



Left Out:

Assessing HIV Counseling, Testing and Referral Services
for the Latino Community in
Montgomery and Prince George's Counties Maryland

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EXECUTIVE SUMMARY

The Maryland HIV-AIDS epidemiological profile as reported in June 30, 2005, reports a worrying prevalence of HIV-AIDS among the Hispanic community of 2.1%.¹ This high percentage of cases illustrates an epidemic that goes beyond the groups traditionally considered at higher risk (men having sex with other men, commercial sexual workers and intravenous drug users) and extends to the general Latino community in the state. Despite this data, there are ample indications that prevention efforts are not keeping pace with the changing epidemic. This is clearly reflected in the inadequate access of the Latino community to HIV counseling, testing and referral (CTR) services that are linguistically and culturally appropriate. The following report documents a needs-assessment of the competency of these services for the Hispanic population of Prince George's and Montgomery Counties performed in 2004. The document also provides recommendations of the basic reforms needed to bring HIV CTR services in Montgomery and Prince George's Counties up to compliance with state and federal law, as well as with the ethical principals recognized internationally in the battle against the HIV-AIDS pandemic.

Since HIV reporting began in 1994, Maryland has detected approximately 2,200 new infections per year; as of June 30, 2004, there were a total of 28,226 HIV-AIDS cases in the state. Of these, 15,799 (56%) corresponded to HIV cases (infected individuals without advanced-stage disease) and 12,427 (44%) were AIDS cases. To put this into perspective, while Maryland ranks 19th among the 50 states and the District of Columbia in total population, it was 9th in cumulative number of AIDS cases and 3rd in AIDS incidence rate.² Furthermore, the two counties adjacent to Washington, D.C., Montgomery and Prince George's Counties (with 8% and 15% of cases, respectively) contributed to 23% of the State's HIV-AIDS caseload, significantly above other jurisdictions except for Baltimore City.³

Nationwide, the Latino community accounts for 18.3% of the people living with HIV-AIDS.⁴ In Maryland, HIV-AIDS in the Hispanic community has already reached the epidemic level (>1%). Linguistically and culturally appropriate services that respond to this situation need to be a priority. Figures from Census 2000 indicate that in Maryland, more than 600,000 residents speak a language other than English in the home, with almost a quarter of a million of those speaking English less than "very well." A 2001 survey conducted by the National Foreign Language Center at the University of Maryland, found Spanish to be the language most commonly encountered.⁵ Hispanics currently represent the fastest growing ethnic group in Maryland.

Even outside of HIV-AIDS services, the need for culturally competent health care in the United States is great. While racial and ethnic minorities are burdened with higher rates of disease,

1 Incident cases are cases newly diagnosed during the 12 month period. Rate is number of cases per 100,000 population. Population is based on 2000 Census. <http://dhmh.state.md.us/AIDS/Data&Statistics/NewMDQtrEpi.pdf>

² 28.5 cases per 100,000 population during 2003.

³ AIDS Administration, Maryland

⁴ CDC. HIV-AIDS Surveillance Report. 2000

⁵ Carter-Pokra O, et cols.

disability and death, they tend to receive a lower quality of health care than non-minorities, even when access-related factors, such as insurance status and income, are taken into account.⁶ To curtail this situation, and in accordance with applicable state and federal law (principally, Title VI of the Civil Rights Act of 1964 and the Annotated Code of Maryland, State Government Article, §§ 10-1101 - 10-1104), the Maryland Department of Health and Mental Hygiene (DHMH) seeks to make programs, services and benefits accessible to eligible individuals who, as a result of race, ethnicity or national origin, are limited in their English proficiency.

An inability to communicate with a healthcare provider not only creates a barrier to accessing health care, it also undermines trust in the quality of medical care received and decreases the likelihood of appropriate follow-up. Culture and ethnicity create a unique pattern of beliefs and perceptions as to what “health” or “illness” actually means. In turn, this pattern of beliefs influences how symptoms are recognized, to what they are attributed, and how they are interpreted and affects how and when health services are sought. Overcoming language and cultural barriers between patients and providers leads to increased compliance with medications and appointments, fewer emergency department visits, better recall of information discussed during consultation, and more questions being asked. All of these are indispensable for any HIV-AIDS prevention and care program.

Cost-efficiency may also be improved if services are provided in a patient’s native language. Some physicians who cannot fully understand their patients appear to compensate for the unaccustomed lack of information by altering their management to a more cautious, conservative style (e.g. more tests are ordered and there are more frequent hospital admissions), a phenomenon known as “language-barrier premium”.⁷ Non-English-speaking patients may be reluctant to deal with providers who cannot communicate with them, seeking care only when their conditions become acute and more costly.

Furthermore, for HIV CTR programs the use of interpreters is far from ideal. Interpretation by untrained interpreters is frequently inadequate and can lead to misunderstandings and a violation of informed consent. Confidentiality is difficult to maintain in this situation, and clients may not be as forthcoming about discussing high-risk behavior when an interpreter is involved (especially when children are interpreting for parents - something commonly seen - or when the interpreter’s gender is different than the client’s).

