



Alleviating Stigma from the HIV+ Community

Mario Alberto Viveros Espinoza

Comparative Ethnic Studies Major

California Polytechnic State University San Luis Obispo, CA 2015

Comparative Ethnic Studies Department
CALIFORNIA POLYTECHNIC STATE UNIVERSITY

San Luis Obispo, CA

2015

Copyright © 2015

By

Mario Alberto Viveros Espinoza

APPROVAL PAGE

TITLE:

Know Your Status

Alleviating Stigma from the HIV Positive Community of San Luis Obispo, CA

AUTHOR:

Mario Alberto Viveros Espinoza

DATE SUBMITTED:

June 2015

Dr. Grace Yeh

Mario Alberto V. Espinoza

Abstract

The purpose of this project is to alleviate stigma from the HIV community in San Luis Obispo, CA by creating an outreach program, “Know Your Status,” that raises awareness of HIV education and prevention. Research on HIV stigma and on ideologies for program development and implementation shows that HIV positive individuals face both internalized and externalized stigma. Program development and implementation can be effective by assessing and addressing the specific needs of those living within the community. This project includes the data needed for program development and implementation, collected through anonymous surveys from HIV positive community members, interviews with professionals in the field of HIV health services, and my volunteer service at the AIDS Support Network. Compelling insights from this fieldwork research as well as from the “Know Your Status” event feedback lead to the conclusion that alleviating stigma would be most effective through education of pre-exposure prophylaxis (PrEP) and by providing the community with compelling responses and messages from HIV positive community members. It is my hope that this project be used for future implementation of outreach events to educate the community and normalize the conversation in regards to HIV, thus alleviating stigma from the HIV community.

In Memory of Juan Espinoza

My father's last words to me before he passed away from metastasized lung cancer were, "Hechale muchas ganas en la escuela mijo, supérate," which means, "Give it your best in school son, and better yourself." Those last words were the perfect words for me to hear because now more than ever I am driven to persevere and succeed in all of my educational endeavors as well as my personal ones.

Special Thanks

My biggest thank you goes to the HIV positive community for participating in the anonymous surveys that were distributed by the AIDS Support Network. Your compelling responses have touched my heart and raised awareness of HIV stigma to the broader community of San Luis Obispo.

Thank you to the AIDS Support Network for being the strongest collaborator for this project. As a Comparative Ethnic Studies major, I recognize the importance of collaborative knowledge, and it is of utter importance when representing the community you work with to do so in a fashion that not only includes them, but involves them in every way possible. Leah Campbell, a third year Food Science major at Cal Poly, contributed to this project immensely by co-coordinating and organizing the event “Know Your Status.”

Don Golinveaux is a graduating senior who helped by facilitating the focus group and constructing a canvas model for organizational purposes.

Thank you to everyone who contributed their time in any way and supported me through this journey.

TABLE OF CONTENTS

Notes on Terminology	xii
Acknowledgments	xvii
Preface	xix
Chapter I: Introduction	1
Part One: Developmental Research	
Chapter II: Literature Review	7
Chapter III: Research Methods	21
Chapter IV: Results and Discussions	27
Chapter V: Conclusion	37
References	41
Part Two: “Know Your Status” Outreach Program Implementation	
Chapter VI: Planning and Promoting	45
Chapter VII: Programmatic Details	51
Chapter VIII: Outcomes	55
Chapter IX: Obstacles	59
Chapter X: Final Thoughts	63

Appendices

Appendix A: Institutional Review Board Forms	67
Appendix B: Anonymous Surveys	71
Appendix C: Interview with Terry Comer	91
Appendix D: Interview with Dr. Taylor	101
Appendix E: Focus Group Session	117
Appendix F: Grant Application	131
Appendix G: Press Release	141
Appendix H: Timeline for the Day	143
Appendix I: Business Cards	145
Appendix J: Flier	149
Appendix K: Instagram Photo Campaign (#KNOWYOURSTATUSCP)	151

NOTES ON TERMINOLOGY

Acquired Immune Deficiency Syndrome (AIDS) - A disease characterized by fever, weight loss, lymphadenopathy, and the occurrence of opportunistic infections and malignant tumors, associated with a reduction in the number of helper T lymphocytes in the blood, and now known to occur as a late stage of infection with human immunodeficiency virus (HIV).

AIDS Support Network (ASN) – Since 1984, the ASN has been known to give support services for community members living with HIV/AIDS and Hepatitis C. It is community-based as well as non-profit. In 2009, approximately \$52 million dollars were cut throughout California as budget cuts were approved by Sacramento lawmakers. Consequently, the County AIDS Program was removed, leaving the ASN to become the primary source for supports services for the community.

The Center for Health and Prevention - The Center for Health and Prevention provides STI prevention services and HIV testing to the community at two friendly and confidential clinics located in Arroyo Grande and San Luis Obispo.

Community Action Partnership of San Luis Obispo CAPSLO – Community Action Partnership of San Luis Obispo County is a nonprofit agency that focuses on helping people and changing lives through serving nearly 40,000 persons across Central and Southern California. We are committed to eliminating poverty by empowering individuals and families to achieve economic self-sufficiency and self-determination through a comprehensive array of community-based programs.

Dual diagnosis - The concurrence of severe or acute mental illness with HIV risk or infection (Penner 128).

Educational Resources on Sexuality E.R.O.S. – Program under P.U.L.S.E. that offers an array of services such as presentations and consultations, as well as sponsor events on topics covering sexual and relational health.

Highly Active Anti-retroviral Therapy (HAART) - Halts the replication of the HIV virus in the body, in turn dramatically reducing the viral load as well as the progression to AIDS for those who are infected with HIV (Borenstein et al. 14).

Human Immunodeficiency Virus (HIV) - a retrovirus which chronically infects cells of the human immune system and causes AIDS, and which is transmitted mainly by sexual activity, by contaminated blood products and needles, and between infected mothers and their babies during delivery or breastfeeding; an isolate, strain, or type of this virus.

Institutional Review Board (IRB) - Research conducted by American University affiliates using human participants is overseen by American University's Institutional Review Board (IRB). Its purpose is to facilitate human subjects' research and to ensure the rights and welfare of human subjects are protected during their participation.

LGBTQIA – Umbrella term for Lesbian, Gay, Bisexual, queer, Transgender, Intersex, and Ally

MSM – Men who have sex with men

Pre-Exposure Prophylaxis (PrEP) - Pre-exposure prophylaxis, or PrEP, is a way for people who do not have HIV but who are at substantial risk of getting it to prevent HIV infection by taking a pill every day. The pill (brand name Truvada) contains two medicines (tenofovir and emtricitabine) that are used in combination with other medicines to treat HIV. When someone is exposed to HIV through sex or injection drug use, these medicines can work to keep the virus from establishing a permanent infection. (Centers for Disease Control and Prevention)

Peers Understanding, Listening, Speaking, and Educating P.U.L.S.E. - Peer Health Education program that supports the health and wellbeing of all Cal Poly students.

Sero-discordant - Couples with one person who is HIV-positive and one who is HIV-negative are sometimes called "serodiscordant" or "mixed serostatus." "Sero-" refers to blood serum. "Serostatus" refers to whether someone has HIV infection or not.

Sexually Transmitted Infections (STIs) – Infections that are transmitted through sexual contact.

Test of Functional Health Literacy for Adults (TOFHLA) – A test which measures their reading comprehension scale and breadth of health status, knowledge and understanding of health status, perceptions of primary care givers, and perceptions of anti-HIV treatments.

Transmittability – The likelihood of something, like a disease, to be transmittable to another person.

Acknowledgments

Dr. Grace Yeh, Dr. Kate Martin, Dr. Jenell Navarro, Dr. Denise

Isom Yolanda Tiscareño

Katie Harris

Dr. Denise Taylor, Dr. Richard Presnell, Paul Urban

Terry Comer

The AIDS Support Network

Leah Campbell, Derek Sisting, Kristen Erb

CAPSLOS's The Center

Charley Newel

HealthWorks

Don Golinveaux

Cross Cultural Centers

Que Dang, Tammie Velasquez, Sandi Wemigwase, Adam Serafin, William

Hatchet Selene Roman, Sydney Tanimoto

Movimiento Estudiantil Xican@ de Aztlan (M.E.X.A.)

Preface

I am an Ethnic Studies major at Cal Poly. I grew up in the city of Modesto, California that was once known as a rural city that was booming with agriculture. Eventually, Modesto was subject to urbanization and a lot of the agricultural land was developed into residences and enterprise zones. After some personal turn of events I found myself residing in San Luis Obispo County by 2010.

Growing up within a marginalized community and being part of an underrepresented group in the university relates to my project because we share similar experiences in regards to estrangement due to stigma. Growing up as a Gay Chicano (Mexican-American) male with cultural backgrounds such as African and Mexican Indigeneity, I have encountered barriers in education that were due to language and acceptance. Being a member of minority groups, such as the Indigenous community and the LGBTQIA community, I have encountered circumstances where someone will dislike me and make it difficult for me to advance because of a bias towards minority groups. Feelings of isolation recur because of the lack of diversity and peers to identify within the Cal Poly community.

Reflecting on my time living in Modesto, I can remember being part of a social circle that was mostly men who had sex with men. The gay community I associated myself with would party and travel to other cities to enjoy the nightlife and, on occasion, engage in HIV testing that was hosted outside of the night clubs. The topic of testing is in constant conversation where I am from and prominent in those metropolitan cities. Re-introducing this topic to Cal Poly and the

broader San Luis Obispo community has been something that has been on my mind since my arrival in 2010.

Chapter 1: Introduction

The mission of this senior project includes alleviating HIV stigma, researching community programs and effective planning, and creating a program of outreach to raise awareness of HIV education and prevention. In our time at Cal Poly we have been made aware of the opportunities there are for improving diversity and inclusivity throughout campus whether it be the lack of representation of people of color or the work environment for faculty and staff. But the conversations on epidemics (HIV) that affect us all have been fairly limited. Did you know that in 2013, the Center for Disease Control and Prevention estimated the majority of diagnosis for HIV by age group to be most prevalent for people ages 20-24? Did you also know that Pre-exposure Prophylaxis (PrEP) has a 99% efficacy rate at preventing HIV for non-HIV infected persons? When is the last time you got tested for the virus? These are the topics that the Cal Poly community does not actively engage in conversations with.

To address the gap in conversation, in Part I of this project I cover the research that has been conducted to understand the needs of the HIV positive community and the broader community of San Luis Obispo. Additionally, I include in the literature review sources that were necessary for effective community planning and understanding the differences between rural and urban communities. The *Epidemiologic Profile HIV/AIDS in San Luis Obispo County* by Penny Borenstein, Pam Dudley, Ann McDowell, Geri Beaman, and Christine Gaiger provides awareness on the realities of the HIV epidemic within San Luis Obispo County. I wish to introduce this awareness to the broader community of San Luis Obispo about the scope of HIV/AIDS in our area and demonstrate that this in fact is an epidemic that affects all of us. Many consider HIV to be a “gay disease” meaning that it only concerns the Lesbian, Gay, Bisexual,

queer, Transgender, Intersex, and Ally (LGBTIA) community and nobody else. While it is true that the highest risk of contraction is between men who have sex with men (MSM) (Borenstein et al.), it is not a disease that is exclusive to gay males. What is more disturbing is that when HIV is in conversation, it is mainly associated with being “unclean” or undesirable. Many times I have sat in different areas around campus and have heard students say things like, “Get away from me I don’t want your AIDS.” Or, “Your nose looks like it got infected with HIV.” Comments like these are not only problematic, they are hurtful and dehumanizing to people who identify as HIV positive. These are examples of stigma.

Through my field research, working with the AIDS Support Network (ASN) as a volunteer and interacting with the HIV positive community, I was able to discover the needs of the HIV positive community in San Luis Obispo and answer the following questions: Why is there such a stigma in regards to HIV, and what can be done to dispel the stereotypes associated with that stigma? Stigmatization is not just the external impressions that are imposed by the general population onto the HIV positive members of this community, but also an internalized condition that have been adopted by the HIV positive participants in this study. Compelling responses by the participants of the anonymous survey are further discussed in Chapter IV, and through the data analysis I found that they believe that alleviating HIV stigma could happen through educating the broader community of San Luis Obispo on the topic. I also found that the factors associated with stigmatization are not only having a positive diagnosis, but also include the lifestyle changes that coincide with their families, social networks, and health care.

The preliminary research supported the development of the “Know Your Status” event and paved the way for an effective outreach program that was intended to raise awareness of

HIV stigma and educate the audience. Part II is more of an explanation of what was required for planning and promoting “Know Your Status.” It provides guidelines for anyone that may want to replicate a similar outreach program in the future. Planning included reaching out to local organizations for funding and representation, businesses for donations, clinics for certified HIV testing counselors, and campus organizations for recruiting volunteers to help facilitate the event for a successful day. Details about weekly meetings with my strongest collaborator, ASN, are also given to provide context on what was discussed during those times. The funds that were acquired through a grant resulted in effective promoting. I explain how the funds were used and what was done to promote the event. All the chapters in Part II could be used as guidelines to ensure a successful event, especially when looking at the programmatic details. The outcomes of this event support my argument that education is needed. I distributed surveys that quantified the audience’s knowledge and analyzed the results to determine their knowledge before and after the event. As I suspected, the event increased participants’ knowledge about HIV stigma and why it’s important to know your status.

Cal Poly could benefit from events like this because it encourages fostering inclusivity and diversity. Furthermore, the broader community of San Luis Obispo benefits, too, by encouraging the population to get tested for HIV and to exercise safe sex practices.

Part One: Developmental Research

Chapter 2: Literature Review

Hypothesis: By researching different community programs available across different areas (rural and urban) and by understanding the language used in regards to HIV and stigma, opportunities can be identified within San Luis Obispo for development and implementation of an active outreach program for HIV support, prevention and education.

Epidemiologic Profile of HIV/AIDS in San Luis Obispo

HIV/AIDS has spread to about 1.2 million people in the United States, giving us an idea of how much this epidemic has affected not only our nation but our community of San Luis Obispo as well. I wanted to understand the epidemic at a more concentrated level so I chose our town of San Luis Obispo, named “Happiest City in America” by Oprah. *Epidemiologic Profile of HIV/AIDS in San Luis Obispo* by Penny Borenstein, Pam Dudley, Ann McDowell, Geri Beaman, and Christine Gaiger is the only available study on the prevalence of HIV in San Luis Obispo County. This report for the SLO County Health Department follows the guidelines suggested by the Centers for Disease Control and Prevention (CDC) and Health Resources Services Administration (HRSA) to develop an in-depth report explaining the progress of HIV prevention and community planning. To structure their report and relay the analysis of the data found within our community, they focused three key questions that would demonstrate the efficacy of the study. Those questions are:

1. What are the sociodemographic characteristics of the population?
2. What is the scope of HIV/AIDS in our community?
3. Who is at risk for becoming infected with HIV? (Borenstein et al. 5)

These three questions serve as components that aid in the production of HIV prevention services and community planning for San Luis Obispo.

When planning to provide a service or program for the community it is important to know the characteristics of the population. According to the 2010 Decennial Census, San Luis Obispo County has a population that is 71.1% white, non-Hispanic, 20.8% Hispanic, 2.6% African-American, 4.5% Asian, and 8.3% comprised of other categories, including Native American, Alaskan Native and Pacific Islander (Borenstein et al. 7). As Borenstein et al. explain, “The County covers 3,316 square miles, and according to the United States Census Bureau, has an estimated population of 276,443 in 2013” (7). Additionally, “as of June 2013, there was a total of 626 persons reported living in San Luis Obispo County who were HIV or AIDS positive. Of these, 357 lived in correctional facilities, and 269 were reported as living in a community setting” (Borenstein et al. 17). It is also important to note that HIV cases in Borenstein et al.’s report are broken down as community cases and cases of incarcerated persons. Since my work is being done within the community outside of a correctional facility I focus on the data that is more relevant to non-incarcerated persons.

The racial breakdown of HIV cases in the community of San Luis Obispo outside of correctional facilities is as follows:

White	74.3%
Black	6.9%
Hispanic	23.8%
Other/ Unknown	18.8%

*Other includes Native American, Alaskan Native and Pacific Islander. (Borenstein et al. 7)

Knowing the statistics provided by Borenstein et al. helps us understand the scope of HIV within the county in relation to the sociodemographics of San Luis Obispo.

