

THE SAN DIEGO LGBT COMMUNITY CENTER
LESBIAN, BISEXUAL, TRANSGENDER WOMEN'S NEEDS ASSESSMENT
2005

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COMPREHENSIVE REPORT

INTRODUCTION

Lesbian, bisexual, and transgender (LBT) women are a vulnerable and historically underserved population who are often without adequate access to needed health and social services. Barriers to care and services include: having no or inadequate health insurance, having low income, living in areas where there is a shortage of culturally competent health and social service providers, and cultural beliefs about health care and health care providers that reduce utilization of available services.¹

Ensuring that vulnerable populations have access to culturally competent health and social services is crucial for eliminating disparities and preventing disease. Research suggests that LBT women often do not access clinical services and, therefore, are at increased risk of not detecting diseases that can be more easily treated in early stages, e.g., breast cancer, diabetes, high blood pressure, and heart disease. In addition, some studies have indicated that LBT women may be disproportionately affected by some types of cancers, including breast cancer, lung cancer, and cancers caused by human papillomavirus. The combination of increased risk and the pattern of decreased service utilization creates higher rates of disease and early mortality.

Additionally, LBT women are a remarkably diverse population, containing members of all races and ethnicities. The barriers to health care created by LBT status are often further compounded by the additional barriers experienced by members of the communities of color. For example, representing 40 percent of uninsured women, Mexican American women have one of the highest uninsured rates in California. Language and cultural health beliefs present additional challenges to access.

Developing successful health and social service programs to address the needs of LBT women is a daunting task, because of the difficulty in adequately measuring the needs of often hidden and isolated populations. To ensure that interventions are culturally appropriate, members of the target population and gatekeepers must be involved in the community assessment process. Towards that end this needs assessment was commissioned.

¹ This review relies heavily upon the Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health--the nation's blue print for eliminating health disparities. The HP 2010 document is published by the Gay and Lesbian Medical Association, 2001.

GOALS AND PURPOSE

In an effort to identify the health care and community needs of San Diego lesbian-, bisexual-, and transgender- (LBT) identified women, the San Diego Lesbian, Gay, Bisexual, Transgender Community Center, with the assistance of The California Endowment, commissioned this needs assessment. The purpose of the needs assessment was twofold:

- 1) To develop a more complete understanding of San Diego LBT women's awareness of, experiences with, and utilization of health care services. Barriers to obtaining appropriate health care are also explored.
- 2) To develop a more complete understanding of San Diego LBT women's experiences within the larger San Diego LGBT community, with a particular focus upon ways that community organizations might better serve both their health care and general socio-cultural needs.

While this document can not provide final nor definitive solutions, it is our hope that it reflects more clearly *which* LBT women are less likely to access health care, what obstacles many LBT women face to obtaining appropriate health care, and what assistance they need from health care providers and community organizations to more fully participate in their care and in the community.

METHOD OVERVIEW

The needs assessment was designed to collect information from a diverse cross-section of women who were likely to represent a variety of experiences and perspectives regarding their health care needs as well as women's experiences within the larger LGBT community. Three primary data collection methods were used.

- 1) Surveys,
- 2) Focus Groups, and
- 3) Key Informant Interviews

A total of three hundred and sixty-eight (368) women participated in some aspect of this study. Specific attention was paid to securing a diverse and representative sample.

SURVEYS.

A brief survey focusing specifically on women's health care experiences was distributed to women during community events, through The Women's Resource Center at The Center, was e-mailed to women on a variety of email lists, and was available on The Center's website. Three hundred and two (302) surveys were collected. A copy of this survey can be found in Appendix A.

FOCUS GROUPS.

Individuals were invited to participate in focus groups in order to provide an opportunity to more fully capture the concerns of participants and to ensure that historically under-represented and hard-to-reach groups were represented in the data. Fifty-eight (58) women participated in the focus groups. Focus groups included: African American Women, Latinas,

Female staff of non-profit LGBT organizations, Bisexual Women's Group, North County Women's Group, Young Activist Women, Moms' Group, Women 50 and Over Group, Transgender (TG) Group, and a General Women's Group (all welcome).

Focus group questions were designed to be open-ended and to facilitate group discussions about women's experiences with their health care needs, within the community, and to extract information about service needs or gaps. The Focus Group Interview Guide can be found under Appendix A. All focus group sessions were recorded and then fully transcribed for data analysis.

KEY INFORMANT INTERVIEWS.

Ten (10) women identified as representative of, or leaders within, target subgroups participated in individual interviews. A copy of the Individual Interview Guide can be found under Appendix A. All interviews were recorded and then fully transcribed for data analysis.