Recognizing the increase in HIV-AIDS prevalence in the traditionally underserved Latino community and the value of linguistically/culturally appropriate HIV CTR services, a needs-assessment was funded by the Washington AIDS Partnership, and carried out by CASA of Maryland. The study, which concluded in December 2004, consisted of the triangulation of qualitative (focus groups, personal interviews) and semi-quantitative tools (mini-survey). Additionally, the Public Information Act (PIA) was utilized to make requests to government agencies to disclose the extent to which they have implemented the requirements of the *Equal Access to Public Services for Individuals with Limited English Proficiency Act of Maryland*. The assessment revealed valuable information, including:

⁶ Id.

⁷ Id.

1. The target community does not recognize HIV-AIDS as a problem of concern pertaining to the Latino community. This may be the effect of the historically low HIV-prevalence in the countries of origin of members of the community, fear of stigmatization, lack of HIV-AIDS education/awareness and the presence of other priorities (e.g. need to find and maintain employment).
2. Access to linguistically and culturally appropriate HIV counseling, testing and referral services is limited due to a combination of factors. These include the reality that interpretation services and increasing the pool of Spanish speaking counselors costs money and current levels of funding are inadequate. Also, recent federal laws regarding immigrants have created confusion about the extent of provider obligations to serve populations with LEP (Limited English Proficiency), and although there are state and federal laws requiring access to linguistically appropriate health care, they are largely unused in practice. Many health care providers are uncertain about the extent to which they can and should provide health care, including interpretation services, to immigrant populations. Clients, particularly the undocumented, are wary of seeking health services due to fear of deportation and the belief that access requires unachievable documentation of identity or proof of income. Potential clients also have poor knowledge regarding location, type and requirements to access the limited HIV CTR facilities available.
3. Access to health care in general is limited. Outpatient services are not commonly delivered without health insurance and clients do not seek care until there is an emergency. Though there is recognition of the right to linguistically and culturally sensitive health care and the expectation of some form of universal health insurance, limited resources for the poor severely limit health coverage.
4. Though information (booklets, posters, TV, radio) in Spanish is available, it is considered of “inappropriately high literacy”, low-quality and not likely to change the behavior of the targeted population. Furthermore, illiteracy, both in Spanish and English, is a serious problem. There is a consensus that television is the most effective channel for distributing information. Another factor to take into account is the diversity of the Spanish language depending on the country of origin.
5. Participants agree that a “face-to-face” approach is the ideal way of delivering HIV CTR services. Outreach must be a key component of such services given that clients generally do not have time or economic resources to visit health care facilities where information has traditionally been distributed. Further, there is widespread distrust of governmental or traditional health industry providers and study participants found community non-profits more effective at providing both information and basic healthcare.
6. Health service providers recognize their limitation in the provision of appropriate HIV CTR services. These institutions offered a comprehensive list of topics to be considered for future training and institutional improvement. They also expressed a willingness to share information, coordinate efforts and work within existing networks to better serve the target population. Most, however, expressed reservations about getting involved in additional activities that would require an investment of extra resources.

7. All the providers and institutions included in the study receive government funding and therefore are subject to federal or state law regarding provision of services to LEP individuals. Despite this, nine of the thirteen respondents (69%) had no LEP specific training. The procedures to improve the access of LEP individuals to health services are diverse in Maryland and do not specifically target HIV-AIDS but are institutional in nature. They range from having no procedures in place to a relatively sophisticated set of policies that include multilingual signage, telephonic interpretation and training bilingual staff. Interpretation is normally performed by bilingual staff available in the health facility who are often neither qualified nor trained and therefore run the risk of providing improvised interpretations.
8. Ten of the thirteen provider/health institutions (76%) questioned did not have data available on their HIV-AIDS services for LEP individuals. At the time of the data request, the only formal data available on LEP access to health services was a 2001 study by the National Foreign Language Center which relied on self-reporting and was of limited accuracy.
9. Hispanics are not the only minorities that are vulnerable due to language/cultural barriers. Appropriate resources should be allocated to these needs for all LEP communities.

While admittedly the situation is complex, there are concrete solutions which must be implemented promptly. Health disparities related to socioeconomic disadvantage can be alleviated, in part, by creating and maintaining culturally competent healthcare systems that can at least overcome communication barriers that may preclude appropriate diagnosis, treatment and follow-up. In the case of HIV-AIDS, this is not only important for the individual patient but also for the sake of public health. A comprehensive strategy must include the following:

On the Part of Government

- ♦ Increase sources of funding allocated specifically to HIV CTR services for LEP individuals to strengthen existing facilities or create new facilities that will enhance the access of the Latino community to HIV-AIDS counseling.
- ♦ Ensure that health-service providers and the appropriate regulating agencies in Montgomery and Prince George's Counties utilize the above funding to provide technical training (e.g. cultural sensitivity, HIV prevention counseling, social service referrals) to bilingual personnel responsible for HIV CTR and develop a pool of trained medical interpreters for use when bilingual HIV prevention counselors are not available.
- ♦ Clarify for government agencies the right of all immigrants, including undocumented, to basic health services and ensure that service providers recognize and follow such requirements.
- ♦ Provide training to empower clients to demand linguistically/culturally appropriate HIV CTR services and access to general health care.
- ♦ Identify, promote and develop community leadership. This should include increasing community participation in decisions regarding health care and sharing community experiences through participation in statewide and nationwide events and conferences.