To alleviate stigma in regards to HIV, we need to understand the scope of HIV/AIDS in our community of San Luis Obispo, as well as the realities that have been found within this report. First we can look at the rate of exposure. For community HIV cases, Borenstein et al. identify men who have sex with men (MSM) as “by far the highest risk category, with 56.4% of cases falling into this category, with the next largest category being heterosexual contact. Heterosexual contact includes females who have sex with bisexual men and HIV positive men” (12). The greatest risk for men is MSM, while the greatest risk for females is heterosexual contact and the use of injected drugs, such as heroin (Borenstein et al.13).

Borenstein et al.'s report offers statistics that propose that HIV cases are dwindling: "In 1989, the cumulative case fatality rate was 90.8%, however by 2013, the cumulative case fatality rate had dropped to 50.9%" (14). This decrease is due to Highly Active Anti-retroviral Therapy, or HAART (Borenstein et al. 5). In essence, HAART halts the replication of the HIV virus in the body, in turn dramatically reducing the viral load as well as the progression to AIDS for those who are infected with HIV (Borenstein et al. 14). This therapy has prolonged the lives of many people in San Luis Obispo and has by and large given hope to newly diagnosed individuals.

Borenstein et al. make a great point when they say "while the trend in progression from HIV to AIDS continues to decline, the HIV epidemic is far from over, and in fact could be in danger of increasing its spread through the population, in part due to a large number of HIV+ persons being unaware of their status. While cases of AIDS have declined, the prevalence of HIV in the population is increasing" (21).

Who is at risk for HIV contraction? Put quite simply, anyone is at risk. The report states that, "a key strategy in any HIV/AIDS program is to prevent HIV transmission in individuals, before the tragedy of HIV and AIDS enters their lives. To do this requires constant surveillance, education and prevention efforts (Borenstein et al. 21)." If awareness of HIV stigma was spread through education and prevention efforts then the scope of HIV/AIDS would minimize.

The spread of sexually transmitted infections (STIs) is considered a marker for behavior that can and does spread HIV. Someone that has been diagnosed with an STI may have participated in unsafe intercourse (unprotected sex), a mode of transmission for HIV. STIs can also increase the chances of becoming infected with HIV. Borenstein et al. explain that these STIs, such as syphilis and herpes (HSV):

can cause open sores that give HIV an increased chance of entering the bloodstream. HSV is the most common genital co-infection in HIV infected men and women (although not reportable in California), and HIV infectiousness from men to women is increased by the presence of STIs. Monitoring STIs allows the AIDS Program to estimate the prevalence of risky sexual behavior occurring in the population. (18)

Their description shows just how vulnerable someone with an STI is to contracting HIV.

Program Models and What to Consider for Planning

I came across different programs that one may consider for program implementation that provide a sense of community and overall life satisfaction. These include a social networking format, and two programs that are readily available for Cal Poly students: Peers Understanding, Listening, Speaking, and Educating (P.U.L.S.E.) and Educational Resources on Sexuality (E.R.O.S.). Programs could be essential in training physicians to provide for HIV positive persons in rural communities, such as San Luis Obispo because of the lack there of HIV specialists. Currently there are only two that service the HIV patients both in the community and in correctional facilities. This warrants a sense of urgency that demands for program implementation to be seriously considered.

In consideration of program development, social networking may be a viable option. In “How does Online Social Networking Enhance Life Satisfaction? The Relationships among Online Supportive Interaction, Affect, Perceived Social Support, Sense of Community, and Life Satisfaction” by Hyun Jung Oh, Elif Ozkaya, and Robert LaRose, they argue that social

networking may enhance quality of life, specifically focusing on two psychological outcomes, sense of community and life satisfaction. As Oh, Ozkaya, and Rose explain, “Social support, defined as the resources or aids exchanged between individuals through interpersonal ties, is one of the key benefits that social networking site (SNS) users perceive from online social networking” (70). If there is a support system that is developed to positively engage with newly diagnosed individuals with HIV, then this will contribute to their life satisfaction. As stated by Oh, Ozkaya, and Rose, “Positive emotions and affect have been studied and confirmed as key predictors of life satisfaction” (71). Sense of community is the feeling of belonging to a particular group within which members share similar characteristics and seek each other for help (Oh, Ozkaya, and Rose 71). These definitions--social support, positive emotions and affect, and sense of community--are important in development of the parameters for which support programs can be founded upon. Current studies “acknowledge that social support seldom directly influences negative affect, but can buffer negative influences of stressful situations on one’s psychological health” (Oh, Ozkaya and Rose 78). This is beneficial to know when considering the development of a social support program whether it be social networking or real world interactions.

One article, “Developing the HIV Workforce: A Case Study of a Training Model for Inexperienced HIV Providers,” focuses on training for HIV professionals in the medical field such as HIV Clinicians and Specialists. One-third of expert HIV-patient providers are expected to retire within the next 10 years, resulting in a critical shortage of clinicians experienced in providing care to HIV-infected individuals (Jacobson et al. 1502). Developing a program for HIV outreach and prevention would educate attendees on this particular issue because if an

expected third of expert HIC-patient providers retire within, who's to say that it won't be the two that serve our community? More importantly, what does that mean for the HIV community in regards to seeking care and treatment? Physicians need to be trained to effectively treat HIV-infected patients and build on caseloads to serve the rural communities. Jacobson et al. express that treatment of HIV-infected individuals and decreasing their viral load could have a public health benefit, which would be the reduction of rate of transmission in a community (1507). Knowing facts like this can have a positive impact on individuals in the community who are HIV positive, in turn creating a sense of security that with treatment of HIV they are reducing the rate of transmission. Most notably, Jacobson et al. express that "individuals in rural areas are more likely than their urban counterparts to engage in high-risk behaviors such as methamphetamine abuse and, for men who have sex with men, are more likely to have sex on their first encounters with partners they find on the Internet" (1503). Assessments of risk in rural areas should be taken into consideration for evaluating potential high-risk behaviors within the San Luis Obispo community. For example, dating applications that are commonly used for hooking up such as Tinder, Grindr, Scruff, Jack'd, and the "Casual Encounters" section on Craigslist may be perpetuating risky behavior in San Luis Obispo, due to the fact that MSM are prone to engage in sexual behavior with partners they may meet on the internet.

San Luis Obispo (SLO) is a rural area, meaning it is not a metropolitan area or big city. The area we live in and the residents within it, in regards to program development and implementation, are going to require a needs assessment. Susan Reif, Kathryn Whetten, Jan Ostermann, and James L Raper explain in their article, "Characteristics of HIV-infected Adults in the Deep South and Their Utilization of Mental Health Services: A Rural vs. Urban

Comparison,” that service planning for HIV-infected individuals must include assessing and addressing the specific needs of those living in rural areas (15). By assessing the needs of SLO’s community members, we can serve them effectively. Reif et al. also inform us that “understanding the utilization of mental health services by HIV-infected individuals living in rural areas is an essential first step in determining whether needs are being met and identifying the most optimal ways to address psychiatric symptoms in these areas” (10). Although there is access to mental health services here in San Luis Obispo, how many HIV positive individuals in the community are actually taking advantage of these services, and if they are not, then why not? Reif et al. identifies that “the stigma often attached to mental illness in rural areas may contribute to reluctance to seek services, as there are many fears about confidentiality in rural mental health settings” (15).

On our campus we have the P.U.L.S.E. and E.R.O.S. programs that are meant to educate peers on sexuality among other things. These resources are available to students and are provided by peer educators. They use a variety of tools to educate peers on sex, for example, a video clip to demonstrate impacts of being diagnosed with HIV. Meg Rust explains in her senior project, “Improving Sexual Health, P.U.L.S.E., and E.R.O.S. at California Polytechnic State University, San Luis Obispo;” that, “In the clip from Rent, portrayed is a character whom [sic] has just found out he may be infected with HIV. The clip is intended to show the dramatic changes to a life that may be made through risky sexual behavior” (Rust 11). This was part of a module that E.R.O.S. uses to educate peers called “running with scissors.” Running with scissors is a thorough tool for presenters to educate their peers while keeping them engaged (Rust 11). The common symptoms of HIV that Rust stated were night sweats, chronic diarrhea, high fever/continued illness, chronic

fatigue, skin discoloration, weight loss, and dizziness (23). The programs that are accessible to students have educated the campus community on HIV symptoms and how HIV has affected people's lives.

Importance of HIV Health Literacy and Acknowledgement of Stigma

E.R.O.S. has had success in planning these educational modules. Rather than replicating their successful presentations I want to understand further what goes into planning to educate a community about health. There were two methods of planning mentioned, Expressive and Symbolic. “Expressive planning voices community needs and problems, and may be useful for advocacy and to increase public awareness and symbolic planning is carried out in order to fulfill regulations, mandates or funding requirements, and frequently involves budget justification procedures” (Penner 133). These modes of planning are significant for the development of outreach programs that focus on alleviating stigma from the HIV community and understanding the language that is used in this field of work. Acknowledging the stigma and knowing the importance of HIV health literacy is essential for educating the community through an outreach program. Seth C. Kalichman, Eric Benotsch, Troy Suarez, Sheryl Catz, Jeff Miller, David Rompa further elaborate in their article, “Health Literacy and Health-Related Knowledge among Persons Living With HIV/AIDS,” that, “Functional health literacy is associated with illness-related knowledge, understanding, and treatment perceptions for several chronic illnesses” (325). Kalichman et al. identify key findings about HIV positive individuals that varied differentially in HIV health literacy.

In Susan Penner's article, "HIV/AIDS and Mental Illness: The Case for Community Health Planning," she gives definitions of key -terms to know in regards to HIV health literacy. She defines "Dual diagnosis" is defined as "the concurrence of severe or acute mental illness with HIV risk or infection" (Penner 128). Similar to Penner, Kalichman et al. also address the term dual diagnosis to elaborate more on HIV positive person's struggle with identity and mental health upon diagnosis. Program planners should take into consideration that the HIV positive community may not just be impacted by their diagnosis as HIV positive, but also that they may be struggling with mental health issues. Kalichman et al. investigate beliefs of people that participated in their study that measured their understanding of HIV health literacy.

They recruited HIV/AIDS positive persons from AIDS service organizations and HIV clinics and required them to complete the Test of Functional Health Literacy for Adults (TOFHLA), which measures their reading comprehension scale and breadth of health status, knowledge and understanding of health status, perceptions of primary care givers, and perceptions of anti-HIV treatments (325). They identified negative ideologies some of their participants had, especially those with lower health literacy. Individuals of lower health literacy were significantly more likely to believe that persons who are taking anti-HIV medications are less likely to transmit HIV to their sex partners (Kalichman et al. 329). Details about the decorum of lower health literacy persons was described by Kalichman et al.: "compared with persons of higher health literacy, individuals of lower health literacy were significantly more likely to state that they find it easier to relax about unsafe sex because of new HIV treatments" (329). These results reinforce the notion that unsafe sex practices are a common mode of transmission for HIV and STIs.

In implementing an outreach program for individuals with HIV it is important to dispel any myths that are prevalent in regards to HAARP or Anti-HIV treatments. Kalichman et al. states that:

Although it is possible that viral suppression may reduce HIV infectivity among people living with HIV/AIDS, the evidence for reduced infectivity is mixed. For example, successful viral suppression has been observed in semen. However, even an undetectable viral load in semen does not guarantee reduced transmittability. Beliefs that HIV-treatment advances and undetectable viral load reduce HIV-transmission risks are particularly dangerous because of the likelihood of transmitting treatment-resistant strains of HIV to both uninfected and infected sex partners (330)

This statement explains that HAART does suppress one's viral load, but this should not endorse unsafe sex because the risk of transmittability is present.

In Allyson Snyder's senior project about communicating educational and preventative messages, she points out what may happen to someone that is tested positive with HIV. As she writes, "If an individual tests positive for HIV, it is not uncommon for him or her to deny the presence of the disease and lash out by continuing his or her unhealthy behavior" (Snyder 2). This project was in regards to training HIV positive speakers to spread the message of prevention and awareness, which in turn can establish some foreground on what it means to be able to communicate with others that are HIV positive. Snyder defines the word Catharsis as providing a "necessary liberation of built up fear and pity, and reminds them that compared to whatever they have just seen, their own life is less tragic" (9). Furthermore, "catharsis applies to those who

have experienced tragedy, as well as those who have not” (9). Perhaps within an outreach program one can consider the use of language in public speaking as a tool to communicate the importance of HIV education and prevention as well as securing a connection that is necessary when building towards a sense of community for an individual that is HIV positive. The AIDS Support Network has a program called the “My Face, My Voice” program, which trains HIV/AIDS positive speakers and places them in schools across the county (Snyder 13). The program is now called “Positively Speaking.”

Stigmatization of AIDS victims in the United States is significantly due to its association with drug use, sexual promiscuity, gay orientation, and death (Snyder 1). This article provides some indication that being HIV positive is an indicator of a foreseen death. Snyder says, “The concept of being an educational speaker not only leads HIV positive individuals to find their identity, it also aids them in accepting the process of dying” (11). While I agree that the Positively Speaking program may provide a better understanding of identity for HIV positive persons, I do not agree with the latter. Being HIV positive is not a death sentence, but due to stigma perceptions of an HIV diagnosis have created a false pretense that being HIV positive leads to death. Thanks to HAART that is simply not the case anymore; people who are HIV positive can lead long healthy lives and if they die it most likely will not be from HIV or AIDS.

Stigma

The stigma around HIV is not one that can just be lifted with ease; awareness and knowledge about the coping strategies are also essential for understanding stigma. The editorial by Maretha Visser, “Women, HIV and Stigma,” focusing on women in southern Africa, suggests

that the language used to describe stigma in another culture is still commonly perceived here in the United States today. Visser says that HIV-related stigma in an African context can be traced back to a series of shared beliefs that being HIV-positive is the consequence of some kind of indecent sexual behavior, religious punishment and lack of adherence to cultural norms.

Because of those perceived consequences, women who are HIV positive are considered to be promiscuous, dirty, irresponsible or bewitched (Visser 529). Visser explains, “People living with HIV are often rejected, abandoned or abused and considered ‘socially dead’” (529). The fear of being stigmatized inhibits HIV testing, disclosure of status, and willingness to get treatment. As Visser states, “It enhances secrecy and denial, which are catalysts for further HIV transmission” (529). Often times these fears are what lead to internal stigmatization and a negative effect on women’s ability to protect themselves and their partners from HIV transmission (Visser 530). Visser emphasizes how HIV has affected the lives of these women in South Africa and provides us with a sense of urgency in regards to alleviating stigma to prevent internalization of stigma and to also prevent risky behaviors within a community.

According to Visser there are two types of coping: active coping and avoidant coping (530). Active coping is associated with low internalized stigma, low depression, high self-esteem, high positive social support, good health, and with knowing someone who is HIV-positive. On the other hand, avoidant coping was associated with low HIV knowledge, low self-esteem, high internalized stigma, and high depression scores (Visser 530). We need to have a strategy when it comes to newly diagnosed individuals with HIV so that avoidant coping may be transitioned into active coping, potentially maximizing life satisfaction and raising moral in regards to one’s HIV status. Visser found that participation in support groups resulted in higher

levels of active coping, improved self-esteem and higher levels of status disclosure and also accelerated the process of adjusting to one's HIV status (530). These ideologies are applicable for the development of a program that can help newly diagnosed individuals cope in a positive way that deters from destructive behaviors to one's self and the community.

This review of literature presents information critical in planning for program development and implementation for an active outreach program for HIV support, prevention, and education. The research was pivoted on the small amount of programs that are readily available to the community, HIV and non-HIV alike, and also a review of why health literacy is important with respect to the HIV community and dispelling of myths that exist within the community regarding one's health and behaviors. Stigma was also addressed in the literature reviewed, giving a comparative view of some of the forms that exist.

Chapter 3: Research Methods

Description of the Context:

My research was conducted in the field, inside the AIDS Support Network (ASN) facility and in San Luis Obispo. Since 1984, the ASN has been known to give support services for community members living with HIV/AIDS and Hepatitis C. It is community-based as well as non-profit. In 2009, approximately \$52 million dollars were cut throughout California as budget cuts were approved by Sacramento lawmakers. Consequently, the County AIDS Program was removed, leaving the ASN to become the primary source for supports services for the community. I gained access to this setting by applying to become a volunteer and contributing my time to them, enabling myself to secure interviews with two professionals, Dr. Denise Taylor and Terry Comer, in San Luis Obispo.