DATA ANALYSIS.

Results from surveys were tabulated and descriptive statistics generated. Results from focus groups and key informant interviews were analyzed using the Maykut and Moorehouse constant comparative method of qualitative data analysis. The NUD*ist software package, NVivo was used to facilitate the data analysis process.

PARTICIPANT CHARACTERISTICS

SURVEY PARTICIPANTS.

Gender: Ninety-eight percent (98%) of the participants in this project identified as female. Among these, 9% identified as transgender Male-to-Female (MTF). Two percent (2%) of respondents left the question blank.

Sexual Orientation: The majority of participants identified as lesbian (65%). Another 17% identified as bisexual, 11% as heterosexual, and 3% as questioning.

Age: Respondents ranged in age from 16 to 75, with the average age of 38-years-old.

Ethnicity: Thirty-eight percent (38%) of the participants identified as women of color and 62% identified as Caucasian.

Education: Sixty-nine percent (69%) of the participants reported having some college education, 21% reported having an advanced college degree and 10% reported having some high school or a high school education.

Relationship Status: Fifty-one (51%) percent of the sample reported their relationship status as "single" and 49% reported being in a committed or partnered relationship.

HIV Status: Seven percent (7%) of the participants identified as HIV-positive.

Parental Status: Approximately one half (50%) of the participants identified as parents.

FOCUS GROUPS AND INTERVIEW PARTICIPANTS.

Gender: Ninety-eight percent (98%) of the participants in this project identified as female. Of these, 13% identified as transgender Male-to-Female (MTF).

Sexual Orientation: Seventy-six percent (76%) of participants identified as lesbian, 20% identified as bisexual, and 2% identified as questioning.

Age: Women ranged in age from 20-years-old to 65-years-old, with a median age of 42.

Ethnicity: A little over 1/3 of the participants were women of color (36%), 64% self-identified as Caucasian.

Income: A little less than half (43%) of the participants earned an annual income below \$35,000, while the other half earned more than \$35,000, with 17% earning \$100,000 or more a year.

Education: Forty-nine percent (49%) had completed some college education, 30% had advanced degrees, and 21% had completed high school.

Relationship Status: 56% were single, 44% were in partnered relationships.

HIV Status: Most of the participants were HIV-negative, however 7% identified as HIV-positive and 10% declined to state.

Parental Status: One quarter of the participants (26%) identified as parents.

HEALTH FACTORS.

Twenty-eight (28%) percent of the women reported smoking,

8% reported having a non-HIV STD,

31% reported having mental health issues,

22% reported having problems with drugs and alcohol,

13% reported experiencing domestic violence,

6% reported having cancer,

5% reported having heart problems, and

2% reported having HIV.

FINDINGS

HEALTH CARE CONCLUSIONS

1. The topic of health care is not a topic many LBT women report that they would consciously choose to discuss (except when specifically and repeatedly prompted) nor do they report spending a great deal of time thinking about health care or health care related messages. Therefore this historically underrepresented population may be very hard to reach with messages about health care related topics.
2. Lack of insurance continues to be an obstacle to accessing health care, as is experienced by one in five LBT women in this study.
3. Further, 50% of the parents in this study indicated that their children had no health care coverage either because they could not afford it or it was not a benefit offered by their employer.
4. Women who were facing a changed lifestyle as they aged and/or retired reported fears of growing older without adequate health insurance.

5. The most prominent concern of LBT women in terms of accessing health care as a lesbian, bisexual, or transgender woman was finding an “LBT-friendly” health care provider.
6. Despite the advanced levels of education represented by this sample, LBT women reported great difficulty finding consistent and reliable resources that would allow them to easily identify “LBT-friendly” health care providers.
7. Many LBT women reported turning to alternative types of health care in response to the questions concerning where and how they got their health care needs met. These alternative health care practices were mentioned both as preferred treatment methods as well as lower cost, more accessible alternatives to traditional Western medicine. Participants did not discuss, nor appear to make, a distinction between which treatment modalities (traditional or alternative) might be more effective for specific health care concerns.
8. The rates of a variety of health risk behaviors among the participants appeared high: tobacco smoking, drug and alcohol abuse, mental health concerns and domestic violence.
9. While rates of obtaining routine pap smears were better than expected, rates of obtaining routine traditional physicals (blood work, blood pressure, etc.) were below desirable levels, despite the age and education of the sample.