Within this context, a special emphasis should be placed on the empowerment of women and adolescents through alliances with specific groups and organizations.

On the Part of Health Service Providers and Health Regulating Institutions

- ♦ Guarantee culturally diverse staff that reflects the communities being served and provide culturally specific healthcare settings; assure the competence of language assistance provided to limited English proficient patients or consumers by interpreters and bilingual staff members; and discontinue the use of family and friends to provide interpretation services.
- ♦ Promote HIV-AIDS awareness among the Hispanic community to increase the demand for HIV CTR services. Do this through outreach activities directed at individuals and communities.
- ♦ Develop competent outreach as well as HIV CTR services specifically directed at women, a group that has an increasing risk of HIV infection and traditionally suffers from even more limited access to health care. This group, according to our findings, is more willing and enthusiastic to work along with the health providers to obtain these services.
- ♦ Maintain a demographic, cultural and epidemiological profile of the community and conduct needs assessments to plan accurately for services that respond to the cultural and linguistic characteristics of the area.
- ♦ Continue the research of this study about the adequacy of HIV CTR services for the LEP Hispanic community, extending interpretation services to other non-English speaking populations, and including an evaluation of the quality of care and the needs of individuals already diagnosed as HIV-positive. Develop and implement strategies and policies in response to the findings.
- ♦ Learn about model programs in the US and similar international settings in order to benefit from lessons learned and best practices.
- ♦ Utilize other modalities of health promotion and prevention rather than solely relying on the traditional written pamphlets, booklets, brochures, and other materials that do not seem to be widely read by LEP clients.
- ♦ Test all materials related to HIV-AIDS currently distributed by the AIDS Administration to assure cultural and linguistic competence.
- ♦ Form coalitions to hold government authorities accountable to the Latino community in terms of LEP policies.

The success of the proposed strategy requires the effort and commitment of the government, community-based organizations (CBO's), health care providers, health regulators and the target population.

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“No person in the United States shall, on ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”

Title VI of the Civil Rights Act of 1964

“The General Assembly finds that the inability to speak, understand, or read the English language is a barrier that prevents access to public services provided by state departments, agencies, and programs, and that the public services available through these entities are essential to the welfare of Maryland residents. It is the policy of the State that state departments, agencies, and programs shall provide equal access to public services to persons or individuals with limited English proficiency.”

Equal Access to Public Services for Individuals with Limited English Proficiency, Maryland Code Annotated, State Government, section 10-1101, *et. seq.*

III. INTRODUCTION

There is an increasing number of people in the United States who cannot speak, read, write or understand the English language at a level that permits them to interact effectively using English. According to the 2000 Census, more than 31 million foreign-born residents live in the United States (11.1% of the total population),⁸ and 47 million residents speak a language other than English in the home (17.9% of the population over age 5 years). Furthermore, 21.3 million residents over age 5 (8.1%) speak English less than “very well.”⁸ In Maryland, figures from the 2000 Census indicate that more than 600,000 residents speak a language other than English in the home, with almost a quarter of a million of those speaking English less than “very well.” Hispanics currently represent the fastest growing ethnic group in the State.

The need for linguistically and culturally competent health care in the United States is great: while racial and ethnic minorities are burdened with higher rates of disease, disability and death, they tend to receive a lower quality of health care than non-minorities, even when access-related factors, such as insurance status and income, are taken into account.⁹ Sixty-three percent of working Latinos have no health insurance and 22% live below the poverty line. These statistics do not include the undocumented population, whose health indicators remain officially unknown.¹⁰

Furthermore, 43% of Hispanics report that they have experienced some form of difficulty communicating with doctors, compared with 33% of African Americans and 16% of non-hispanics.¹¹ This can have serious implications for diagnosis and treatment. An inability to communicate with a healthcare provider not only creates a barrier to accessing health care; it undermines trust in the quality of medical care received and decreases the likelihood of appropriate follow-up. Culture and ethnicity create a unique pattern of beliefs and perceptions as to what “health” or “illness” actually mean. In turn, these patterns of belief influence how symptoms are recognized, to what they are attributed and how they are interpreted and affects how and when health services are sought. Overcoming language and cultural barriers between patients and providers leads to increased compliance with medications and appointments, fewer emergency department visits, better recall of information discussed during consultation and more questions being asked. All of these are indispensable for any HIV-AIDS prevention and care program.