Description of Subjects/Participants:

The HIV positive community of San Luis Obispo is the target population of this study because of the effects of stigma that have entered their lives more personally than those who are HIV negative. All participants in the research and interviews were selected on a voluntary basis. The HIV community was encouraged to take an anonymous online questionnaire via Survey Monkey (see Appendix B). Two professionals, Terry Comer and Dr. Denise Taylor, volunteered for interviews on their experiences with the HIV positive community to speak on their knowledge of stigma within San Luis Obispo (see Appendix C & D). Terry Comer is a HIV

Health Counselor and Dr. Denise Taylor is a Physician at the Community Health Center in San Luis Obispo. There were also participants chosen for a focus group that aimed to understand HIV stigma from a student's perspective and also gather data on how they would market an event like "Know Your Status." This was facilitated by Don Golinveaux and myself; the participants were Cal Poly students that chose to contribute on a voluntary basis.

Personal Perspective:

Working with the HIV community has been fulfilling because of the need for services within this community. Not only is there a need for services for the HIV community, but also the broader San Luis Obispo community has an opportunity to gain collective knowledge with education and outreach programs. The HIV community provides narratives on how important prevention and awareness can be. My volunteer experience has been invaluable in further understanding the HIV positive community that lies within San Luis Obispo and has contributed to a breadth of knowledge that is essential for the alleviation of stigma surrounding the HIV positive community and raising awareness of the importance of HIV testing for those who are HIV negative.

Description of Data Collection Methods:

In order to begin collecting data it was necessary for to submit an application to the Institutional Review Board (IRB). Cal Poly's Human Subjects committee reviewed my

application and approved of the instruments that I have used throughout my surveys, interviews, focus groups and meetings (see Appendix A).

I also collected data from the HIV positive community through an anonymous questionnaire using Survey Monkey. Questions about their life before and after diagnosis were asked and also questions that asked about any stigmatization that has affected their lives (see Appendix B). I reviewed the questionnaire responses after twenty days to categorize the data.

Analyzing the responses from the questionnaires allowed for the coding categories of analysis: lifestyle, community, healthcare, education, and support, to be developed and were used for analyzing the interviews and focus groups. The interviews with Dr. Taylor and Terry Comer were recorded with a voice recorder.

The interviews were then later transcribed and coded for categories of analysis based on the analysis of the questionnaire responses.

A focus group was conducted to gather data on what students at Cal Poly knew about HIV, stigma, and the services available. In order to test my hypothesis I wanted to understand their breadth of knowledge on available programs on campus and within San Luis Obispo; and also understand the language that was used in regards to HIV and stigma. They also participated in a simulation where they acted as stakeholders in marketing an outreach event such as “Know Your Status.”

Interviews and the focus group were done in private and focus groups were facilitated inside a conference room. Participants in either the interviews or the focus groups were reassured of their confidentiality and were given the option to have a pseudonym assigned to them rather than use their actual name in the project. I emphasized to all participants that they can end the

interview at any time, and withdraw from the project at any stage without consequence. After transcription, I provided a copy to participants to make sure they approved what was written. The recorded interviews lasted approximately thirty minutes. The nature of the interview as well as the questions were meant to be free-flowing, meaning that a dialogue is meant to be produced by the responses.

Method of Data Analysis:

The data collected from the anonymous surveys was tabulated by hand by critically analyzing common terms that came amongst respondents. Those were then categorized as lifestyle, community, healthcare, education, and support. These categories of analysis were largely propelled by the kinds of questions asked in my questionnaire. However, education is a category of questions that was not directly asked in the questionnaire but I added as a category of analysis because of obvious recurrences throughout respondent data. I used different colors to highlight responses by categories: yellow for lifestyle, blue for community, green for healthcare, pink for education, and purple for support. In the lifestyle category, themes that appeared were terms such as longevity, routines, HIV positive/negative, and sexual practices. Within the community category, themes included friends, family, and the gay community. In the healthcare category the themes that came up were medicine, doctors, hospitals, and hospital staff. Amongst the education category the themes that I found were education and ignorance. Finally, the support category common themes were support services, advocacy, educational services, and financing.

Having found the categories within the data from the questionnaire responses, the same tabulating methods were used to cross-tabulate the professional interviews after transcribing them by using my voice recorder to playback the audio at a slower tempo for an accurate transcription. The interviews, questionnaire responses, and focus groups that were analyzed helped to answer the questions of why there is such a stigma in regards to HIV, and what can be done to dispel the stereotypes associated with that stigma. (See Appendices C, D, & E for the transcripts of the interviews and the focus group sessions.)

Chapter 4: Results & Discussion

Anonymous Surveys (see Appendix B)

The majority of participants in the anonymous survey provided compelling responses. There was a total of 10 surveys completed on a voluntary basis through an online survey, and of those only one respondent omitted the last question.

The first question posed was, “When were you diagnosed with HIV?” The majority of respondents answered within the year 2000 (56%). Different responses to those questions varied from the 1980s (22%) and 1990s (22%) as well.

Question two was, “How was your daily life changed since diagnosis and what is different now than before diagnosis?” One response was, “Take one pill a night, no other changes other than medical plan.” Another respondent answered: “It distanced me from those who were not HIV and has been a life ruled by medications. My sex life changed dramatically after learning about HIV. I didn’t believe I would live long so I never planned for retirement or a future.” These responses included words that revolved around their lifestyle and healthcare, themes which came up in other respondents’ answers as well (see Appendix B).

The third question asks about a general aspect of respondents’ lives and eludes to an emotional context rather than a routine one: “What aspect of your life has changed the most and what do you miss about your life before diagnosis?” The responses included the following:

1. “Being an open book with family and friends. I feel that I cannot trust my family or friends to keep confidential.”

2. “Having to take meds, get constant labs done, deal [sic] with ignorant people and doctors. I miss not being a ‘stigma.’ Now I’m immediately assumed to be a whore or drug addict and everything about me and my past is questioned!”

Respondents refer to themselves as a “stigma” and having to deal with the ignorance from members of an uninformed community. These responses indicate how stigma has affected some respondents both internally and externally. The repeated use of the word “meds” in the previous question, and those to follow, led to a stronger categorization for healthcare.

The fourth question--“What form of support do you feel is needed within the community?”--elicited responses that revolved around education and support services. As one respondent succinctly states, the needs are “Awareness, education, comfort, knowledge, ENDING THE STIGMA.” Another respondent recommended:

“Having a support group for HIV Poz people where we can meet and discuss what being HIV positive is like and the challenges we face living in an uninformed community. Or asking each other if they need a helping hand with daily life things where they would feel more comfortable if that help were coming from someone walking in their shoes.”

These answers also provide insight on dispelling the stereotypes associated with HIV stigma and theorize why stigma in regards to HIV exists? Simply stated, the community of San Luis Obispo is uninformed. Keywords like “uninformed,” “support,” “awareness,” and “comfort” relate to the categories of education and support that show an increasing need within our community for a program that both educates and supports the community.

The fifth question--“Have you been subject to any stigmatization or stereotype? If so where?”--include the following feedback:

1. “Only by the gay community... Heterosexuals seem to have less concern.”
2. “Online dating community sees Poz as slaves and whores.”
3. “Having a hospital nurse ask another nurse if he needed to put on gloves just to adjust the sheet on my bed while I was in the hospital for minor surgery. The nurse asking for the help did not have gloves on. That incident really stuck in my mind because the nurse asking should have already known he didn't need gloves. A person who is HIV+ should most definitely not be open about their status in this community.”

Unfortunately we see several different communities ranging from the gay community, hospitals, and friends stigmatizing this community. The stigmatization of the HIV community leads to isolation and having to live behind closed doors. Due to stigma that revolves around HIV, the third respondent feels like no one should be open about their status as an HIV positive person in San Luis Obispo and it causes difficulty when trying to find a partner because of the voyeurs that fetishize HIV positive people.

Answers to the sixth question--“Is your friend base any different after diagnosis? If so how?”--reflected 60% of respondents agreeing that their friends or members of the community had changed. The seventh question, “Have you received any support from your family?” alluded to the fact that the majority (60%) have received support from their family.

The last question--“What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?”--the answers helped to narrow down

what the real needs are within the community: education and support. Some of the responses indicated this need for education and support services. Consider the following:

1. “A lesson explaining to all HIV negative people in ALL of the myths people believe about how you can catch HIV. Such as sharing the same hand towel, toilet seat, getting a kiss or a hug, sipping from the same soda or cup, a handshake, just simply being in the same room, the list is huge.”
2. “I believe the ASN is one of the biggest HIV/HEP C support groups in this community. The issues lie with the people who don’t know and don’t know how to get tested or learn more about the disease.”

These recommendations are opportunities for education and outreach programs within San Luis Obispo and also provide us with some topics that can maybe be expanded upon in a presentation about HIV stigma. The ASN’s contribution to the HIV positive community of San Luis Obispo has earned them positive feedback from respondents and also clearly identify that the problem behind HIV stigma is lack of awareness of prevention and education.

Data collected from the anonymous surveys was tabulated by critically analyzing common terms that came amongst respondents. Those terms fell under the following categories: lifestyle, community, healthcare, education and support. As described in the last chapter, themes that appeared in the lifestyle category were terms such as longevity, routines, HIV positive/negative, and sexual practices. Within the community category the themes included friends, family and the gay community. In the healthcare category the themes that came up were medicine, doctors, hospitals and hospital staff. Amongst the education category the themes that I found were education and ignorance. Finally, amongst the support category common themes

were support services, advocacy, educational services and financing. I chose these categories because they include recurrences that are most prevalent with the responses that were given on the surveys.

The categories of lifestyle, community, healthcare, education, and support are chosen because anyone can identify with these categories whether you are HIV positive or negative. We live our life in a way that is relevant to ourselves and by categorizing responses by lifestyle it made clear how the respondents' lives have changed since diagnosis. Would your interactions with your daily routine be affected if you were diagnosed with HIV? Respondents shared that they had to take a pill to suppress HIV infection every day and for some instead of one pill it's two, three or more. This gives way to awareness on their daily routines that have been modified because HIV has entered their lives.

Community really should have been labeled as communities because not everyone is part of just one community. These participants of the anonymous survey were not always part of the HIV positive community, this happened due to their diagnosis as HIV positive, but along with that came repercussions that respondents were not expecting. Dating almost seems seamless to most people, but for my respondents the dating community either shut them out or turned them into a fetish. Their interactions with friends, families and healthcare providers also changed negatively.

Thinking back to the response where the HIV positive person was subject of a debate between two nurses on whether or not they were required to wear gloves when handling their sheets was something that just was outrageous. They had a great point that these nurses should already have known the answer to that question, no. Not only did the respondents have to deal

with hostile interactions such as the one previously mentioned, but their healthcare regimen was also subject to change. Taking our multi-vitamins is something that is generally emphasized, but for HIV positive persons they are required to take daily antiretroviral medications, routine labs and visits with doctors that are impacted due to the lack of HIV healthcare providers.

Everyday there is an opportunity to learn something or explain how something or someone is affecting a particular issue and if we don't understand something all we have to do is ask. Surprisingly, education was a category that emerged within the responses and not one that was intended with the preliminary design of the surveys. HIV negative persons can educate themselves by asking about the realities of HIV and also by becoming aware of how not being informed affects people who are HIV positive. By doing so, HIV stigma can then be alleviated by filling the void in education that is indicated by HIV positive respondents. Getting tested regularly was also a recommendation.

The ASN is the only source of support for the HIV positive community in San Luis Obispo, aside from mental health counseling and visits with Dr. Taylor. There were some comments made that more support is needed, like maybe a support group for HIV positive persons where they can come together and have discussions about the issues they face. On the other hand, a majority of the HIV negative community has access to resources for support because they are not coerced to be ashamed of their status and fear to be open about their HIV status.

These surveys provided context for me to be able to conduct the interviews with Dr. Taylor and Terry Comer and really understand how they are providing support for the HIV positive community.

Professional Interviews (see Appendix C & D)

Survey data set the perspective from the HIV positive community's standpoint, whereas the interviews focused on the perspective of professionals providing support services for HIV patients and clients. My interviews with Dr. Taylor, a physician at the Community Health Center, and Terry Comer, an HIV health counselor and Physician Assistant, at the AIDS Support Network, provides insight on their involvement with the HIV positive community and on what forms of stigma their patients and clients have experienced.

Both Dr. Taylor and Terry Comer work within the county of San Luis Obispo and are dedicated to providing support services and medical service to their patients and clients. They do so because, as they indicated within their responses, it is rewarding and makes them feel good. Dr. Taylor has been working for the Community Health Centers for 13 years and also holds a position at the county jail and the prison, California Men's Colony. Terry Comer has been the HIV Health Counselor and has also been involved in clinical work as a Physician Assistant for 22 years.

The categories that were formed from the responses of the anonymous surveys--lifestyle, community, healthcare, education and support--were used to cross-tabulate the professional interviews since this is a community-based project. These interviewees answered the questions from an external perspective of what they see from working with the HIV community. Some responses to the question, "How does working with community make you Feel?" indicated that they feel happy because they can help alleviate anxiety. Moreover, providing medical care and

counseling services to a high risk population definitely needed “a lot of involvement from the community” (Comer).

Dr. Taylor states that “giving people information and helping them have control can also help alleviate some of the issues they have with the stigma.” This response corroborated the survey responses: that the way that stigma could be dispelled was through education and support services. In addition to Dr. Taylor’s response, Terry Comer suggests that there is a “level of ignorance” and that “people do not have a strong understanding” of HIV and therefore they “fear it.” Thus, their responses make it clear that there is a need for an outreach program that educates the community about HIV and the preventative methods available, such as PrEP. As they are well involved with the community at a personal level they have the ability to help the HIV positive community meet their needs by helping them get their questions answered so that they can be informed for when questions about their status may arise.

Prior to these interviews, I assumed that the HIV community was encouraged to be anonymous because I had not encountered many until my experience working with the ASN. I was proven to be wrong because both Dr. Taylor and Terry Comer clarified with me that they were not encouraged to be anonymous. As Dr. Taylor mentions, “I just say, ‘hey, let’s go get some information first before you go and tell everybody.’” His argument makes sense because being informed about a diagnosis would be ideal before you tell someone about it so that you can answer the questions that may come up. Terry declared that the HIV community are given a choice and that he would support them with whatever they choose to do.

In their feedback, the professionals recognized some internalized stigmas that their patients and clients have experienced, including the feelings or beliefs: of not being able to have

sex anymore, that they're infectious, that they were going to die soon, that they would not be able to have children, and of stupidity or guilt. The question, "Why do you believe there is stigma in the community in regards to HIV?" was answered by Dr. Taylor as, "people having the perception that people who have HIV did something 'wrong' or have done something 'bad.'" Further, this negative perception "could be attributed to the fact that this community is sheltered and people just don't see themselves as being at risk." She indicates that, in earlier times, an HIV diagnosis outed [sic] people as gay to their friends and families, even employers in some cases. Perhaps the community of San Luis Obispo is past that, but a sense of judging towards the HIV positive community still lingers in a sense that they must have done something bad (Taylor).

In a more positive light, Dr. Taylor recommends that her patients and clients have more of a forgiving attitude and patience towards themselves. HIV is very treatable now and she tries to normalize this condition by saying that outcomes for cancer and diabetes are far worse: "Diabetes can really seriously affect your life on a minute by minute basis." Sharing examples of clients that have been living with HIV for well over thirty years and are in their 80s is really compelling. To discover that longevity is evident due to new medicine available gives them hope.

Focus Groups (Co-facilitated with Don Golinveaux) (see Appendix E)

Focus groups were held in a conference room of the university union. Students' identities were protected by using pseudonyms. The discussion revolved around students' exposure to information about HIV in formal settings. The majority of the students said the only time they had heard about HIV and talked about it was during their high school sexual education class or

through their friends. One participant said, “For me, specifically on campus, I don’t feel like I’ve been exposed to any education about it. No awareness either. I remember coming into Cal Poly and learning about consent and sexual assault. I feel like they could have continued into talking about the possibilities of HIV and something like that.” Most have not participated in sexual health education programs.

We also asked students to imagine themselves as part of the committee for marketing an event such as “Know Your Status.” The ideas included how testing would be conducted. The focus group noted how before someone gets tested they might want to know whether or not they would have blood withdrawn, and knowing that that the test requires only a cheek swab would help make testing seem less of a hurdle. Another idea that was conveyed was the possibility of incorporating education on the topic of HIV and the importance of HIV testing to campus orientation programs. The participants of the focused displayed a strong desire for wanting to learn more about the subject and also expressed interest in attending the upcoming event.