COMMUNITY PARTICIPATION AND CONNECTION

Much previous literature has suggested that in both the larger general population and the LGBT population, feeling connected to one's own community improves a community member's sense of self-worth, improves access to and awareness of available resources, reduces health risk behaviors, and contributes to overall health and happiness. While this study did not attempt to directly test those assertions, we did find evidence in the data to suggest that LBT women who experienced a greater sense of connection to the LBT women's community, as well as to the larger LGBT community, did experience fewer health care challenges, had more information about available resources, and expressed much more hopeful views of themselves and their possibilities.

In this portion of the needs assessment, we attempted to assess participants' sense of connection to the broader LGBT community (or lack thereof) and the obstacles to participants feeling connected and able to fully participate in that broader community.

COMMUNITY PARTICIPATION CONCLUSIONS

- All participants in this study spontaneously discussed the ideas of “connection”, community, and friendship/support networks. Most described small, tight-knit groups of family and friends as their primary source of connection, support, and information.
- Repeated over and over, with many variations, was a reported desire to belong to a/the “larger” community.
- Unfortunately, this desire to participate or feel connected to a larger community was, for many women, often paired with a perception of either not fitting in with some section of the community, or a feeling that the women's community as a whole was fragmented or rejecting of some women in some way.
- The overwhelming majority of participants described either perceiving or experiencing *disconnection* in their attempts to participate in, or their perceptions of, the San Diego women's community.
- Many women articulated a perception that the primary barriers to their experiencing a sense of “belonging” or community include what they described as the fractured, or cliquish, nature of the San Diego LBT women's community. Specific divisions frequently discussed included perceptions of divisions created by money/power/prestige and age.
- For women who described themselves as having multiple, valued identities, being supported or valued in one identity was insufficient.
- The idea of needing to see oneself “reflected” or “mirrored” in the broader community was repeated in both obvious and subtle ways throughout the focus groups and key informant interviews. The most often identified other identities were ethnicity, gender identity, sexual orientation, and parental status.
- Participants who described themselves as “regular” without multiple identities or strong affiliations to either groups or issues expressed also feeling disconnected from the community as a function of their “just being regular.”

- Other types of community involvement or means of participating/connecting were explored, specifically civic participation and giving time or money.
- Sixty-one percent (61%) of participants described participating in civic or political activities. The most commonly discussed political activity participants identified was voting.
- Seventy percent (70%) of the participants described giving either time or money to participate in the larger community. Most participants (64%) identified giving their time rather than their financial resources. The most frequent reason given by participants for deciding to give was that an issue or organization had personally become relevant to them or their family.
- Service and activity gaps were explored with participants, yielding a wide-ranging list of services and opportunities they wished were available to them.
- Over and over again, women described how difficult it was to find this connection, how so many organizations failed to meet this need, and how deeply disappointed they were that no one could create this experience for them.

WHAT THE PARTICIPANTS DID NOT SAY: POWERLESSNESS

In any study of this kind, often what is not said is as important as what is said. Many of the women who participated in this study were successful, well-educated women. As reported earlier, 69% of the women had attended at least some college and 21% had graduate degrees. Thirty-two percent of the participants made over \$50,000 a year.

Yet, throughout the interviews, participants described all of the places and people in which they could not find a “mirror experience.” They described in direct and indirect ways their deep longing for connection and a sense of belonging to a community larger than themselves. Over and over again, women described how difficult it was to find this connection, how so many organizations failed to meet this need, and how deeply disappointed they were that no one could create this experience for them.

The participants were more than sad, they were angry. Through their report of their perceptions of the male community, they appeared to believe that men were given this experience of connection, but that the women were not. The participants were equally disappointed and angry at each other for the “cliques” and fragmented quality of the community. Many described feeling unimportant, neglected, and invisible. The anger and hurt appeared to fuel an even greater sense of disconnection and mistrust that may motivate women to move farther away from each other, rather than closer together. The absence of recognition of their power to create or influence connection was profound in these interviews.