Accordingly, identifying the extent to which culturally and linguistically competent HIV counseling, testing and referral (CTR) services are available in Prince George’s and Montgomery Counties is important. CASA of Maryland, Inc., with the support of the Washington AIDS Partnership, developed and carried out the following needs assessment of both clients and health

⁸ US Census Bureau. American FactFinder.

⁹ Carter-Pokra O, et cols.

¹⁰ Andalo P.

¹¹ Reyes C, Van de Putte L, Falcon A, Levy R

workers regarding HIV CTR training and services and HIV-AIDS information/education materials. The goal was to make HIV-AIDS CTR services in Montgomery and Prince George's Counties compliant with state and federal law, as well as with the ethical principals recognized internationally in the battle against the HIV-AIDS pandemic.

The **Left Out** study utilized focus group discussions, interviews with field-experts, program managers and government officials and the completion of mini-surveys by front-line health workers. This report also includes information from requests to government agencies to disclose the extent to which they have implemented the requirements of the *Equal Access to Public Services for Individuals with Limited English Proficiency Act of Maryland*, a strategy stipulated in the Public Information Act (PIA).

Finally, this research makes comprehensive recommendations related to model HIV CTR programming and identifies challenges and funding concerns as well as the possible activities and feasible partnerships or networks that can be appropriate for Montgomery and Prince George's Counties.

IV. BACKGROUND

Limited English Proficiency (LEP), Maryland Regulation

In 2002, there were 38.8 million Hispanics living in the United States, representing an increase of 58% since 1990. They are currently the fastest growing ethnic group in the state of Maryland.

In accordance with state and federal law (Title VI of the Civil Rights Act of 1964, and the Annotated Code of Maryland, State Government Article, §§ 10-1101 - 10-1104), the Department of Health and Mental Hygiene (DHMH) seeks to make programs, services and benefits accessible to eligible individuals who, as a result of race, ethnicity or national origin, are limited in their English proficiency. This policy applies to those programs operated or funded by DHMH that provide services or benefits directly to the public; to grant-in-aid programs; and to providers of health services, contractors and sub-contractors that receive Federal or State funds. These programs and providers are collectively referred to as “covered entities.”

Each covered entity that provides services or benefits directly to the public shall develop language assistance procedures for (1) assessing the language needs of the population served; (2) translating both oral and written communications and documentation; (3) training staff in the language assistance program requirements; and (4) monitoring to assure that LEP individuals¹² are receiving equal access to services and are not treated in a discriminatory manner.

Moreover, at a June 2002 meeting of almost 200 Latinos with the AIDS Administration of the Maryland Department of Health and Mental Hygiene, participants all agreed that the Latino community needs more bilingual/bicultural HIV CTR services. Accordingly, CASA of Maryland, in partnership with La Clinica del Pueblo, has worked to increase accessibility and availability of culturally and linguistically appropriate basic services, including HIV CTR services, in Montgomery and Prince Georges Counties.¹³

HIV-AIDS in the Latino Community

Since HIV reporting began in 1994, Maryland has detected approximately 2,200 new infections per year; as of June 30, 2004, there were a total of 28,226 HIV-AIDS cases in the state. Of these, 15,799 (56%) corresponded to HIV cases (infected individuals without advanced-stage disease) and 12,427 (44%) were AIDS cases (symptomatic cases). To put this into perspective, while Maryland ranks 19th among the 50 states and the District of Columbia in total population, it was

¹² For the purposes of this study and its recommendations, a Limited English Proficiency (LEP) person is defined as “an individual who cannot communicate – speak, read, write, or understand - in English well enough to interact with the State government.”

¹³ In 1999, CASA and the Public Justice Center issued a report entitled Unequal Justice: Barriers to the Justice System for Latinos in Maryland. Unequal Justice presented the results of a three-year study of justice barriers for Latinos across Maryland including, *inter alia*, significant linguistic barriers at state agencies. Upon publication, the authors immediately established a statewide coalition, the Maryland Latino Coalition for Justice to advocate for change at a state level and in 2002 succeeded in passage of the Equal Access to Public Services for Individuals with Limited English Proficiency, Maryland Code Annotated, State Government, section 10-1101, *et. seq.*

9th in cumulative number of AIDS cases and 3rd in AIDS incidence rate.¹⁴ Furthermore, the two counties adjacent to Washington, D.C., Montgomery and Prince George's Counties (with 8% and 15% of cases, respectively) contributed to 23% of the State's HIV-AIDS caseload, significantly above other jurisdictions except for Baltimore City.¹⁵

Nationwide, the Latino community accounts for 18.3% of the people living with HIV-AIDS.¹⁶ In Maryland, HIV-AIDS in the Hispanic community has already reached the epidemic level (>1%), and it extends beyond the traditional groups at higher risk of infection (men having sex with other men, commercial sex-workers, intravenous drug users) to the general Latino population. In order to limit the spread of infection and to provide the most appropriate care for individuals already infected with HIV, overcoming language and cultural barriers between patients and providers is essential. It will lead to increased compliance with medications and appointments, fewer emergency department visits, better recall of information discussed during consultation and more questions being asked. All of these are crucial for any HIV-AIDS prevention and care program.