Chapter 5: Conclusion

The developmental research was used to answer the question: Why is there such a stigma in regards to HIV and what can be done to dispel the stereotypes associated with that stigma? Within reviewing the literature, I found target points that could be expressed in a form of public dialogue to effectively educate the audience, specifically given San Luis Obispo County's epidemiological profile. Findings such as the breakdown of community HIV cases by race and who is at risk for HIV contraction produce better awareness of who is affected and why. Jacobson et al. mentions that an expected third of HIV specialists are to retire within the course of 10 years. Having only two specialists servicing San Luis Obispo County is an alarming statistic and should be noted as an area of improvement for San Luis Obispo County. Becoming informed on what stigma has been researched and what resources are available gave context on what to expect when assessing the needs of the HIV community. To prepare for developing an outreach program, Penner's "HIV/AIDS and Mental Illness: The Case for Community Health Planning" provided me with the knowledge of planning (expressively and symbolically) an event, and what was going to be needed for program implementation.

Based on the surveys, interviews, and focus groups that were conducted for this project, I was able to learn about what was missing within the community of San Luis Obispo and how I could contribute after analyzing the data that was collected. The anonymous surveys asked about the personal lives of the participants who responded and allowed for a glimpse of how their lives have changed after being diagnosed with HIV. Coding allowed for the categories lifestyle, community, healthcare, education, and support to be developed and were used for analyzing the interviews that followed. I asked what was missing within the San Luis Obispo community and the majority of respondents answers fell under the categories education and support. I learned that being diagnosed with HIV contributes to an erasure of their identity and some stated that they are now known as a “stigma.” HIV stigma has entered their lives and affected their interactions with the communities they are involved in, daily routines (lifestyle), and their healthcare.

The interviews with Dr. Taylor and Terry Comer enlightened my point of view by discussing how their involvement with the HIV community has affected their lives and of what stigmas they were aware. I was pleased to hear how working with the HIV community made them feel good and that providing service to people that need help is rewarding. They have both been involved in the field of HIV services for over 10 years. The insightful comments about how their clients feel about HIV stigma was very compelling because most of the time people are diagnosed with HIV and do not know what to expect. They only know what the stigma is, that the disease is life threatening. Dr. Taylor dispels this belief by telling her patients that, no, they are not going to die and that they can lead a meaningful life. Both interviewees stated that they recommend that their clients get informed before they make any decisions on telling their

families and social networks. Moreover, they concur that there is such a stigma in regards to HIV because we live in an uninformed community and that education is needed.

The focus group that was facilitated by Cal Poly senior Don Golinveaux gathered input from Cal Poly students on their experience with the topic of HIV and if they had been exposed to any education surrounding HIV. Their identities were protected by using pseudonyms. The students agreed that an event like this would be most effective during orientation. I got to transcribe the focus group discussions and I found that there was little exposure to HIV education on campus, besides the condoms that are distributed during Week of Welcome (WOW). Most recommended that orientation programs could incorporate HIV education and awareness.

The overarching conclusion was that there is a need for education and awareness on HIV stigma. Further research can be done in the area of collecting survey responses and getting more participation from the HIV positive community.

References

- Borenstein, Penny, Pam Dudley, Ann McDowell, Geri Beaman, and Christine Gaiger.
Epidemiologic Profile HIV/AIDS in San Luis Obispo County, CA. Rep. San Luis Obispo:
2 San Luis Obispo County Public Health Department. (2014): 5-21 Print.
- Comer, Terry. Personal Interview. 25 Feb 2015.
- Jacobson, Kathleen, Annie Wong, Lilia Espinoza, Jenica Ryu, Ron Chacko, Dixie Fisher, and
Jerry Gates. "Developing the HIV Workforce: A Case Study of a Training Model for
Inexperienced HIV Providers." *Journal of Health Care for the Poor and
Underserved*. 23.4 (2012): 1502-1511. Print.
- Kalichman, Seth C., Eric Benotsch, Troy Suarez, Sheryl Catz, Jeff Miller, David Rompa.
"Health Literacy and Health-Related Knowledge among Persons Living With
HIV/AIDS." *American Journal of Preventive Medicine* 18.4 (2000): 325-331. Print.
- Oh, H.J., E. Ozkaya, and R. LaRose. "How Does Online Social Networking Enhance Life
Satisfaction? The Relationships Among Online Supportive Interaction, Affect,
Perceived Social Support, Sense of Community, and Life Satisfaction." *Computers in
Human Behavior* 30 (2014): 69-78. Print.
- Penner, Susan. "HIV/AIDS and Mental Illness: The Case for Community Health Planning."
Psychosocial Rehabilitation Journal 17.4 (1994): 127. Web. 17 Oct. 2014.
- Reif, Susan, Kathryn Whetten, Jan Ostermann, and James L Raper. "Characteristics of HIV-
infected Adults in the Deep South and Their Utilization of Mental Health Services: A
Rural vs. Urban Comparison." *AIDS Care*, 18 Suppl 1.supp 1 (2006): S10-S17. Print.

Rust, Meg. "Improving Sexual Health, P.U.L.S.E., and E.R.O.S. at California Polytechnic State University, San Luis Obispo" Senior Project, California Polytechnic State University San Luis Obispo, 2010. DigitalCommons@Calpoly. Web. 20 Oct. 2014.

Snyder, Allyson. "Promoting HIV Prevention and Awareness through Personal Communication: Training Seminar for HIV Positive Speakers." Senior Project, California Polytechnic State University San Luis Obispo, 2012. DigitalCommons@Calpoly. Web. 20 Oct. 2014.

Taylor, Denise. Personal Interview. 22 March 2015.

Visser, Maretha. "Women, HIV and Stigma." *Future Virology* 7.6 (2012): 529-532. Print.

Part 2: “Know Your Status” Planning, Promoting, Program Details, Outcomes, and Suggestions for Future Programs

Chapter 6: Planning and Promoting

I contacted organizations of HIV advocacy and local public health offices to assist me with the planning of the on-campus event “Know Your Status.” The mission is to normalize HIV and open the floor for discussion in an equal playing field for HIV positive and negative persons alike. Weekly meetings were held with the staff of the ASN on Fridays from 9:30 a.m. to 11:30 a.m., later changed to Tuesdays from 3:15 p.m. to 4:30 p.m. We reported our progress to one another on outreach efforts and tracked communications with event participants. These communication included meetings, e-mails, and phone calls with local organizations, businesses and clinics, campus organizations and resources. Recruiting volunteers for the day was also essential for a successful day.

Local Organizations and Funding

Events like these do not just appear out of thin air; these events require intense planning, teamwork and overall funding. At first I thought I could just organize this event with the help of different entities coming together, which could be possible, but would it be effective? For the amount of people I wanted to reach I knew that I had to do more. I had to find funding. The money that was required to effectively educate the community of San Luis Obispo and Cal Poly was more than what a low-income, first-generation college student such as myself could afford. I applied for the Growing Together Initiative fund that was established in 2001 through grants from the National Lesbian and Gay Funding Partnership and contributions from local donors. We were awarded \$1,000 (see appendix F). This award was possible thanks to the fiscal

representation of the AIDS Support Network. The funds were used to compensate the sponsored guests for their travel to participate as panelists, to provide refreshments for the attendees of those panels and to purchase promoting materials such as graphic design, printing, posters, markers and miscellaneous materials related to the event.

Businesses

For the incentives that were required to perpetuate discussion and attract attendees to the free HIV testing, I reached out to local businesses around San Luis Obispo. Of nine businesses solicited, the only ones that were able to make donations were SLO Donut Company, Haggen, and Olive Garden. Twenty-eight coupons for a free donut and coffee were provided for by SLO Donut Company, which were used to incentivize getting free HIV testing. Haggen donated 100 bottles of water, two gourmet cakes, and a dozen donuts for the enjoyment of the volunteers and attendants of the “Know Your Status” presentation and HIV stigma panel. Olive Garden donated five pans of pasta and five dozen breadsticks to accompany the refreshments that were purchased for the intermission before the panel on PrEP started.

Clinics

The clinics that were involved in the event were Planned Parenthood, The Center for Health and Prevention, and HealthWorks. Gloria Soto from Planned Parenthood was contacted for help in distributing resources during the afternoon at the presentation. Charles Newel from The Center for Health and Prevention was contacted because of his reputation for having

successful boothing events where they engage with passers-by with fun activities and giveaways. HealthWorks is the only private Family Planning, Access, Care, and Treatment (PACT) provider in San Luis Obispo County. Director of HealthWorks, Donella Jenkins, was contacted and she provided the certified HIV testing counselors.

Campus Organizations

Reaching out to the Cross Cultural Centers was essential because of their renowned success at holding campus events. Que Dang, Coordinator of the Multicultural Center, helped reserve UU 220 as well as the booth spaces in the University Union's Plaza, to serve as the venue on May 21, 2015. It was necessary in order for us to have the presentations and resource fair in UU 220 because it is a prime location for high traffic and visibility inside of the University Union.

The space for the focus groups was reserved through Tammie Velasquez, Coordinator of the Gender Equity Center. Adam Serafin, Coordinator of Cal Poly's Pride Center, made props for the photo campaign available for us as well as signage materials for announcing the presentations and panels in UU 220. The Pride Center also provided a student assistant to greet attendees at the door and make sure the students that were required to sign in for extra credit did so. Tablecloths, plates, utensils, and resource materials were also made accessible thanks to the Cross Cultural Centers' Staff. SAFER was contacted for boothing and providing resources during the photo campaign and the presentation. Cal Poly's Peers Understanding Listening Supporting Educating (P.U.L.S.E) Health Education team was contacted for boothing and

providing resources during the presentation as well. They provided us with custom condoms with the Know Your Status Logo on it and also were distributing resources that focused on STIs and HIV.

Volunteers

The volunteers were recruited through a link that was emailed through the Cross Cultural Centers by Sandi Wemigwase (Coordinator at MultiCultural Center), Selene Roman (Graduate Assistant) and Yolanda Tiscareño at the Comparative Ethnic Studies Department. The link that was provided forwarded the volunteers to a Google sheet (see Figure 1), which I created to appoint shifts amongst volunteers. Through the Google sheet, volunteers were able to find what their duties were by hovering over the titles. Having volunteers was necessary because they helped with photo-taking, event promoting, and also keeping everything organized and running smoothly. Attached to the sheet was a space to include contact information for communication throughout the day. That was important to include to find out where everyone was at and if there were questions that needed to be answered.

*Hover over the Titles of segments for info of what will be asked of for volunteers						
Time	Setup	Instagram	HIV Testing	Presentation / "Resource Fair"	Panel Greeters	Clean Up
	9:00-11:00am	11:00am-1:00pm	12:00pm-4:00pm	2:00pm-3:00pm	3:30pm-7:30pm	7:30pm-8:00pm
	Meet in UU 220	Meet at the UU Plaza	Meet at the UU Plaza	Meet in UU 220	Meet in UU220	Meet in UU 220
Please type your name in the shift you would like to volunteer for.						
	Kim	Luis	Xavier	Kim	Kim til 5pm	Luis
	Cathy	Kou Xiong	Brianti (leave at 3)	Luis	Luis	
	Yvette	Erica	Erica (leave at 3)	Xavier	Xavier	Xavier
	Naycari	Cathy (Leave at 12)	Elizabeth Trujillo	Amy G.	Naycari (arriving	Cathy
	Lauren	Brianti	Lauren		Renee (5-6pm)	Naycari
		Naycari	Renee (1-2pm)			
		Lauren				
This event will be held at Cal Poly.						

Figure 1: Volunteer Google Sheet

Promoting:

Promoting is something that goes hand-in-hand with an outreach event. So that we could have as much attendance as possible and spread our message to a wide reach, we needed to get the word out to the community of San Luis Obispo. Promoting efforts included distributing fliers, submitting a request to the Cross Cultural Centers to be put on calendar, writing press releases to the *New Times*, *Mustang News*, *The Tribune*, and KCOY (see Appendix G), an sending proposals to multiple departments and faculty at Cal Poly for offering an extra credit opportunity for students and to announce the event in class.

With the funds from The Community Foundation of San Luis Obispo, we were able to print out the fliers that were drafted by the graphic designers we hired. Fliers included the date, time, and the location of the scheduled events and the description of the panels. These fliers were printed in sizes 4” x 6”, 8.5” x 11”, and 11” x 17”. Leah Campbell, a Cal Poly junior in Food

Science, helped to distribute the fliers throughout the city of San Luis Obispo's downtown areas, public health offices, and clinics.

By connecting with various locations I was able to network and meet with important people that were vital for promoting this event campus wide. I was able to meet with Jessica Fred from University Housing to inquire about advertising my event through University Housing Television (UHTV) and having the Resident Assistants post up 20 fliers throughout the halls of university housing.

Sending out invitations via e-mail to clubs and organizations around campus, GREEK life, and multiple entities (Faculty, Staff, Colleges, Deans, Faculty Staff Associations, and Cuesta College) to ignite discussion was also very helpful in marketing "Know Your Status." Certain faculty members provided extra credit for their classes as well as the ones who announced this event in their classrooms as an event that was important. Faculty members' announcements made a great impact on attendance.

Promoting the event could not have been as successful without the help of the Fraternity and Sorority Life Coordinator Travis Roberts, Cross Cultural Centers, Comparative Ethnic Studies Department, and The AIDS Support Network

Chapter 7: Programmatic Details

I worked in collaboration with the AIDS Support Network, Cal Poly's Cross Cultural Centers, Safer, P.U.L.S.E., and Community Action Plan of San Luis Obispo's The Center, and Planned Parenthood. "Know Your Status" promoted an equal and safe environment for HIV positive and negative persons, as well as awareness of preventative medicine and the importance of HIV testing. In an effort to reach the broader San Luis Obispo community, the general public was invited to engage in conversation with us surrounding the topic of HIV stigma. This event ran from 11:00 a.m. to 7:00 p.m. and consisted of different activities that worked to raise awareness on HIV and testing. That then transitioned into educational presentations on HIV stigma and preventative medicine for HIV called Pre-exposure Prophylaxis (PrEP). To ensure that the day was planned effectively, I constructed a timeline to keep myself and my team organized (see Appendix I).

At the beginning of the day booths were set up in the UU Plaza by The ASN, The Center, SAFER, and P.U.L.S.E. The volunteers helped Leah and I prepare the backdrop for taking pictures for our social media campaign with the hashtag, "#KNOWYOURSTATUSCP" (see Appendix K). Photos for the Instagram photo campaign were only taken of students and community members who consented by signature on a form that described what the photos were being used for and that they were to be published to an online source. The campaign was inspired by other organizations that are battling HIV stigma and raising awareness such as HIV Equal, HIV Ends With Me, and HIV Stops With Me.

Alleviating stigma from the HIV community also means alleviating the stigma that exists for HIV testing as well. In an effort to combat the stigma, free HIV testing was offered concurrently in UU 218 inside the University Union from 12:30 p.m. to 4:00 p.m. Participation for HIV testing was incentivized with giveaways donated by SLO Donut Company. Testing was made possible by certified HIV testing counselors through HealthWorks and the rapid HIV testing kits were provided by the AIDS Support Network. The testing kits are administered by a swab of the cheek and results are known within 20 minutes. Over 40 attendees participated in testing and were proud to show their support. I was aware that testing could be a sensitive activity; to ensure that the maximum amount of care and support was ready for the attendees that participated in the Free HIV testing during the event, crisis counselors were available to intervene in case of a reactive test. During the testing, a presentation was being delivered in UU 220 from 2:00 p.m. to 3:00 p.m. It was during this time that KCOY arrived and interviewed me about my efforts to alleviate stigma from the HIV positive community before we began the presentation.

My presentation on alleviating stigma from the HIV community demonstrated what other organizations such as HIV Equal, HIV Ends With Me, and HIV Stops With Me are doing in an effort to combat the stigmatization of HIV and its harmful effects. It also included compelling responses from the anonymous surveys. I disclosed important details from my developmental research during the presentation. At the close, a slideshow made of the photos that were taken a few hours prior was played and the audience was encouraged to walk around the room and participate in learning about the resources available around campus and in the city of San Luis Obispo.

In between this time (4:00 p.m.) Kris from The ASN went to pick up the refreshments from Costco so that they would be fresh upon arrival. These included veggie trays, water bottles, cookies, chips, and assorted fruit. My brother, Luis Espinoza, went to pick up the hot food with another volunteer around 5:00 p.m. from Olive Garden so that the food would be fresh during the time refreshments were served (5:30 p.m. to 6:00 p.m.).