IMPLICATIONS FOR HEALTH CARE PROVIDERS AND HEALTH-RELATED PROGRAMMING

1. This study indicates that the fear of sexual orientation bias among LBT women by medical care providers serves as a significant barrier to care, even among women who have adequate financial resources and/or health care insurance. If a provider wishes to

- increase the utilization of their services by LBT women, clearly three things will be required:
- a. Perception changing interventions/marketing
 - b. Targeted and effective outreach to the LBT women's population to ensure that LBT women become more aware of their services
 - c. Effective training programs within the provider organization to ensure that negative interactions do not take place. (Bad experiences spread and reinforce perceptions and undermine attempts to change perception.)
2. Additionally, this study provides some evidence that, as a group, LBT women hold a generally negative view of traditional medicine and traditional medical care providers. Success with this population will also likely require perception-changing efforts directed toward changing this view.
 3. This study indicates that, as a group, LBT women are inclined toward the use of "alternative" or "non-traditional" health care. In addition, the participants also indicated a lack of knowledge about ways to effectively combine complementary approaches with traditional medicine or the ability to discern the specific areas of strength of each. Providers seeking to serve this population will likely increase their effectiveness and reduce barriers to care by offering accurate information about effective strategies for combining the two different medical approaches.
 4. One in five LBT women in this study do not have health care insurance. Fifty percent of the women who have children do not have health care insurance for their children and 50% of the women who were in significant committed partnerships, reported that their partners had no health care insurance. Service providers can reduce barriers to care by providing information to LBT women about low- or no-cost programs that can provide assistance in obtaining health care services.
 5. Participation in the development of a listing or resource directory of "friendly" providers for LBT women would significantly reduce one barrier to care.
 6. The rates of health risk behaviors in this study suggest that health care providers should provide screening and referrals to culturally competent treatment providers for LBT women regarding drug and alcohol abuse, domestic violence and smoking cessation.
 7. Programs that hope to provide health education, community health services or health messages will likely need to be combined with other, more "fun" or interesting activities. Women report a low level of interest in programming that is health specific.
 8. Women in this study appear to be aware, in general, of the need for pap smears and mammograms, however there was less awareness of the need for (as well as less utilization of) basic health screenings, e.g., heart health, diabetes screening, or blood pressure screening.
 9. As in many studies regarding barriers to access for populations seeking or needing health care, this study found evidence that simple agency or provider procedures inadvertently serve as barriers to care: difficulty reaching someone on the phone to provide information or schedule appointments, difficulty filling out or obtaining information about payment options or service eligibility requirements, the lack of child care on-site for medical appointments, hours of operation (particularly after-

work hours), the length of wait for service, and the lack of repeated access to the same providers.

IMPLICATIONS FOR SERVICE PROVIDERS AND ORGANIZATIONS

One of the findings in this study mirrored other studies; the greater the community involvement and sense of belonging, the greater the likelihood that the participants had accurate health information and accessed health care services. Therefore, connecting women to and increasing their participation in community organizations and activities is likely to increase the access to health care for women.

The clearest set of implications for LGBT community organizations and health care/social service providers involves the wide-spread perception amongst these LBT women that they are not welcome even in LGBT community-based organizations and the belief that their concerns will not be addressed nor represented. While this finding is not surprising among a historically underserved and underrepresented population, it is nonetheless the most important, because until this perception is changed or managed, real progress toward community inclusion will be unlikely.

Historically underserved populations often come to understand and/or perceive themselves as less valued and less important relative to the larger societal whole. Over time, the “unwanted and unrepresented” perception becomes a part of the group’s world-view, such that out of disappointment, frustration and low expectations, they withdraw their attention and participation. Such perceptions are extremely resistant to change, in no small part because changing perceptions requires encountering new experiences. New experiences cannot be had if there is no longer group-level participation. This phenomenon is not unique to LBT women, but is instead generally true amongst all historically underserved and underrepresented communities. What is notable in this study is that the negative perception held by LBT women applies to *the larger LGBT community*, not just the broader “mainstream” society.

In order to change these perceptions and negative expectations, the consistent effort and dedication of resources is required. Without a changed perception, attaining significant participation by LBT women in the maintenance of their own health will likely not be possible.

IMPLICATIONS FOR LGBT COMMUNITY ORGANIZATIONS AND PROGRAMS

The following suggestions may be helpful to those organizations interested in increasing the comfort and participation of LBT women in their organization.

1. The breadth and depth of the negative perceptions held by LBT women will require the organization to:
 - a. Create a plan that will outline the steps required across several years to identify, recruit, sustain, and develop the participation of a variety of women among its membership base, volunteer base, staff, and board of directors. Less organized and well-planned efforts are not likely to succeed and may result only in wasted expenditure of resources.