Cost-efficiency may also be improved: Some physicians who cannot fully understand their patients appear to compensate for the unaccustomed lack of information by altering their management to a more cautious, conservative style (e.g. more tests are ordered and there are more frequent hospital admissions), a phenomenon known as "language-barrier premium".¹⁷ Non-English-speaking patients may be reluctant to deal with providers who cannot communicate with them, seeking care only when their conditions become acute and more costly.

Moreover, for HIV CTR programs the use of interpreters is far from ideal. Interpretation, when not conducted by trained medical interpreters, is frequently inadequate and can lead to misunderstandings and a violation of informed consent. Confidentiality is difficult to maintain in this situation and clients may not be as forthcoming about discussing high-risk behavior when an interpreter is involved (especially when children are interpreting for parents which is something commonly seen or when the interpreter's gender is different than the client's).

¹⁴ 28.5 cases per 100,000 population during 2003

¹⁵ <http://www.dhmh.state.md.us/AIDS/>

¹⁶ CDC. HIV-AIDS Surveillance Report. 2000

¹⁷ Carter-Pokra O, et cols.

V. METHODOLOGY

The study's design consisted of the triangulation of qualitative, semi-quantitative tools and document review. The qualitative and semi-quantitative tools involved focus groups, in-depth interviews and mini-surveys. Data collection began in April of 2004.¹⁸

Focus Groups

Six focus groups were conducted in Spanish and were transcribed, translated, summarized and analyzed by the researcher. The qualitative analysis covers the practices, beliefs and attitudes regarding the topic of HIV CTR services, HIV-AIDS treatment services and healthcare services for LEP individuals. The topics discussed included: utilization of and access to health services (by participants and/or their families); awareness and knowledge about HIV-AIDS specific health services; educational information found on the streets, public transportation, and media; other sources of information including parents and school counselors; and specific language related concerns.

The sample was comprised of 57 participants: 18 men, 17 women, and 22 adolescents (14 girls and 8 boys). All were Hispanics from Latin American countries. All were residents of Montgomery or Prince George's Counties in Maryland (*Table 1*). Most participants had immigrated to the US within the last five years.

The adult participants were recruited by health promoters trained by CASA's Health Program. All participants received an explanation of the study procedure and filled out a demographic information form. The adolescent participants were recruited by Identity, Inc. and were mostly students who attended Gaithersburg High School in Montgomery County. Most were between 15 and 17 years old and already spoke or were learning English.

Interviews

Interviews were conducted with 13 participants working as public officers, program coordinators/administrators, site managers or HIV-AIDS prevention field experts from university-based programs, local faith-based organizations, government health centers, publicly funded private non-profit agencies and school-based programs. All were recruited by telephone or e-mail, based on a list provided by the Health Program Senior Manager at CASA and the State of Maryland AIDS Administration's CTR Coordinator.

These professionals were questioned about their (1) Institution's/organization's profile (population served, services provided); (2) Language needs and services provided to LEP individuals; (3) Procedures to monitor services provided to LEP individuals; (4) Specific HIV-AIDS prevention and treatment services; (5) Knowledge of regulations on LEP specific services.

¹⁸ All data collection tools available upon request to CASA

Surveys

Surveys were carried out among 28 health service providers. Fifty mini-surveys were distributed among program officers, project managers or directors. The survey tool consisted of two sections. The first requested information on the services provided to clients at the work place including an assessment of language needs, translation and interpreter services available, HIV-AIDS specific services and information regarding clients' rights in the case of LEP. The second section focused on the providers' needs, including satisfaction with current knowledge and/or information on HIV CTR services, availability of interpretation services and the need for additional features to improve their performance as HIV-AIDS direct service providers. Scores were given on a scale of one through 5: 1 being the lowest and 5 being the highest quality possibly achieved.

Document review

Under Executive Order 13166 and Maryland State Code, State Government § 10-1101 *et seq.*, state agencies are required to provide equal access to consumers with LEP. Under the auspices of the Access to Public Records Act (Public Information Act),¹⁹ relevant institutional documents were requested from the AIDS Administration, the Department of Health and Mental Hygiene, the Department of Human Resources and the State Department of Education in order to measure and compare attempts to comply with LEP-specific stipulated law. Documents requested included: the agency's policies for LEP-specific services; the agency's sources of funding and provision for HIV CTR services; the agency's administrative and operational structure; and the existence of civil rights complaints due to lack of linguistically and culturally competent services and information.