In the evening, professional speakers Kristen Erb and Derek Sisting presented on their experiences with HIV Stigma and delivered their preventative messages to the audience. After their presentations, I opened the floor for discussion alongside the panel of speakers in regards to HIV stigma. The audience asked about HIV and the importance of working together as a community to alleviate stigma and normalize the conversation. These discussions were incentivized with four gift cards donated by Haggen; the same was done for the panel on PrEP.

Leah Campbell organized the segment on pre-exposure prophylaxis (PrEP) and how to finance for PrEP. The panel consisted of a local Physician (Dr. Taylor) speaking on their experience with prescribing Truvada (PrEP) to patients, a representative from the Gilead Group (Dr. Richard Presnell) spoke on the options for financing PrEP and who an eligible candidate would be, and an individual who has had experience with being prescribed PrEP (Paul Urban), delivered a presentation about his experiences, both medically and intimately, with their partners and their social circle. To my surprise we had another guest panelist show up on behalf of Project Inform (Robert Peterson) who is also the Vice President of the PFLAG Chapter in Bakersfield. For all the panels, questions were prepared ahead of time and were designed to be informative for the audience.

Chapter 8: Outcomes

I didn't know what to expect because the duration of the event was throughout the day and all segments were held at separate times. I was also unsure of who would attend because of the stigma attached to the topic of HIV. To my surprise there were thirty-two signatories on the media release forms for the photo campaign (#KNOWYOURSTATUSCP photo campaign; see Appendix K). Over forty HIV-testing kits were used, and 114 surveys were collected at the end of the day. Those surveys were collected at the end of each segment (Know Your Status Presentation, HIV Stigma Panel, and PrEP Panel). Surveys were used to measure the prior knowledge of the audience, the knowledge after participation and asked if their knowledge was increased after the event. They were also used to identify how they were made aware of the event. Keep in mind the following table for the Know Your Status presentation:

Levels	Knowledge Prior	Knowledge After	Increased knowledge
1	9%	0%	0%
2	20%	3%	3%
3	51%	0%	14%
4	17%	51%	40%
5	3%	46%	43%

The attendance count for the Know Your Status presentation on research methods and findings, based on the surveys that were collected towards the end, totaled 35 attendees. Fifty-one percent rated their knowledge prior to attending (on a scale from one to five) at a level three and 51% rated their knowledge after as a level four. When asked if this event increased their knowledge, 42% rated the event as a level five being the highest. Topics of interest included the statistics of HIV and its prevalence and the compelling stories of the HIV positive community.

Consider the following table for the HIV stigma panel:

Levels	Knowledge Prior	Knowledge After	Increased knowledge
1	28%	0%	0%
2	21%	0%	9%
3	33%	12%	14%
4	16%	70%	42%
5	2%	18%	35%

Forty-three audience members turned in surveys after the HIV Stigma panel. There was a close range between the audience that rated their knowledge prior to coming a level one (28%) and three (33%). The majority (70%) rated their knowledge after as a level four. Levels four (42%) and five (35%) were the highest rated for increasing their knowledge on HIV stigma. Audience members commented that this segment was most effective because of the panelists’ stories on their experience with HIV stigma and the facts that were presented to them during the discussion.

The availability of PrEP was a new concept for the thirty-five attendees during this panel.

Consider the following table on the PrEP panel:

Levels	Knowledge Prior	Knowledge After	Increased knowledge
1	71%	0%	0%
2	20%	9%	3%
3	6%	13%	14%
4	3%	46%	32%
5	0%	32%	51%

An outstanding 71% of attendees came in with little to no prior knowledge. Forty-six percent rated their knowledge after attending the panel as a level four, and another 32% rated their knowledge as a level five. Fifty-one percent answered with level five as the rating of increased knowledge after attending this panel. Attendees are now more aware of the options available for obtaining and financing PrEP as well as what resources are available on campus for students.

Overall, survey data indicated that the most effective form of advertisement was through faculty members. The surveys allude to the fact that this outreach program served its purpose in raising awareness of HIV stigma and also educating the audience on topics that are not continuously in conversation. Furthermore, the surveys support the conclusion that education is needed within the community of San Luis Obispo, providing an opportunity for future “Know Your Status” events.

Chapter 9: Obstacles

The research itself was not an obstacle, but there is an opportunity for more research because the survey data only included 11 respondents. Most of the research for the literature review was looking for academic articles that would relate to our city of San Luis Obispo and then finding sources on what planning needed to be done to carry out my plan for developing a program to serve the HIV positive community of San Luis Obispo. Not until I made the decision to implement the plans of an outreach program and organize an event like this that obstacles started to appear. “Know Your Status” was my priority and enrolling in twenty units during the quarter that it was to be unveiled was probably not the wisest decision I could have made. My mentors and Faculty Advisor encouraged me, motivated me and provided me a support system that I am most grateful for in order to push through and achieve the overarching goal of this project: to raise awareness and education through a program of outreach.

Some obstacles that are most prominent were securing a guest speaker, holding free HIV testing on campus, and organizing some aspects of the event. We first were going to be sponsoring Eric Paul Leue as our guest speaker for the PrEP panel. He had committed for the date, but unfortunately something came up and he was unable to attend. Then we had another speaker in mind, Shannon Weber. Shannon is the Director of HIVE in San Francisco and has also been featured on a Ted Talk. Unfortunately, Shannon was unable to make it because of transportation issues because she had somewhere else she needed to be the day after. Then there was Paul Urban. Paul was interested in being a panelist, but was unsure if he would have been

able to make it. As the day came closer he let us know that he would be our sponsored guest speaker and he was an amazing addition to our panel.

Holding HIV testing on campus was almost not going to be an option. I say this because I first thought that it would be a good idea to conduct the free HIV testing in house, but when I approached Cal Poly Health Services with the idea I was informed that they would not be able to sponsor free testing for one day out of the year. Their reasoning was that there are privacy laws that prevent them from holding group screening events attached to HIV. I was able to bring testing to the event because the testing was conducted by a private organization not affiliated with Cal Poly, HealthWorks, which gathered consent from the students to allow them to test for HIV. I would encourage further research to be done on these laws and how other CSU chapters are able to sponsor free HIV testing on campus.

The day before the event I was supposed to pick up a few things to be prepared. I was supposed to pick up the resources from Gloria Soto, the donations from Haggen, and the boothing materials from ASN. Unfortunately I was delayed in time even though I had planned to be thirty minutes ahead of time just in case I happened to run into an obstacle. I expected to have something come up that would delay time, but I only planned thirty minutes ahead of schedule because I didn't want to sacrifice an hour of my class. I also had to be in Guadalupe, CA at a certain time (5:00 p.m.) for a focus group I was helping facilitate with a professor. I was short on time because of a problem in securing parking passes for the panelists that would be arriving from off campus the day after. That cost me the thirty minutes I had allotted for any time inconsistencies. Fortunately we were able to secure the parking permits the day after. I called ahead of time to Planned Parenthood to see if any materials were ready for me to pick up, but the

person on the phone did not know what I was talking about. So I decided to see if the boothing materials were ready to pick up at the ASN, but my car was too small to have been able to pick them up, so we arranged to pick them up the day after. I stopped by Haggen to pick up the donations and everything was ready except for the waters, so I had to wait for that as well. Gloria Soto called me around that time (4:45 p.m.) and came to deliver the materials to the Haggen parking lot. I should have made more time for delays and not have made any commitments on the day before my event.

The day of the event, particularly in the morning, was also a challenge. It was a challenge because I did not anticipate having to load up my car with two EZ-up canopies, large banners and boothing materials. I previously thought about using a truck, but I didn't have that available. Alas, we made it work and fit everything into that small car of mine and took it to Cal Poly where, thankfully, all the volunteers had showed up and helped unload all the materials and then set up the booth in the plaza.

Planning ahead of time, more so allotting more extra time in case of delays, would be an opportunity for future planning. Going through a private organization for free HIV testing would be a good place to start unless the privacy laws are somehow negotiated with Cal Poly's Health Services and advocated for sponsorship. And finally, one maybe should find multiple guest speakers ahead of time so that if one drops out you have a contingency plan and will not have to worry about being short one speaker, which we were. But it all worked out in the end.

Chapter 10: Final Thoughts

Based on my research and on my experiences with the event, I believe that educational programming and events like "Know Your Status" will help alleviate stigma from HIV community and that offensive language can be minimized when it comes to HIV discussions. HIV testing will also become normalized because of the awareness that is raised with the Instagram photo campaign that encourages others to know their HIV status.

The purpose of this project was to provide researched justification and a model for programs that alleviate stigma, and to encourage others to continue the work that I have found rewarding and important. Event planning is no easy task, but with the right support and staffing, it can be successful. Future organizers should begin planning nine months ahead of time. I started my literature review in September 2014 and my fieldwork research (interviews and collecting surveys) in January 2015. Although I did have a great team of collaborators, ideally I would not have been enrolled in 20 units while organizing this event. I am glad to have had organizational support from the ASN, Leah Campbell, and Don Golinveaux. In the future, it may be beneficial to include co-organizers to take care of analytics and oversee committees and committee heads for (1) community outreach to seek donations, (2) funding and sponsorship opportunities, (3) public relations to send out press releases to the local papers and news networks and also to promote the event, and (4) facilities to reserve venues and be in charge of setting up and cleaning up (audio/visual, booths, etc.).

I encourage that the data collected and the planning that has been documented be used for future outreach events within the San Luis Obispo community and abroad. I really hope you enjoyed reading both parts 1 and 2 of this project. My wish is that, by now, not only do you have an understanding of what stigmatization has done to the HIV positive community of San Luis Obispo, but also that you experience the same passion, drive, and excitement that I had when I was organizing this event. It was rewarding being able to work with the AIDS Support Network and develop those relationships with individuals who are working towards the same goal: alleviating stigma from the HIV community and fighting for a better quality of life for these San Luis Obispo residents. As well, I enjoyed making the connections to the local business owners, managers, and clinicians that were willing to support me along the way. When considering organizing another “Know Your Status” event, think not only about how you will benefit from the experience, but also how your community will benefit. I guarantee that you will learn valuable skills that will be applicable to any endeavor that you may face and some challenges along the way. Overcoming the challenges that were encountered have benefitted myself because I was able to deliver a strong message to the community of San Luis Obispo: stigma is harmful to the HIV positive and negative community, and education is desired amongst the attendees of the event. Knowing your status begins with you, and like one of my brave participants from the photo campaign said, knowing is only half the battle.

Appendices

Appendix A: Institutional Review Board Forms

Informed Consent Form

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

"Alleviating HIV Stigma"

A research senior project on HIV stigma is being conducted by Mario Alberto Viséres Espinoza, a student in the Department of Comparative Ethnic Studies at Cal Poly, San Luis Obispo, under the supervision of Dr. Jenell Navarro. The purpose of the study is to determine what is needed to develop a program of support for HIV positive diagnosed individuals.

You are being asked to take part in this study by participating in an interview. Your participation will take approximately 30-45 minutes. Please be aware that you are not required to participate in this research and you may discontinue your participation at any time without penalty. You may also decline to discuss any topics that you would prefer not to discuss.

The possible risks associated with participation in this study include psychological harm by revisiting emotional times in the past. If you should experience emotional distress, please be aware that you may contact the AIDS support network at 805-781-3660 for assistance.

Your responses will be provided confidentially to protect your privacy. Your name will not be used in any reports of this research without your permission, but it may be possible for others to identify you as the source of your comments if your statements are unique and familiar to those who read the research report. Potential benefits associated with the study include developing a program for the HIV positive community of San Luis Obispo that may provide assistance and an emotional support system.

If you have questions regarding this study or would like to be informed of the results when the study is completed, please feel free to contact Mario Alberto Viséres Espinoza at 805-904-9225. If you have concerns regarding the manner in which the study is conducted, you may contact Dr. Steve Davis, Chair of the Cal Poly Human Subjects Committee, at (805) 756-2734, sdavis@calpoly.edu, or Dr. Dean Wendt, Dean of Research, at (805) 756-1508, dwendt@calpoly.edu.

If you agree to voluntarily participate in this research project as described, please indicate your agreement by signing below and participating in the interview. Please retain a copy of this consent form for your reference, and thank you for your participation in this research.

Signature of Volunteer

Date

Signature of Researcher

Date

Informed Consent Form

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

“Alleviating HIV Stigma”

A research senior project on HIV stigma is being conducted by Mario Alberto Viveros Espinoza, a student in the Department of Comparative Ethnic Studies at Cal Poly, San Luis Obispo, under the supervision of Dr. Jenell Navarro. The purpose of the study is to determine what is needed to develop a program of support for HIV positive diagnosed individuals.

You are being asked to take part in this study by completing the attached/enclosed questionnaire. Your participation will take approximately 20-30 minutes. Please be aware that you are not required to participate in this research and you may discontinue your participation at any time without penalty. You may also omit any questions that you would prefer not to answer.

The possible risks associated with participation in this study include psychological harm by revisiting emotional times in the past. If you should experience emotional distress, please be aware that you may contact the AIDS support network at 805-781-3660 for assistance.

Your responses will be provided anonymously to protect your privacy. Potential benefits associated with the study include developing a program for the HIV positive community of San Luis Obispo that may provide assistance and an emotional support system.

If you have questions regarding this study or would like to be informed of the results when the study is completed, please feel free to contact Mario Alberto Viveros Espinoza at 805-904-9225. If you have concerns regarding the manner in which the study is conducted, you may contact Dr. Steve Davis, Chair of the Cal Poly Human Subjects Committee, at (805) 756-2754, sdavis@calpoly.edu, or Dr. Dean Wendt, Dean of Research, at (805) 756-1508, dwendt@calpoly.edu.

If you agree to voluntarily participate in this research project as described, please indicate your agreement by completing and returning the attached questionnaire. Please retain this consent form for your reference, and thank you for your participation in this research.

Appendix B: Anonymous Surveys

Anonymous Survey Questions for the HIV Positive Community:

1. When were you diagnosed with HIV?
2. How has your daily life changed since diagnosis and what is different now than before diagnosis?
3. What aspect of your life has changed the most and what do you miss about your life before diagnosis?
4. What form of support do you feel is needed within the community?
5. Have you been subject to any stigmatization or stereotype? If so where?
6. Is your friend base any different after diagnosis? If so how?
7. Have you received any support from your family?
8. What do you feel is missing within the San Luis Obispo community that can be seen as a resource for the HIV community?

Respondent #1

Q1: When were you diagnosed with HIV?

The 80's

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I was supposed to die before my 35th birthday I'm now 54

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Side effects from all the meds. No worries at all before

Q4: What form of support do you feel is needed within the community?

ASN is GREAT

Q5: Have you been subject to any stigmatization or stereotype? If so where?

By Christians and homophobes

Q6: Is your friend base any different after diagnosis? If so how?

Not at all my friends are true to the end

Q7: Have you received any support from your family?

Yes I have a strict catholic mother and father and once they knew of course they I've and support me

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

More financial support most of us are on disability and living on very LITTLE \$\$ each month

Respondent #2

Q1: When were you diagnosed with HIV?

May 2012

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

Take one pill a night, no other changes other than medical plan

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Being an open book with family and friends. I feel that I cannot trust my family or friends to keep confidential.

Q4: What form of support do you feel is needed within the community?

My diagnosis is confidential, my family doesn't know. They would worry, panic, or gossip.

Q5: Have you been subject to any stigmatization or stereotype? If so where?

No, I haven't told anyone other than doctors and medical personnel.

Q6: Is your friend base any different after diagnosis? If so how?

No, other than my lack of disclosure.

Q7: Have you received any support from your family?

They don't know.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

Education that the diagnosis is not terminal as it is believed. Because of misinformation about the disease, being completely open about it is not available.

Respondent #3

Q1: When were you diagnosed with HIV?

2002

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I take medications 2x per day

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Redundant question ... See number 2

Q4: What form of support do you feel is needed within the community?

None really

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Only by the gay community ... Heterosexuals seem to have less concern

Q6: Is your friend base any different after diagnosis? If so how?

No

Q7: Have you received any support from your family?

No family to speak of ... I was the youngest ... They are deceased.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

I moved from LA ... SLO is much more responsive

Respondent #4

Q1: When were you diagnosed with HIV?

Sero-converted in 1983 but wasn't tested until 1993

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

It distanced me from those who were not HIV and has been a life ruled by medications. My sex life changed dramatically after learning about HIV. I didn't believe I would live long so I never planned for a retirement or a future.

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

I miss the carefree attitude and the "ignorance" is bliss existence. Living through an epidemic is life changing in every way. Nothing is ever the same again.