- b. Create a targeted communications plan with the goal to assist the organization in recruiting women participants to its client, donor, supporter, and volunteer bases. The communications must be consistent and repetitive and extend across a long enough period (several years) to begin to impact all levels of perception. This requires a significant commitment of resources and funds. Less coordinated or strategic efforts will not likely produce the desired result, and may result only in wasted expenditure of resources.
2. Given the fragmented nature of the women's community, a generalized, single source, outreach approach to the LBT women's community will continue to prove difficult. A multi-pronged outreach and communications approach will be required. The data clearly indicate that there are not effective, centralized vehicles in place to reach even the majority of women. While the long-term goal for any organization may be to develop a comprehensive list of women's contacts, no such list currently exists. Instead, the fragmented community has many small group networks connected in a variety of ways. Successful outreach will, therefore, likely need to employ **ALL of the following strategies** in order to adequately reach a majority of the target population:
 - a. Communications and marketing materials need to be more specifically targeted to the (multiple) sub-groups and types of women who might most need a service or enjoy the activity to be advertised. General "all women's" advertising will not likely reach those with a matrix of important identities: women of color, parents, bisexual women, TG women, etc. It will be necessary to outreach to *all* groups, not just one of them, in order to have a significant impact.
 - b. Advertising will need to be placed in a *variety* of papers including the GLT, Lavender Lens and small neighborhood newspapers or newsletters. However, a significant number of women do not report reading these papers, indicating that this single strategy will be insufficient to promote any message.
 - c. E-mail postings are a significant source of information for many LBT women. Organizations that have the capacity should consider the continual building of a comprehensive women's email list as an outreach and informational tool. Organizations without that capacity should consider links to and postings in the communications of those organizations with the capacity. As many smaller women's network groups have email lists, an effort should be made to ensure that women from those lists are included in this project so that information can be forwarded to these smaller lists.
 - d. For women who do read local community papers, an increase in the number of public service announcements, press releases, and news announcements for women will likely increase the visibility of efforts to involve them in the community.
 - e. There are a variety of women's nights, women's gatherings, and a few women's spaces in the San Diego LGBT community. Some women report that flyers and information that is available to them at these venues are their primary source of community information.
 - f. The nature of the existing women's community (small friendship networks based primarily on close, personal relationships) makes the continued use of

- personal contact important for organizations that wish to reach out to the LBT women's community. Personal telephone calls to invite women to events or activities will likely be effective.
3. There is a clear need for increased social and educational programming for women in the LGBT community. However, such programming will likely need to pay as much attention to the overall design as to the specific content of the programs. The following are some program design suggestions extracted from the data in this study.
 - a. Program design should include a women's community advisory board, in order to increase community involvement in the program planning.
 - b. The most frequently listed needs expressed by the participants involved activities that were low-cost, demanded little from them (were themselves entertaining: art exhibits, music, comedy, movies, etc.) and were easy to access.
 - c. The recruitment, retention and development of groups of project-specific volunteers may help to increase outreach, ensure programs meet the goals and expectations of the targeted populations, and assist in providing a group of women who are "reflecting" the target group.
 - d. Clear attention in the advertising and design should be given to the needs of specific groups and to the matrix of identities valued by women (ethnicity, sexual orientation, age, wealth). Special attention and programming needs to be designed for women of color, parents, TG women, and bisexual women.
 - e. Safe and reliable child care needs to be available at an increased number of community events and activities in order for parenting women to participate.
 4. Many community organizations have expressed concern regarding the historic inability of women's programming to generate sufficient numbers of female donors or community support to sustain their programs. The findings of this study do indicate that many women are not aware of, nor educated about, the power that lies in giving (e.g., the power to set program agendas or to ensure the stability of programs they think of as important). Additionally, many women expressed feeling as if they do not often have "extra" resources to give. Clearly education and community dialogue will be required before the existing obstacles to participation can be addressed.

IMMEDIATE RECOMMENDATIONS FOR THE CENTER

Since this needs assessment was commissioned by The Center, the researcher offers, in addition to the above suggestions, the following set of recommendations for immediate implementation.

- Use this needs assessment and the information contained in it as a catalyst for community-wide discussion of the needs of women and potential for increasing the inclusion of women in Center activities and perhaps community-wide.
- Develop a women's advisory committee in order to continue development of gender appropriate programs and activities.
- Develop targeted programming or activity mechanisms that will allow increased attention to the needs of women of color, parents, TG women, and bisexual women.
- Convene an "LBT-friendly" advisory group of health care and health-related providers who can assist The Center with the development of a LBT-friendly

women's resource guide (hard print and web-based) that is updated annually. This resource guide should also include social service and health supportive/education programming.

- Develop a brief set of materials designed to educate community-based health care providers, e.g., needs, perceptions, fears of LBT women and easy to implement solutions.
- Develop a strategic marketing/communications plan for communicating with LBT women about women's opportunities and activities.
- Convene a working group focused upon the identification and development of LBT women's leadership within the LGBT community and in the larger community as a whole.