¹⁹ Md. Code Ann., State Gov't § 10-611 *et seq*

VI. RESULTS

A. Focus Groups

As previously described, six different focus groups were held with Latino immigrant men, women and adolescents. Each group provided rich observations regarding their personal experiences attempting to access healthcare and their analysis of the quality and availability of education regarding HIV infection and prevention. Complete redactions and observations, too lengthy to append here, are available upon request to CASA. The following are the main findings of the focus group discussions:

Access and utilization of general health services:

- ♦ Health services are mainly sought in case of emergencies. Access to outpatient services depends greatly on having health insurance. Limited income is therefore the main reason given for the limited seeking of health care.
- ♦ Immigration status was mentioned in several circumstances as an additional and central barrier to seeking health care.
- ♦ General health care is usually sought at a local hospital. El Centro Católico Hispano was repeatedly mentioned as an alternative source of care.
- ♦ Awareness about available health services widely varied from newcomers to experienced residents living in the U.S. for over 10 years. Regardless, regular health care access is limited.
- ♦ Language was a major barrier mentioned by all three groups in terms of communicating their health problems and being fully understood. A Hispanic health provider or at least a Spanish speaker is always preferred in health care situations.
- ♦ Adolescents feel they receive unsatisfactory health services through school.

HIV-AIDS Awareness:

- ♦ The range of knowledge varied from very knowledgeable, to minimal, to no knowledge on this topic. Misconceptions were frequent. Most of the participants were very interested in receiving more and clearer information on HIV-AIDS.
- ♦ Hesitancy to talk about HIV-AIDS was evident in all groups, although less so among adult women. Stigmatization remains a serious barrier.
- ♦ Adolescents do not believe they receive enough information in health classes at school.

- ♦ Many adults believe they received better information in their home countries than in the U.S. This fact is related to language barriers and modality of communication.
- ♦ CASA of Maryland, *La Clínica del Pueblo* and Identity were consistently mentioned among participants as the main providers of information on the topic of HIV-AIDS. Other organizations mentioned were the Dennis Avenue Clinic and the Greenbelt Health Center.
- ♦ Knowledge of resources and HIV-AIDS specific health services is closely linked to whether the participant has access to basic health care.
- ♦ Men were hesitant to refer people to HIV CTR services, either because of reluctance or ignorance. Women and adolescents were more open and knowledgeable about how to find services.
- ♦ Women consider community outreach activities as the most effective way to communicate about HIV-AIDS. For instance, one woman said “Most people DO NOT attend the health services so there is no use in having booklets, fliers and other materials distributed at the health facilities.”
- ♦ HIV-AIDS information should be personalized and delivered “face to face” in schools, churches, health fairs and other events (sports, parades, etc.) in order to increase access of minorities and to preserve confidentiality.
- ♦ Adolescents agreed that parents are not a good source of information. Women emphasized the importance of school as the most important mechanism to transmit HIV-AIDS information to children and their parents.
- ♦ Television is the best mass media format to deliver information regarding HIV-AIDS. Information through the radio is also helpful. Information in newspapers, magazines and other printed media was not mentioned as a frequently utilized source.

Language-specific concerns:

- ♦ Participants agreed that the lack of Spanish materials is the main barrier to understanding health related information. Most information is available in English. Therefore, translation and/or interpretation services in Spanish should be available to deal with HIV-AIDS.
- ♦ Spanish-language illiteracy is a significant barrier.
- ♦ There is heterogeneity even within the Spanish language (i.e. words carry different meaning depending on the country of origin, different accents, etc.). This may present another barrier when delivering health services to Hispanics.

Expectations from Hispanics:

- ♦ There is fear of reprisals by immigration authorities for “not having papers” or identification when seeking health services. This impairs the individual’s ability to care for his/her own health and that of his/her family. Both men and women underscore the unfairness of serving as an important labor force yet lacking the right to health care under their current work conditions.
- ♦ Participants recognized that everyone has the right to access quality health care. Participants argue that universal health insurance for low-income individuals, immigrants and LEP individuals should be a reality.
- ♦ There was recognition that other minorities suffer the same limitations. Other languages should be taken into account when addressing LEP needs.

B. Interviews

The following is the principal data extracted from the thirteen interviews with program directors of private agencies and with employees from state agencies and county health departments in the target counties.²⁰

- ♦ All of the organizations/providers included in the sample receive government funding that makes them accountable to federal or state requirements for LEP access. Nine of thirteen respondents (69%) reported that their organizations or departments have had no LEP-specific training. The procedures to improve the access of LEP individuals to health services are diverse in Maryland and do not specifically target HIV-AIDS but are institutional in nature. They range from having no procedures in place to a relatively sophisticated set of policies that address multilingual signage, telephonic interpretation and training bilingual staff. Interpretation is normally performed by bilingual staff available in the health facility, often neither qualified nor trained, with the risk of improvised or translations.
- ♦ Monitoring procedures to assure that LEP individuals are receiving equal access to services were deficient. There is confusion about the degree to which these organizations should track information on race and ethnicity of the population being served. This wariness extends to the tracking of information on language and country of origin.
- ♦ Ten of the thirteen provider institutions (76%) questioned did not have data available on their HIV-AIDS services for LEP individuals. At the time of the data request, the only formal data available on LEP access to health services had been performed by the National Foreign Language Center in their 2001 study which relied on self-reporting and was of limited accuracy.