Q4: What form of support do you feel is needed within the community?

I am so isolated now that I wouldn't know how to answer that. It is by choice, but I feel that support is there if you want it.

Q5: Have you been subject to any stigmatization or stereotype? If so where?

I have been very careful to live very privately. Most people in my daily life do not know I am HIV pos. With the exception of close family and my partner, I keep it private.

Q6: Is your friend base any different after diagnosis? If so how?

Most of my friends have passed which left me feeling lonely and also wondering why I am alive. As far as making new friends, I really do not have much interest.

Q7: Have you received any support from your family?

Yes, I have received emotional strength from my family.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

A bar!!! It is just so difficult to meet people here. A bar or similar scene would be good for our community.

Respondent #5

Q1: When were you diagnosed with HIV?

Summer 2012

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

Inordinate amount of time spent working on healthcare

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Lack of freedom of attachment to healthcare

Q4: What form of support do you feel is needed within the community?

Healthcare advocates

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Online dating community sees Poz as slaves & whores

Q6: Is your friend base any different after diagnosis? If so how?

No

Q7: Have you received any support from your family?

Immeasurable

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

AIDS support organization which actually understands and helps, one that's not in it for the glory, but for the clients

Respondent# 6

Q1: When were you diagnosed with HIV?

2001

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I now live quite a different life. My social base now involves mostly HIV Poz people.

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Having to limit my sexual contacts to mostly HIV Poz people even when not doing anything to put someone else at risk. This is because of the other person's ignorance of the risk factors.

Q4: What form of support do you feel is needed within the community?

Having a support group for HIV Poz people where we can meet and discuss what being HIV positive is like and the challenges we face living in an uninformed community. Or asking each other if they need a helping hand with daily life things where they would feel more comfortable if that help were coming from someone walking in their shoes.

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Being asked if I should take extra precautions when sneezing while in the same car with someone them or having seen former close intimate non intimate friends suddenly drift away. My partner's family wanted him to use separate utensils from them. Having a hospital nurse ask another nurse if he needed to put on gloves just to adjust the sheet on my bed while I was in the hospital for minor surgery. The nurse asking for the help did not have gloves on. That incident

really stuck in my mind because the nurse asking should have already known he didn't need gloves. A person who is HIV+ should most definitely not be open about their status in this community.

Q6: Is your friend base any different after diagnosis? If so how?

Yes it is different. Most of my closest friends now consist of mainly HIV Poz persons.

Q7: Have you received any support from your family?

For the most part yes I have. After explaining the multitude of myths which exist on how you can and cannot contract HIV, explaining what it means to have an undetectable viral load like me, my family has been very supportive.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

A lesson explaining to HIV negative people in ALL of the myths people believe about how you can catch HIV. Such as sharing the same hand towel, toilet seat, getting a kiss or a hug, sipping from the same soda or cup, a hand shake, just simply being in the same room, the list is huge.

Respondent # 7

Q1: When were you diagnosed with HIV?

In 2006, age 21, from a tattoo in San Diego County

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

Before, I wasn't aware for nearly 2 years, I found out during a pregnancy screening with my first daughter. So things were normal prior to my diagnosis. Life now has been difficult, shameful, filled with guilt and stigma!

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Having to take meds, get constant labs done, and deal with ignorant people and doctors. I miss not being a "stigma". Now I'm immediately assumed to be a whore or drug addict and everything about me and my past is questioned!

Q4: What form of support do you feel is needed within the community?

Awareness, education, comfort, knowledge, ENDING THE STIGMA

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Yes, everywhere. I've dealt with doctors, family members, friends, and people who know nothing about me. The stigma is still fully alive in 2015 and it's so easy to end!

Q6: Is your friend base any different after diagnosis? If so how?

Yes, lost many friends due to this disease. But I still have many close, supportive friends. They didn't know enough about the disease and were concerned with their own health.

Q7: Have you received any support from your family?

Yes all my family support me, except my mom whom I'm not close with, but when I told her she said "oh God, don't touch your brother" who was nearly 12 at the time.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

I believe that ASN is one of the biggest HIV/HEP C support groups in this community. The issues lie with the people who don't know and don't know how to get tested or learn more about the disease.

Respondent # 8

Q1: When were you diagnosed with HIV?

First diagnosed in 1984. Date of birth: 8/12/1934. Don't pass out! Yes, I am 80 years old and still "a truckin".

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I was in at the beginning of the outbreak of the disease. There were no tests and no treatment at that time and people were in severe depression and panic mode. I was married and in the closet at the time but I knew I had to get away from my wife so I would not expose her to this unknown disease that was ravaging the man gay community. For all practical purposes, the marriage was over already. I cared about and respected my wife greatly but I had been telling her for ten years that when the kids were gone, I was gone.

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

In a way, my life got better because the diagnosis of HIV forced me out of the closet, I became isolated from my family and I had to keep a secret from my family and colleagues. Secrets kill! I missed being an active father to my grown children. I missed being included in family gatherings. I became more focused on health. I could not be as free sexually. I missed being able to ride "bareback". I miss being open and honest with people.

Q4: What form of support do you feel is needed within the community?

I have a good retirement income and good insurance, but many HIV people do not.

Psychological support and comradery are important. It is important to have good doctors with accurate, up to date information available. Learning up to date, technical information about meds can be overwhelming, frustrating and depressing. Get a good doctor you trust and rely on that person! Concentrate on eating properly, getting adequate sleep and exercise. Lower your stress level.

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Yes, many times and in many ways. With family, friends, treatment care by some doctors, job opportunities and insurance coverage.

Q6: Is your friend base any different after diagnosis? If so how?

Yes. I tend to feel more comfortable with people who are HIV because they know the pain understand the feeling of being shunned and rejected.

Q7: Have you received any support from your family?

At first I kept my diagnosis as a secret. As it became known there was total rejection, then rejection and hostility. I became a nonentity and responded with being MIA. I tried to live myself to death with alcohol, drugs and wild, wild men! No matter how hard I tried, I just would not die so I had to change my strategy. By this time I had lost everything: my partner (death due to Aids), two homes, and six apartments, quit paying my income tax and spent all retirement funds. This was after being diagnosed with cancer and given an ear to live. Went into rehab and after four tries I left LA and moved to SLO to help with my mother in a local nursing home. ASN was instrumental in stabilizing my life.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

Better local HIV doctors.

Respondent # 9

Q1: When were you diagnosed with HIV?

June 1998

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I am more conscious regarding taking care of myself and my health

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

I feel that the meds have taken their toll on my body. There are some days that they just exhaust me.

Q4: What form of support do you feel is needed within the community?

HIV education. I feel that the community is not educated on basis HIV facts

Q5: Have you been subject to any stigmatization or stereotype? If so where?

I am very open about my HIV status. If someone cannot except it or handle it, that is their issue

Q6: Is your friend base any different after diagnosis? If so how?

No

Q7: Have you received any support from your family?

Very little

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

Respondent skipped this question

Respondent #10

Q1: When were you diagnosed with HIV?

San Francisco

Q2: How was your daily life changed since diagnosis and what is different now than before diagnosis?

I don't party like I use too. I take care of myself. I'm really careful about a lot of things I use to just take for granted.

Q3: What aspect of your life has changed the most and what do you miss about your life before diagnosis?

Dating people. It is hard for me to just open up to someone.....thinking they or I don't really want them knowing my business if it wouldn't work out and then would know.

Q4: What form of support do you feel is needed within the community?

I guess if we all came out of the closet and let everyone know we had it, made people aware of how many folks had it.

Q5: Have you been subject to any stigmatization or stereotype? If so where?

Yes, up in Oregon. In Cayucos when I didn't want to be someone's friend anymore they use that on me and try to tell everyone in town.

Q6: Is your friend base any different after diagnosis? If so how?

Not really, I'm selective in who I tell. Some people really try to use it against you in what you should do in your life and what you can do in your life.

Q7: Have you received any support from your family?

Yes, I have received lots of support from my mother. Even when I didn't want to go on anymore, she really has pushed me.

Q8: What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?

SLO is a wonderful place, but very conservative to alternative lifestyles and people. Sometimes I just don't feel like I fit in here all that well being a woman with HIV from San Francisco and being such a liberal person.

Appendix C: Interview with Terry Comer

Interview Questions for Dr. Taylor and Terry Comer:

1. How does working with the HIV community make you feel?
2. What stigmas are attached to the HIV community and why?
3. Why is the HIV community encouraged to be anonymous?
4. What other resources are available for the HIV community through your organization?
5. Is there room for change within the San Luis Obispo community to be accepting of people with HIV?
6. Why do you believe there is a stigma in the San Luis Obispo community in regards to HIV?
7. Are these people in the communities who have HIV defined by their diagnosis?
8. Have you noticed a change in mental state with patients and clients that have HIV before and after diagnosis?
9. What do you recommend for the newly diagnosed HIV patients or clients that are having difficulty coping with their diagnosis and living with HIV?

Mario: my name is Mario Espinoza I am interviewing Terri comer for the project alleviating stigma from the HIV community. The date is February 25, 2015 and the time is 9:30 a.m. This Interview is designed to take into account your own experiences in an effort to alleviate stigma from the HIV community here in San Luis Obispo. Your identity will only be used for data collection and will only be used to alleviate stigma from the HIV community. Thank you for taking the time to answer these questions. If at any time you choose to end the interview you may do so. The first question is how does working with the HIV community make you feel?

Terry: I have been doing it for like 22 years. So I guess it makes me feel pretty good because I continue to do it. I think it is rewarding in a lot of ways umm... One obviously you're helping you are providing service. Two, you're providing the service to a high risk population that definitely needs a lot of involvement from the community. Both the professional community and the counseling community. Yeah, I think it makes me feel really good that you know you go home with a good feeling that you have helped a lot of people. Not every day, but most days.

Mario: What stigmas are attached to the HIV community and why?

Terry: Yeah, I think that there is a lot of stigma involved that has never diminished and I think a lot of it comes from the fact that if there is not a family member or a close friend or you're not working in the field as a professional umm then you don't know much about HIV. It's a level of ignorance that we still have in the country. It's just a subject that people do not have a strong understanding of therefore they fear it and what they fear umm becomes problematic whenever. That's a part of the stigma that

Mario: Why is the HIV community encouraged to be anonymous?

Terry: Well I don't think that they're always encouraged to be anonymous. I think that they are always given the choice if they want to be anonymous. I do new intakes of people that are newly diagnosed I always tell them that you have a choice to be made and a choice is if you don't want anybody to know you're diagnosis your HIV status then I tell them how to do that. If people do want to be known then I support them in that. As a health counselor there is no other avenue to go. I have clients had tattoos on their forehead that said HIV positive, wear t-shirts that have HIV positive on it, I have people that NOBODY except for the two of us know that they're HIV positive and umm so that's pretty much what that's about.

Mario: What other resources are available for the HIV community through your organization at the AIDS Support Network?

Terry: So I mean our main function is providing an education to people who are newly diagnosed with HIV and to people that have been clients for a really long time and just providing supportive services. Supportive services are things like assistance with food, we have a food bank. Assistance with food vouchers. Assistance with their inability to keep up with bills we help them with utility payments umm probably the most common things that we do is providing them referrals. Referrals for counseling, mental health counseling, referrals for physicians, referrals for dental work, legal referrals and that type of thing. So referrals is a large part of our job, but the MAIN thing is we are here for supportive services for our clients. It doesn't mean we don't go out into the community and do education for the community, we definitely do. I go out to the local prisons and counsel a large amount of people that are HIV positive there. I do lectures at Cal Poly for certain groups every year I do it for the nursing program and I lecture to every year. So there is some education to the community that we are involved in. We have speakers, speaker

groups that are HIV positive that go out into the community and give lectures. We provide enrollment service for the assistance program and there is a number of things that you know a number of other services that I can go on and on about and bore you.

Mario: (laughs) Thank You. Is there room for change within the San Luis Obispo community to be accepting of people with HIV?

Terry: Definitely. Umm what we already talked about as far as stigma is that it is an ongoing problem. *(interrupted by telephone)*

Mario: It's Ok

Terry: ...

Mario: so then there is room for change?

Terry: yes. Yeah it's obvious, I don't think there is any community in the world that couldn't do better as far as decreasing the stigma. Interestingly enough there is places in Europe that there is a lot less stigma and a lot more acceptance. I was just talking to someone the other day and I was very interested in the fact that there a lot more countries that are supportive of their gay community and a lot more supportive of their HIV community than the United States.

Mario: Do you know which country?

Terry: Paris, France for one, but I don't think that's unique for them I think that there is probably a number of countries in Europe. Truthfully I couldn't tell you 100 percent why that is, but it could be a great research project

Mario: yeah right

Terry: For someone.

Mario: I heard that in Denmark as well they are a lot more open

Terry: Amsterdam

Mario: yeah

Terry: I think that it's just, yeah, I know for sure about France and that's why I mentioned it, I know because of resources.

Mario: Why do you believe there is a stigma in the San Luis Obispo community in regards to HIV? I feel like that question is repetitive.

Terry: It is repetitive, but I don't think that the whole question is. San Luis isn't different than any place else it's really not if we are just looking at the united states umm... it's a conservative small city, but in all reality I DON'T THINK THERE IS ANY MORE OR any less stigma here than any place else. It is a problem here, there is a stigma with a lot of other things. There is a stigma with mental health problems, there is a stigma with drug addiction. There is a lot of other areas of stigma, but HIV definitely has its share.

Mario: Yeah, thank you. Are these people in the communities who have HIV defined by their diagnosis?

Terry: By the community?

Mario: Yeah, I mean, I guess what I am trying to ask is umm... When they're diagnosed with HIV do you notice them feeling like, "oh this is me, I'm HIV," or do you feel like they are defined by their diagnosis or...

Terry: I don't think for everyone, I think there is some that have that feeling. It is unfortunate, because if they are out as far as their diagnosis it does affect their identity in a big way. No longer are they known as the great carpenter that lives at the end of the street. Now they are the HIV positive guy that lives down the street. So we have that type of the situation and that may be one of the fears why people don't want to come out, because they don't want their identity changed. It definitely could happen.

Mario: thank you. Have you noticed a change in mental state with patients and clients that have HIV? Before and after their diagnosis.

Terry: For sure. That's one of the reasons that we give counseling referrals and that's probably what half of my time and my job is taken up with is umm problems that they have of relating to their diagnosis if they are newly diagnosed or they have been diagnosed for thirty years umm It's an ongoing problem for a number of reasons. If you want all the reasons I could give you a lot of them.

Mario: Yeah. If you want to share that would be great, you don't have to do them all, just probably a lot. (Laughs)

Terry: I think when we look at this and the affect that it has on people's personal lives and just the question you asked previously on identity. That in itself is a hug effect on your mental health you know. We are dealing with a lot of personal laws. We're dealing with um... people in the early days of being diagnosed feel like they have to tell everybody that they are infectious, which obviously is not the case. Second thing is they feel like they can't have sex anymore because they are going to infect somebody or somebody is going to find out that they are HIV after they

have sex with them if they tell them or not. They feel if they use condoms that there is a high risk. All this stuff just adds stress in their lives umm... Another part of this is, besides their mental health, a lot of times they'll lose their partners, their relationship long-term partners. People that they have lived with in the last 10, 15, 20 years and sometimes why they lose their partners is that their partners get to a point where they have a hard time dealing with their HIV positive partner diagnosis. In that their sex lives change, maybe they have to use condoms now where they didn't feel like they had to in the past because of a long term relationship and that affects the relationship so that puts more stress on a person after their partner leaves. They're dealing with stress that definitely lends itself to diagnosis of anxiety/ depression. We have clients that have both anxiety and depression. Very few people are not affected mentally when they get a diagnosis. Not many years ago it was considered a life threatening disease.

Mario: What do you recommend for the newly diagnosed HIV patients or clients that are having difficulty coping with their diagnosis and living with HIV?

Terry: I usually recommend that they keep a healthy lifestyle and remind them that when you get this diagnosis that you also get some positive things out of it. You take life a lot more serious, you become a lot more humble. Sunsets look a lot better, music sounds a lot better, your friends care about you more than they ever did before. So there are some positive things that you get from the diagnosis. Umm. Can you re-read that question?

Mario: Yeah. What do you recommend for the newly diagnosed HIV patients or clients that are having difficulty coping with their diagnosis and living with HIV?

