hands on me.

"Tener donde comer y que te atiendan, es una de las razones por las que me vine de San Antonio TX, para SF."

To have somewhere to eat and where they understand you, it's one of the reasons why I left San Antonio for San Francisco.

"Cuando Sali de la carcel, estuve dando vuelta por los shelters por casi un anio."

When I left jail, I was back and forth between shelters for almost a year.

"Aunque tenia mi 'residencia en transicion' me trataban como si fuera illegal. "

Even though I had my "transitional residency", they treated me like I was an illegal immigrant.

"El asilo politico por orientacion sexual me ayudo muchisimo y me devolvio la esperanza....deje de pensar que me iva a morir pronto."

Political asylum for sexual orientation helped me a lot and gave me hope. I stopped thinking that I was going to die soon.

"Los servicios legales de imigracion son muy importantes...por primera vez vi que me trataban con dignidad"

The immigration legal services are very important. For the first time I saw that they treated me with dignity.

"El tema de tener cancer y sida, hace mas complicada la situacion, y tus posibilidades de pedir ayuda."

The idea of having cancer and AIDS makes your situation and the possibility of finding help more complicated.

"No todos los case management y trabajadores sociales tienen la misma informacion y competencia."

Not all of the case managers and social workers have the same information and competency.

"El primer ano solo sobrevivi porque comia gratis en los grupos de apoyo."

The first year I only survived because I ate the free food in the support groups.

"Me aterrorizaba ir a las agencias por miedo a que nadie me entendiera. Cuando no te puedes comunicar en tu idioma es como si desaparecieras."

I was terrified to go to the agencies for fear that no one would understand me. When you can't communicate in your own language it's like you disappear.

"El dominio del idioma es una de las barrera mas importantes, es mucho mas que entender lo que te dicen es entender como funcionan los servicios y quien te puede y quien NO te puede ayudar."

Command of the language is one of the most important barriers, it's much more than understanding what they say to you, it's understanding how the services function and who can and can't help you.

CONCLUSIONS

- 1. Due to the large number of Latino MSM living with HIV/AIDS in San Francisco, as well as the disproportionate level of socioeconomic, cultural, and linguistic challenges that this community faces, reducing barriers to care for Latino MSM is a critical component of successfully meeting the needs of this population.
 - Providing services in Spanish and bridging language barriers are essential for addressing the needs of this population.
 - Addressing Latino immigrants' cultural and social differences is an important element to reduce isolation.
- 2. Planning for programs culturally and socially sensitive programs for Latino MSM living with HIV/AIDS should consider the stark funding environment and look at the development of innovative and collaborative programs that are cost effective and ideally cost neutral.
 - There are several types of organizations, including immigration, housing, and medical services, that already provide important services for this population. An increased level of communication and collaboration between these organizations could address how to better and more effectively serve this target population.
- 3. Despite significant barriers and challenges, the self-reported high level of adherence and viral suppression by focus group participants suggests that the San Francisco Model of Care is working to engage and retain those focus group participants in care. However, many focus group participants noted that late diagnosis is still a challenge.
- 4. Although the self-reported high rates of treatment adherence and viral suppression are indicators of success, there is also a high level of severe poverty in this population. Once in care, focus group participants continued to be engaged in care. A challenge is to develop prevention and early engagement before an HIV diagnosis or to quickly identify recently infected Latino immigrant MSM and bring them into care. When combining a propensity towards indigence with additional linguistic challenges and issues with legal status, the following becomes clear:
 - It is important to measure non-clinical health indicators in order to better address socioeconomic barriers to wellness.
 - Support Services providers must be equal partners with medical providers in order to ensure quality support in addition to quality medical care.
- 5. As we move into an era of healthcare reform, it is crucial to ensure that this population does not fall through the cracks or that services are not disrupted due to changing funding sources and eligibility criteria. The HIV+ Latino MSM community faces issues that not only constitute barriers to care, but also barriers to voice and representation. ACA changes have the potential to disproportionately affect this community, and it is important that the SF EMA HHSPC build in additional considerations to preserve Latino MSM access to care and services.

Although this needs assessment illustrates many of the successes of implementing a system of care that is accessible to HIV+ Latino MSM, it is essential for Latino MSM to be able to successfully navigate the many unknowns and the complexity of the San Francisco EMA's changing landscape in order to enjoy better health and a sustainable quality of life.

THANK YOU

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