²⁰ Names and contact information of interviewees as well as more extensive interview notes available upon request to CASA.

- ♦ Advocacy addressing LEP policy compliance is not a usual practice among respondents, except for those that represent advocacy oriented community-based organizations.
- ♦ Providers believe the use of interpreters is far from ideal. Interpretation by untrained interpreters is frequently inadequate and can lead to misunderstandings and a violation of informed consent. Confidentiality is difficult to maintain in this situation, and clients may not be as forthcoming about discussing high-risk behavior when an interpreter is involved (especially when children are interpreting for parents, something commonly seen, or when the interpreter's gender is different than the client's).
- ♦ Existing information and education material is considered of inappropriately high literacy, low quality and unlikely to create behavior change. The participating institutions prepared few materials.
- ♦ The quality and usefulness of HIV CTR specific training was questioned by some of the participants.
- ♦ Most respondents expressed enthusiasm about joining a network; however, most expressed resource constraints.

C. Surveys²¹

The surveys evaluated the cultural/linguistic competence of the services provided to clients as well as the providers' perceived challenges to reach such competency. The following were the key findings:

- ♦ The quality of health services provided was given the two highest scores (4 - 5 out of 5) by all providers participating in the study. Low scores were given when asked about community awareness about services available and provided by the institutions. Low scores were also observed when asked about treatment options being offered to clients diagnosed as HIV-positive.
- ♦ Providers gave the HIV CTR services they were providing a minimum score of 4. They generally consider their services of high quality. At least 50% consider that high quality HIV-AIDS specific services depend on the availability of language competency. The remaining respondents suggested other key factors besides language specific issues in the delivery of HIV-AIDS services.
- ♦ At least 90% of the respondents affirmed that their services are provided in the client's own language. Still, they manifested a need for more interpreters.

²¹ More extensive survey responses are available upon request to CASA.

- ♦ The needs of the front line health providers expressed through this survey (such as more incentives and additional training) should be taken into account when designing and implementing any HIV-AIDS program addressed to LEP individuals.

D. Document Review

Only two responses were received, one from the Maryland AIDS Administration and the second from the Department of Human Resources. The AIDS Administration principally submitted documents related to its HIV-AIDS and LEP procedures and policies. The Department of Human Resources submitted an internal document adapting LEP policy to their agency practices, language related documents and a form on discrimination complaints. One agency included for comparison purposes, the Maryland State Department of Education, simply replied with a letter stating that receiving the request had initiated an internal discussion regarding the lack of responsive documents.

VII. STUDY LIMITATIONS

Due to time and access constraints, most of the participants in the study were recruited from community members familiar with CASA of Maryland who already may have better access to HIV-AIDS information and referral options than the general Latino population.

The lack of experience in the community with the tools used in the study, mainly the focus group discussions, was expressed on some occasions as a lack of interest and cooperation. Some participants felt inhibited to respond.

Despite the fact that interviews and focus group discussion in the community were carried out in Spanish, some information may have been misunderstood or not registered due to variations in the Spanish language depending on the country of origin.

VIII. CONCLUSIONS

In January 2001, a study commissioned by the Montgomery County Latino Health Initiative (LHI) found significant access and knowledge barriers for Latinos in Montgomery County in accessing health care and information regarding health as well as quality of care differentials. The **Left Out** study illustrates that significant barriers continue to exist. For Latinos living in Montgomery and Prince Georges Counties, we found:

1. The Latino immigrant community does not recognize HIV-AIDS as a problem of concern pertaining to the Latino community. This may be the effect of the historically low HIV-prevalence in the country of origin, fear of stigmatization, lack of HIV-AIDS education/awareness and the presence of other priorities (e.g. the need to find and maintain employment).
2. Access to linguistically and culturally appropriate HIV counseling, testing and referral services is limited due to a combination of factors. Among these factors is the reality that interpretation services and increasing the pool of Spanish speaking counselors cost money, and current levels of funding are inadequate. Also, providers have various interpretations of recent federal laws regarding LEP populations. Although there are state and federal laws requiring access to linguistically appropriate health care, they are largely unused in practice. Many health care providers are uncertain about the extent to which they can and should provide health care, including interpretation services, to immigrant populations. Clients, particularly the undocumented, are wary of seeking health services due to fear of deportation and the belief that access requires unachievable documentation of identity or proof of income. They also have poor knowledge regarding location, type and qualifications for the limited HIV CTR services available.
3. Access to health care in general is limited. Outpatient services are not commonly delivered without health insurance and clients do not seek care until the presentation of an emergency. Though there is recognition of the right to linguistically and culturally sensitive health care and the expectation of some form of universal health insurance, slight resources for the poor severely limit health coverage.
4. Though information (booklets, posters, TV, radio) in Spanish is available, it is considered of “inappropriately high literacy”, low quality and not likely to change the behavior or the targeted population. Furthermore, illiteracy, both in Spanish and English, is a serious barrier. There was a consensus that the television is the most effective channel for distributing information. Another factor to keep in mind is the diversity of the Spanish language depending on the country of origin.
5. Participants agree that a “face-to-face” approach is the ideal way of delivering HIV CTR services. Outreach is vital because clients generally do not have time or economic resources to visit health care facilities where information has traditionally been distributed. Further, there is widespread distrust of government or traditional health

industry providers, and study participants found community non-profits more effective at providing both information and basic healthcare access.