Terry: Having said that I kind of review that with them because of my personal diagnosis of having a heart attack that had an effect on me in that way. You know life is a little bit more precious now than it was before I had a heart attack. So, having said that what I always encourage them to do is have a healthy life. Healthy life means, having a good diet, the other thing is to get some exercise and if exercise is difficult then take a lot of walks and spend a lot of time outside. It could be alone or with friends, but spend a lot of time outside. Umm... Do things that are good for your mind. You know, use your mind as much as possible and do things like daily relaxation techniques or meditation. I am a firm believer in both of those things because you're doing some things to improve your insight and improve yourself overall. And past that get a spiritual sense, everybody has a spiritual sense I think even the devil himself has a spiritual sense.

Mario: Yeah.

Terry: you know. I could talk about these things forever.

Mario: That concludes the interview, If there is any other comments or questions you have for me, they're appropriate if you want.

Terry: No, I hope it's useful

Mario: Thank You

Appendix D: Interview with Dr. Denise Taylor

Interview Questions for Dr. Taylor and Terry Comer:

1. How does working with the HIV community make you feel?
2. What stigmas are attached to the HIV community and why?
3. Why is the HIV community encouraged to be anonymous?
4. What other resources are available for the HIV community through your organization?
5. Is there room for change within the San Luis Obispo community to be accepting of people with HIV?
6. Why do you believe there is a stigma in the San Luis Obispo community in regards to HIV?
7. Are these people in the communities who have HIV defined by their diagnosis?
8. Have you noticed a change in mental state with patients and clients that have HIV before and after diagnosis?
9. What do you recommend for the newly diagnosed HIV patients or clients that are having difficulty coping with their diagnosis and living with HIV?

Mario: My name is Mario Espinoza I am interviewing Terri comer for the project alleviating stigma from the HIV community. The date is March 22, 2015 and the time is 5:30 p.m. This Interview is designed to take into account your own experiences in an effort to alleviate stigma from the HIV community here in San Luis Obispo. Your identity will only be used for data collection and will only be used to alleviate stigma from the HIV community. Thank you for taking the time to answer these questions. If at any time you choose to end the interview you may do so. The first question is how does working with the HIV community make you feel?

Dr. Taylor: Well as a physician I feel happy that I can be helpful. I think that I approach patients in a pretty non-judgmental way and I do believe that I am able to alleviate anxiety by providing information and obviously by providing medical care, but also you know providing information to them about how they can take care of themselves and I think when people feel in charge of their own health then usually they can feel like they have some control over the situation. Then it usually lessens their anxiety.

Mario: Great.

Dr. Taylor: So I think giving people information and helping them have control also can help alleviate some of the issues they have with the stigma because I think most people are pretty anxious when they come in for the first visit and then trying to normalize it and say this is just another medical condition, but you do have to take a few extra precautions. I think hopefully, it seems to help people feel better about their situation.

Mario: Yeah. Have you noticed umm...? Like well because you have patients and stuff like when they come back after their first diagnosis are they feeling umm... Have they improved their sense of their identity afterwards?

Dr. Taylor: I believe they do. I think I am able, because I have been doing this for a while and it's a small town and I know what most of the resources are so whatever particular issues they have I think I am usually able to point them in the right direction to get their questions answered and so then they go off and do those things hopefully and then come back and have seen that maybe the things I suggested maybe helped so then we create and build trust and they are more willing to kind of take suggestions and they usually have more questions and I think the more involved anyone is in their healthcare the better they'll feel about it.

Mario: Thank you. What stigma are you aware of that revolves around the HIV community?

Dr. Taylor: One of the things that I see especially with patients whom are newly diagnosed is the people feel really like guilty and 'how can I be so stupid?' and 'why did I do what I did' and rather than thinking that everyone does all those risky behaviors. Everyone does and they just got caught you know. Drinking and driving you know probably lots of people have had a drink when maybe they shouldn't have and they just didn't get caught, or you know running a red light you know sometimes we're lucky and there's a car there that you just happened not to see. I mean there are so many things that happen in our lives where you know none of us are perfect and you slip up and make honest mistakes and then most of the time nothing bad happens and every once in a while something gets you that has you know a serious consequence and even having HIV I think is, while it is not something that anyone is super happy about, it's not like any more really like a serious [sic] consequence. Certainly it's not life threatening and people could lead a normal life s I think part of it is there is misinformation so people come and think 'that's it I'm gonna die' I mean I hear that or 'that's it I'm never having sex again' or 'that's it I'm never having kids' or you know just all these notions they have in their head and I try to say yeah you know

you feel that way now, BUT yes you can have kids yes you can have a meaningful relationship, yes people will still love you, yes this treatable, no you're not going to die. I think they get into this self-judging, but you know all of us do when we make bad mistakes and then trying to forgive themselves and also through getting more information I think it can help alleviate the stigma that they feel.

Mario: Yeah like towards themselves, an internalized stigma.

Dr. Taylor: Yeah this is that.

Mario: Why is the HIV community encouraged to be anonymous?

Dr. Taylor: I am not really sure, I remember reading that question and thinking I am not entirely sure what that is supposed to mean, but I do believe. Like I know with Terry Comer at AIDS Support Network (ASN) and I suggest this to patients too that you know when they come in and they're diagnosed I don't say "oh my god you should hide this from everyone" I just say "hey lets go get some more information first before you go and tell everybody" because everyone else out there you know if you go find a young man who is diagnosed and he's going to go tell his parents his mom might be like "oh that's it you're gonna die" or "I'll never have grandkids" you know, "What about this? Have you seen the doctor?" what about this blah blah blah [sic] and I say you know what get a little information and then when the questions start coming you've got the answers. Instead of them getting you all anxious. The other thing I'd say is if you had syphilis would you go tell your mom? If you had herpes? I mean if any of those things the answer is probably no so it's like you know this isn't something you have to go and broadcast to everybody. I mean people that really need to know are your intimate partners, but on the other hand it is kind of a big deal it's like maybe say having cancer you know you're living with

something and you're like well or diabetes or you know your like I want some support for this... to talk to people and so I think you try to find some sort of middle ground and then usually once someone has information and is on treatment and is feeling secure of themselves then I think they can kind of go outside and start telling other people because then if they get a little backlash they are already feeling okay about themselves or just say "hey look I'm taking care of this don't give me any grief about it." Versus if they're feeling uncertain about what's going on with their treatment, and this is usually for more newly diagnosed, then other people are going to upset them further because they won't have the answers so if that kind of makes sense. That's my general approach, but if people want to tell everyone you know I'm like have at it. I think most people nowadays are fairly understanding I think.

Mario: I've seen a lot, like even with like when I become more aware of like HIV advocacy that there is like advocates who are HIV positive who are open about their status. For example one of them, his name is Jack Mackenroth, he says that it is an empowering stage of having HIV. It's like coming out of the closet again and it feels great. And so I kind of understand that question from his perspective on like how he felt like he was back in the closet all over again.

Dr. Taylor: Oh yeah that is true. There is that "back-in-the-closet" kind of sense to it.

Mario: What other resources are available for the HIV community through your organization?

Dr. Taylor: Basically I work at the Community Health Center (CHC) so I provide medical care.

(Laughter)

Mario: I think that question was more geared to the AIDS Support Network.

Dr. Taylor: Those are our basic services, umm I mostly refer out to other organizations and I'm not sure that CHC really does a whole lot more. I mean I know there is some health education

and there is maybe some benefits counseling. Especially for maybe people who are undocumented residents they may need some benefits counseling. I mean mostly they can do that at ASN, but I think there is a certain amount that can be done there too. For the most part I do the medical care. I guess one thing I can do or what I've started doing is recommending PrEP for the HIV community, their partners who are HIV negative which is still part of their community so their partners trying to keep them negative. Trying to get the word out a little bit more.

Mario: I heard the term when we went to the conference on Thursday, “Sero-Discordant”

Dr. Taylor: “Sero-Discordant” yeah S-E-R-O.

Mario: Does that mean positive and negative? Is that what it means?

Dr. Taylor: Yeah, so like “serology”, because serology is when you are measuring antibodies, antibody negative and antibody positive. So it is sero-discordant.

Mario: That makes sense, when I was doing my research I found the term, “magnetic couples”

Dr. Taylor: I like that better

(Laughter)

Mario: I was like that makes light of the situation.

Dr. Taylor: Yeah, well yeah it puts it in a more positive light.

Mario: Is there room for change within the San Luis Obispo community to be accepting of people with HIV?

Dr. Taylor: I'm sure there is always room for change. Yeah, I mean we could hopefully find more providers like within CHC especially who are willing to do primary care for people who have HIV. I think there is definitely room for that. I'm guessing there is probably still room for

education regarding just testing in general. There is definitely room. Actually one of the main places I see room for improvement is at the jail because we don't have the resources and the funding to do routine testing and I know of a few people who have come out of the jail who requested testing there apparently, they told me this, and then once they got out they went somewhere and got tested and were positive and think the jail is like the perfect place to just test everybody like they haven't been tested in the last six months you just offer them a test, but that would cost thousands of dollars from the county medical budget think pretty much operates on a shoestring you know.

Mario: For HIV testing?

Dr. Taylor: Yeah. And so that is one of the places I really see that there is a problem and then of course once they're positive there is a lot of money that would have to go towards testing, the further lack of laboratory testing and then treatment and I don't want to say that they don't want to treat people because they do.

(Approached by an artist selling craft art)

Mario: For the jail, since you mentioned it, is it difficult to arrange like an event like that, to have like a group screening if it is funded from the outside?

Dr. Taylor: No actually it probably wouldn't and what used to happen when I first started working there back in 2009 is that the public health department, who no longer really does a lot of testing, would come in. An inmate could write a request to get tested for HIV and I think also Hepatitis C and then the jail nurse would generate a list and I don't know once a week or every couple of weeks a nurse from the public health department would come out and do all the testing. And then they stopped doing that. I don't know if their funds ran out or I know there has

been a lot of decrease in funds overall statewide and so at that point it was decided that the jail was going to have to pay for any testing and we just don't do that.

Mario: That's unfortunate.

Dr. Taylor: I know it is because that's the perfect place to do screening.

Mario: This is kind of a repetitive question, but it says why do you believe there is stigma in the community in regards to HIV?

Dr. Taylor: Well, I think in this community, I mean the joke is that we are the happiest place or whatever you know and at least you know we are a predominantly white community, people are mostly middle to upper-class you know we are kind of sheltered I think and I think people just don't see themselves as being at risk. So therefore if you have HIV you did something "wrong." You know you did something "bad" you made a big whopper of a mistake. I don't think it's like in the old days where it's like oh my god you have HIV and then I know you're gay and that's really bad, that was the thing, that HIV outed you about being gay and that's what people you know took offense at more so then the HIV almost although then they also think oh you're going to give me HIV. I think people are past all that, but I think there is still this judging about you now you did something bad.

Mario: Yeah like a negative connotation to it

Dr. Taylor: And I think because we are this kind of sheltered community here I think we are going to have maybe more of that. I mean that's just kind of what I would think off of the top of my head.

Mario: Thank you. Are these people in the community who have HIV defined by their diagnosis?

Dr. Taylor: I hope not. No I think, at least I'd like to think, you know with my patients that once they get treated and they're going about their business usually what I hear back from people a couple of years later is they're like "God I don't even think about it anymore" you know they're just.. they're working, they're in school, people have gone back to school to become a nurse, they have gotten new jobs, people are getting married, I have some couples that are trying to have kids where the wife is HIV negative and I think they're seeing that their lives are going to march on. So I think initially they may feel defined by their diagnosis, but I think eventually they move past that. I think perhaps maybe for people who are still single and looking for someone to have as an intimate partner that they probably, I would guess, maybe feel a little more defined by that, like I got to have that discussion with somebody. That's, I mean for me, I think with HIV that's like the only downside you know it's like it's so treatable, it's like a lot of other chronic diseases, but if you have diabetes you don't have to have that discussion you know?

Mario: Yeah

Dr. Taylor: You can tell someone later, "Oh by the way I have diabetes and I give myself insulin injections." And they might say "oh that's too much for me to handle," but it's not like I am going to get diabetes from somebody. And so I think that's the one aspect of it that I would think perhaps people, when they're dating, might feel more like that. I don't know if that is accurate, but that's kind of what I would say from feedback I get from patients.

Mario: Yeah. Umm... I think that we answered #8 Have you noticed a change in mental state with patients and clients that have HIV, before and after diagnosis? Yeah.

Dr. Taylor: Pretty much all my patients I didn't know them before. All I have is an after diagnosis, but I see a big change from the immediate after diagnosis to a year, two years, and five years down the line you know with what they're doing with their lives and how they feel about their health care.

Mario: Yeah. If I may ask, what's the biggest range that you have had a patient that's been HIV positive? Anywhere from 10-30 years or like 10-15?

Dr. Taylor: Well I've been at the clinic now for 13 years, so I have taken care of people for 13 years. I have many patients who have had HIV since the 80s.

Mario: Yeah that's kind of like what I meant.

Dr. Taylor: So definitely people who have had it 30 plus years. I have got, let's see my youngest patients probably, I don't know if I have anyone under 20 right now, but definitely in the young 20s like 21, 22 up to I think my oldest patient is 80 something, They've had it for a long time and I got a number of patients in their 60s maybe 10 in their 60s and 70s.

Mario: Most of my responses on my survey were from like the younger generation, but I had one that was in their 80s.

Dr. Taylor: Is this from ASN?

Mario: Yeah, from the anonymous surveys. It was really cool to see kind of like where the age variances were. So it's not just affecting just like one predominant group, but increasingly there has been more within like the age group 18-25 that I noticed. What do you recommend for the newly diagnosed HIV patients or clients that are having difficulty coping with their diagnosis and living with HIV?

Dr. Taylor: Well I guess I recommend patience you know and a forgiving attitude towards themselves and like I said before I try really hard to normalize this and say this is like you know if I told you I had diabetes you know or what if I told you I had cancer? Cancer is worse you know or even diabetes honestly if I- to give yourself injections 2 or 3 times a day and have an insulin pump implanted it can really seriously affect your life on a minute by minute basis where you are having to think about it all the time and still have serious consequences at the end so you know if I had to have a choice personally if someone said you have to choose between the two you know I would be hard pressed. You know I would be like oh yeah no way I don't want HIV it's like well that's pretty treatable now. So you know I just try to tell people to you know take a deep breath this isn't the end of the world and kind of the things I said before it's just like let's get some test, let's see where things are at, this is totally treatable, look at all these pills there's lots that are one pill a day and you know and lots of patients are doing well I tell them about the 80 year old patient and you know people have kids and people are working and you know moving on with their lives and try to give them hope too that you know what I see really what I am trying to do is bridge until someday there is a cure you know. I really believe that will probably happen in my lifetime. People who are way smarter than me are going to figure that out and you know that's what we are looking for, but let's keep people healthy before then so that they can take advantage of that. I guess I just try to instill some hope. Hopefully I do that.

Mario: Yeah I agree. Well that concludes the questions for the interview, I do have a last minute question though if you're okay with that. I know what I am doing to try and alleviate stigma, but I wanted to ask you is there a way, other than what you are doing now for the community, is there a solution that you have in mind for alleviating stigma from the HIV community?

Dr. Taylor: Well I think more universal testing really. I think just testing everyone. A few years ago I took a break from the prison. I paroled for a couple of years and went back, I didn't behave, and I was working in the urgent care on Santa Rosa and so you know, I'm an HIV physician and I knew what the recommendations were: that everyone should be tested between, I think then it was like 18-65 or whatever, so I'd get your average San Luis Obispo citizen you know 50 year old coming in and I'd be like, "Hey have you been tested for HIV?" and they're like, "what?" kind of like "who do you think I am?" and then I would just say, "Hey you know what, did you know that the center for disease control recommends that everyone between the ages of 18 and 65 should be tested at least once if you have ever had sex? And you have kids so I'm guessing you have had sex so we are going to run some labs why don't just throw in an HIV test?" and sometimes people would be like "nah, that's okay." Or some people would be like "Oh, well if that's a recommendation then..." and I say, "Hey you just get tested once you never know." And I would always tell them, "Oh I am an HIV doctor and that's why it's on my mind." Just to try to make them think that it wasn't something, especially the men, it wasn't something funny about them that made me suspicious or anything that they said that made me you know worried, but I think if that were adopted, and perhaps it is, I am guessing it's not. I think that goes a long ways because then everyone could see themselves as potentially at risk and then be less judging towards people who are HIV positive.

Mario: I see that at institutions, especially at Cal Poly, when I was asking about having like a group screening event through Cal Poly so we wouldn't have to go out and they said that there is a lot of privacy laws and regulations that prevent group screening events and so that was really like weird to me--

Dr. Taylor: That's weird they have health fairs all the time.