6. Health providers and institution managers recognize their limitations in providing appropriate HIV CTR services. These institutions offered a list of topics to be considered for future training and institutional improvement. They also expressed a willingness to share information, coordinate efforts and work within existing networks to better serve the target population. Most, however, expressed constraints in terms of activities that represent investment of extra resources.
7. All the providers and institutions included in the study receive government funding and therefore are subject to federal or state law regarding provision of services to LEP individuals. Unfortunately, nine of thirteen respondents (69%) had no LEP specific training. The procedures to improve the access of LEP individuals to health services are diverse in Maryland and do not specifically target HIV-AIDS but are institutional in nature. They range from having no procedures in place to a relatively sophisticated set of policies that include multilingual signage, telephonic interpretation and training bilingual staff. Interpretation is normally performed by bilingual staff available in the health facility, often neither qualified nor trained, with the risk of improvised or empirical translations.
8. Ten of the thirteen provider/health institutions (76%) questioned did not have data available on their HIV-AIDS services for LEP individuals. At the time of the data request, the only formal data available on LEP access to health services was given by the National Foreign Language Center study of 2001, which relied on self-reporting and was of limited accuracy.
9. Hispanics are not the only minorities that that are vulnerable due to language/cultural barriers. Appropriate resources should be allocated to address the linguistic and cultural needs of all LEP individuals.

IX. RECOMMENDATIONS

Health disparities related to socioeconomic disadvantage can be alleviated, in part, by creating and maintaining culturally competent healthcare systems that can at least overcome communication barriers that may preclude appropriate diagnosis, treatment and follow-up. In the case of HIV-AIDS, this is not only important for the individual patient but for the sake of public health. A comprehensive strategy must include the following:

On the Part of Government

- ♦ Increase sources of funding allocated specifically to HIV CTR services for LEP individuals to strengthen existing or create new facilities that will enhance the access of the Latino community to HIV-AIDS counseling, testing and referral.
- ♦ Ensure that health-service providers and the respective regulating agencies in Montgomery and Prince George's Counties utilize the above funding to provide technical training (e.g. cultural sensitivity, HIV prevention counseling, social service referrals) to bilingual personnel responsible for HIV CTR services and develop a pool of trained medical interpreters for use when bilingual HIV prevention counselors are not available.
- ♦ Clarify, on the part of government agencies, the right of all immigrants, including undocumented, to basic health services and ensure that service providers recognize and follow such requirements.
- ♦ Provide training to empower clients to demand linguistically/culturally appropriate HIV CTR services and access to general health care.
- ♦ Identify, promote and develop community leadership. This should include increasing community participation in decisions regarding health care and sharing community experiences through participation in statewide and nationwide events and conferences. Within this context, a special emphasis should be placed on the empowerment of women and adolescents through alliances with specific groups and organizations.

On the Part of Health Service Providers and Health Regulating Institutions

- ♦ Guarantee culturally diverse staff that reflects the communities being served, and provide culturally specific healthcare settings; assure the competence of language assistance provided to limited English proficient patients or consumers by interpreters and bilingual staff members; and discontinue the use of family and friends to provide interpretation services.
- ♦ Promote HIV-AIDS awareness among the Hispanic community to increase the demand for HIV CTR services. Do this through outreach activities directed at individuals and communities.

- ♦ Develop competent outreach as well as HIV CTR services specifically directed at women, a group that has an increasing risk of HIV infection and traditionally suffers from even more limited access to health care. This group, according to our findings, is more willing and enthusiastic to work with health providers to obtain these services.
- ♦ Maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment tool to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.
- ♦ Develop and conduct ongoing research on the adequacy of HIV CTR services for the LEP Hispanic community, extending to other non-English speaking populations, and including the evaluation of the quality of care and the needs of individuals already diagnosed as HIV-positive. Develop and implement strategies and policies in response to the findings.
- ♦ Promote the analysis of other model programs in the US and similar international settings in order to benefit from lessons learned and best practices.
- ♦ Find other modalities of health promotion and prevention rather than solely relying on the conventional written pamphlets, booklets, brochures, and other materials that do not seem to be widely read by LEP clients.
- ♦ Test all materials related to HIV-AIDS currently distributed by the AIDS Administration to assure cultural and linguistic competence.
- ♦ Form coalitions among organizations to hold government authorities accountable to the Latino community in terms of LEP policies.

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CASA of Maryland is a 501(c) (3) tax exempt, non-profit, community-based organization dedicated to improving the quality of life, social, and economic well-being of the Latino community in Maryland, through direct client services, including prevention education and HIV counseling, testing and referral services, education and leadership development, advocacy and community organizing.