Mario: And they are like taking people's blood, doing flu shots, and I'm like so it is fine to like poke someone with a needle, but to swab somebody's mouth with a cotton swab, for example Oraquick, is like heaven forbid, we don't want to have a group screening event. Because we don't want to, what was it...? They are mandatory reporters is what the terminology was used. They have to report it and if anyone had a reactive test they'd have to report it because it is a reportable disease or something like that.

Dr. Taylor: That would be something to bring up with ASN, because I don't think that is totally true. I think that there is a lot of stuff like that where they just say, "oh no we can't do that." Because they don't want to think too deeply about it. In fact, my husband works at Cal Poly and he tells me that's it all the time. There's a lot of stuff he brings up because he thinks oh we can do something differently whatever it is; teaching or some policy and they're just like, "No... no we can't do that." You know and they don't really have an answer they're just like yeah... privacy, yeah that's it it's a privacy issue.

Mario: I was forwarded through three different entities about who do I go to and that there were these different steps to take to do what you want to do and I'm like okay what are the steps and they would send me to somebody and then they would send me to somebody else and the final answer was "please check with your project advisor." And I was like okay.

Dr. Taylor: Well if you could get the student health center to buy in on it somehow or you get an advocate in the medical community and probably it would be better. You know Thomas...

Mario: Tom Maier?

Dr. Taylor: No not Tom Maier, umm... Greg Thomas. Yeah Greg Thomas, because he was the Director of Public Health before the current one and he works at Cal Poly. So he is very pro let's test, let's do these things. In fact I think he may have even been an HIV provider at some point in time. So if you talk to him about that and say, "How can we make this happen?" He may have some different ideas or he may even be able to go to the same people and say I want to do this and they'll be like oh okay. Because then they have to deal with an MD and that always carries a little more clout with it. I mean I have found that with things that I want to do.

Mario: Yeah. Thank you. So that concludes our interview, if there is any comments or questions that you have for me I would be definitely willing to answer them.

Dr. Taylor: It seems like a great project and I hope that people respond well to your event and, you're not doing testing at the event right?

Mario: I am still trying to make it happen. My plan B is to have assigned pledges to go to either Planned Parenthood or The Center to get testing within the week and I will have you know list for people to sign and they'll get like a ribbon because they have taken the pledge. That's just like worse comes to worse and I don't get to have testing provided, we'll do pledges.

Dr. Taylor: Well that's good. Yeah. If you had an incentive of some sort, I don't know what it would be, but like if you go you get to go get a free donut or something. Maybe if you get some place to donate something if they show up with their pledge within the week at one of these two places then they get uh—

Mario: A five dollar gift card.

Dr. Taylor: yeah or even like a free donuts buck, you might get SLO Do Co to donate a bunch of free donut tickets or free coffee at Starbucks or you know because it gets people into their

business so it's something that will be good. Or Emily's cinnamon bun place that's another place. One of these places that maybe students would go to and it's something that can be only a couple of dollars.

Mario: Totally I will try to do that, I am supposed to be making rounds in SLO asking for donations of the giveaways and incentives for the event. Well thank you.

Dr. Taylor: You're welcome.

Appendix E: Focus Group Sessions

Cal Poly Student Focus Group Questions:

1. Let's do a quick round of introductions. Can each of you tell the group your name, major, and what cross-cultural services/centers you have used on campus?
2. What exposure have you had to HIV education of any sort on campus?
 - a. *Probe:* Do you feel the information given was adequate?
3. First, we'd like to hear about the existing cause-awareness programs at this college that you or someone you know has attended on Cal Poly Campus (such as Ally Training, "101" Events, cancer-awareness, sexual assault awareness)
 - a. In what ways were these events helpful to you?
 - b. In what ways do you feel that the classes fell short in helping educate?
4. Now imagine that you are part of a committee of people designing an HIV awareness event for people in your age group. This is an event that students may be required to attend, or are interested in attending.
 - a. What are the factors that you will make sure your committee considers in designing the event? What are the things that you are sure would attract people like you to the event?
 - b. *Probe:* Remember, these can be in many areas: the facts provided, the event length, the time of day it's offered, the presentation style,

the course materials, whether resources are available (testing, counseling), whether the course promotes volunteering, or anything else you can think of.

- c. *[If this issue has not already been addressed as the questions above were answered:]* What type of event do you think people in your age group are most interested in: those that are required for a class or program, or those that can be taken purely out of interest? What are the upsides and downsides of each type of event?
5. At this point we'd like to hear about any HIV/STD testing/sexual health programs you've participated in? Remember this is purely confidential and what you say does not leave this space.
 - a. In what ways were the services helpful to you?
 - b. In what ways do you feel that the services fell short in helping you or others reach your goals?
6. Now imagine that you are part of a committee representing a local STD/Testing clinic (Like the Center, or AIDS Support Network) and are aiming to increase the number of local students getting tested.
 - a. What are the factors that you will make sure your committee considers in marketing these services? What are the things that you are sure would attract people like you to these services?

- b. *Probe:* Remember, these can be in many areas: the marketing materials used, the ease of access to testing, the approach of volunteers, or anything else you can think of.
- 7. We would like to know how to make our campus and local environment more welcoming to the HIV positive community, and want to hear your thoughts on how we could do that.
 - a. What are your suggestions for services the college could offer to make it easier for HIV positive people in your age group to integrate into campus life?
 - b. *Probe:* This can be a wide range of services – safe-space dialogues, testing, education of general student population, special health services, financial assistance, or anything else you can think of.
 - c. What should the service designers keep in mind to make these services very high quality?
- 8. Is there anything else we haven't discussed yet that you think is important for Cal Poly and the AIDS Support Network to know about as we consider tailoring an HIV awareness/support program on campus?

Participants: (Identities of students protected by use of pseudonyms)

Celery - Introduced to CCC through Spectrum, became involved with members of the Pride Center.

Apple - 2nd year computer science, uses the Pride Center daily.

Pineapple - 1st year Econ major, works in the Pride Center as a student assistant.

Blueberry - 3rd year Industrial Engineer, works in the Pride Center as a student assistant.

Grape - 3rd year Biochem major, frequents the Pride Center.

Dialogue:

Don: What exposure have you had to HIV education of any sort on campus?

Grape: None

Apple: None

Celery: Like through...anything?

Don: Yeah anything. Like the cross cultural centers, campus housing, the health center: any sort of health related event

Celery: I can't think of anyplace.

Blueberry: For me just talking to friends

Pineapple: Same

Don: Was that experience informative?

Blueberry: Yeah, I guess. It actually encouraged me to look stuff up.

Don: What setting was this in?

Blueberry: I was just at my friend's house, I don't know how it came up.

Pineapple: For me, specifically on campus, I don't feel like I've been exposed to any education about it. No awareness either. I remember coming in to Cal Poly and learning about consent and sexual assault. I feel like they could have continued into talking about the possibilities of HIV and something like that

Blueberry: I agree, this shouldn't be ignored. This isn't something you should learn just on the internet. For incoming freshman it'd be cool if they did stuff at WOW.

Apple: They hand out condoms at WOW, I guess there's instructions on them.

Don: Have you done any research on your own?

Grape: YouTube knows I'm gay, so I always get the "HIV Equal Ads"

Apple: What's the HIV equal?

Grape: It's like, an equal stance on people with no judgment, for positive people and negative

Apple: Is it like a logo?

Grape: I don't remember.

Don: Do you feel like the information given, or the lack thereof, was adequate?

Celery: Through different programs?

Don: Yes.

Celery: Yes and no, it depends on where you're getting the information from. I know at WOW my freshman year they had a lot of panels on stuff like alcohol and abuse. They didn't hit on the topic of HIV. I'm sure if they hit something like that, it wouldn't hurt.

Apple: When I did WOW I didn't hear about safe sex at all. The AIDS support network booth was there. I didn't approach it, a lot of people didn't

Purple: I had no idea they had a booth.

Celery: Me neither.

Don: We'd like to hear about the existing cause awareness programs at this college, such as ally training, 101 events, cancer-awareness events, sexual assault events, etc. Tell me about your experience.

Apple: We have like, Trans awareness events

Don: Do you have any experience with those?

Apple: Not really.

Celery: There's a couple panels I've been to that have talked about stuff like this. I've been to a couple at the pride center.

Don: Describe those.

Celery: I went to this monologue thing for men, Pen 15 club? Other events as well.

Don: Was the material informative?

Celery: Yeah just different topics, one woman came in and talked about herself and her partner.

She was a pregnant woman who got her sperm from a donor. She talked about her whole experience with that. Different things were talked about, it was interview-based and I liked that.

I also was involved with some other panels within the pride center. I went to an ally training my freshman year with my friend Ian, I thought that was very informative because I was very new to the LGBT community. I really had no information about it prior, just what I'd heard from other adults and friends and stuff. Panels like that are informative.

Grape: I went to Queer 101 a few weeks back

Don: Could you describe that experience?

Grape: I don't remember much, I remember the end they talked a little about protection.

That was about it.

Blueberry: Well I helped with the 101 series. I felt like they went ok this month. Not many went to the first one. We've had ally training; before but this is completely different. It's hard to get people to go at first.

Don: In what way were these events helpful to the attendees?

Blueberry: I feel like they were helpful, they could ask questions and not feel dumb. Like, they were curious, or if they misunderstood stuff. It was ok, they could ask anything.

Pineapple: Yeah, some of the panels I've been to, like the queer family panel in the pride center was helpful. I helped organize it, it's helpful having resources to educate on the possibilities and provide influence from people who have been through it already.

Don: In what ways do you feel the classes fell short?

Blueberry: Probably just the lack of them, there's so few of them. They had a class every Monday, after the first one it was full. The first one was low attendance, but the other three were packed.

Don: Now imagine that you are part of a committee of people designing an HIV awareness event, what would you do to attract people?

Celery: Anybody can go to it. In our own age group. No restrictions.

Pineapple: I feel like the anonymity is important, beneficial and encourage people to go. They feel like they're going to a safe place, won't be held accountable for saying the wrong thing. That matters.

Don: The facts provided at the event? What would be relevant or helpful?

Grape: It can't be overbearing, like oh my god this is so much information. Ok more like, we need to get tested. Where do we get tested? Not making other people feel like, oh I have HIV. Outlets for people to go to the doctor, what doctors are working better to diminish the effects of HIV. Places people can go where HIV positive people can become 99% healthy again. Giving light information, in depth a little bit on what each doctor can do, this and that, or whatever. Where to get tested, what the additional aspects of getting tested are just besides getting the initial test.

Apple: I feel like a lot of times events like this just read aloud a website. There's a difference between giving people information and informing them on general trends and how to get things.

Grape: More community based. I want to be able to find a doctor around here, we have great surgeons in here, doctors in general. Somebody who helps with HIV is definitely here, community based. Community driven, not just information that's out in the middle of nowhere.

Celery: Recent and relevant information.

Don: What resources would you imagine would be present at the event?

Celery: A panel might be cool, q and a sessions might be helpful. Especially if people don't know what to ask. In a group setting, if there's someone like a doctor or a few of them that sounds like it would be good resources.

Don: Requirement vs interest-based, should an event that's required be offered?

Grape: I don't know the demographic of people who would be affected by HIV in the area.

Celery: Good point.

Grape: That takes a big hit on how many people you'll get.

Celery: I agree with that

Grape: I don't know anybody personally who's affected by it. This affects whether or not the event is mandatory. It's like hey who will be interested. By not knowing how many people are affected, I would understand how important it is to broaden it and such. It has to be determined based on statistics.

Apple: I think if the goal is to eliminate stigma, people won't go if it isn't mandatory. Maybe a WOW event, or a, like a...

Grape: Yeah a wow event

Pineapple: WOW isn't mandatory

Apple: Yeah but it's common. And the information will osmose if a majority go.

Grape: At WOW they have the little sit down moment after they watch something. If it is mandatory then you'll have to talk about it.

Blueberry: I agree to have it as mandatory. It can affect anyone even if you're not HIV positive.

Pineapple: Like Haven

Grape: No, I know for HAVEN and some of those other ones you don't even have to read it. You just click. You can just scroll through for some of those videos and click next. So no, I don't think it would be beneficial.

Blueberry: I don't even remember taking it

Pineapple: There will be a portion who takes the test seriously

Apple: Even then, there's such a huge proportion of people who know nothing about HIV. There's a lot of people who don't know about it. Even scrolling would help. I have a family friend whose sibling got divorced because their spouse drank out of the cup of an HIV positive person. Which is totally wrong. Even if 95% of people scroll through, there's still some impact. There is need.

Part 2: Participants: Green and Red; Facilitator: Kangaroo

Kangaroo: Now imagine that you are part of a committee representing a local STD/testing clinic, like the center or AIDS Support Network and are aiming to increase the number of local students getting tested. What are the factors that you will make sure your current committee considers in marketing these services? What are the things you are sure would attract people like you to these services?

Celery: If they have any suspicion that they may have contracted something like that then there will be an interest for that, but if they don't or aren't sure that they do, I mean if I was going to offer a service like that I would want to make sure that the people are aware they are getting that information. I think its valuable information even if they haven't contracted an STD or an STI. They would be able to protect themselves.

Apple: I just want to know what the procedures in place are, do they have to stab me to test me? What is the test like? Where do I go? Is it free? What do I say?

Kangaroo: Okay, so just getting the information out there and trying to market it so that people will understand what they are actually getting into so they feel safe doing it?

Apple: Yes. I mean they should get more people going because it is important, but they also need to let people know how and where and when.

Celery: I think one of the things that people struggle with are, if you really want to get a resource like that you would have to have an interest yourself to want to participate.

Kangaroo: Anything else you guys can think of that might affect how easy it can be to go to these things and get it done?

Celery: Again, I don't really know how the process is because I have never been in that situation so I don't know if it takes a long time or if it is difficult. I could definitely use some more education in this area.

Kangaroo: We would like to know how to make our campus and local environment more welcoming to the HIV positive community, and want to hear your thoughts on how we could do that. What are your suggestions for services the college could offer to make it easier for HIV positive people in your age group to integrate into campus life?

Celery: Are there resources for this right now?

Kangaroo: I have no idea? It's a Mario question.

Celery: That would be the first thing to find out, if there are any resources available and then the next question I had is how are those resources reaching out to students at the moment and is there another way to do so. I'd say it would probably have to be a little bit more than just word of mouth for that kind of information to get around, especially for the people who need it.

Kangaroo: Okay

Apple: I think the only time that HIV status is really relevant is when doing hookups and things like that and realize you don't have to tell someone you're HIV positive. You can pass as HIV

negative pretty easily. People who are HIV positive, I see people write “POZ” on their Grindr profiles. I imagine they sometimes get slack about it and that kind of sucks, but I don’t really know.

Kangaroo: Could you think of any new services that may be a good idea to provide?

Apple: Providing condoms for people to just have safe sex and who are sexually active with people who are HIV positive.

Kangaroo: Thank You

Kangaroo: Is there anything else we haven’t discussed yet that you think is important for Cal Poly and the AIDS Support Network to know about as we consider tailoring an HIV awareness/support program on campus?

Celery: Is there a resource for people who have knowledge that they have contracted something like that to have someone to talk to about it? Does that exist?

Apple: Like counseling?

Kangaroo: I am unaware if there is counseling for that kind of thing, but I am aware of the counseling clinic down in the health center.

Celery: Would they be able to refer you to someone?

Kangaroo: Most likely, they do work as part of the agency within the school and within San Luis Obispo County, so they would have referrals. Although, their referrals tend to be for more specific forms of counseling that are necessary and for long term counseling. Because the counseling clinic on our campus are only suited for brief counseling, so about 10 visits for a specific problem.

Apple: I think if we had more statistics about who had HIV it would be more effective.

Kangaroo: Thank you for your time and your answers. If you would like to leave you can.

End of Focus Group Questions.

Appendix F: Grant Application

THE COMMUNITY FOUNDATION SAN LUIS OBISPO COUNTY

Growing Together Fund
Community Action Project
Application Cover Sheet

Applicant Information

Organization Name: San Luis Obispo County AIDS Support Network

Address: _____

Contact Person: Mario Espinoza

Phone: _____

Fax: _____

E-mail: _____

Grant Request Amount: \$ 1000 (maximum of \$1000)

Brief Grant Request Description (if applicable, project name): "Know Your Status"

Outreach program for HIV education & prevention

Application Checklist

- Application Cover Sheet
- Proposal Narrative Questions Sheet with Your Responses Attached
- Line-Item Budget Form with Attachments if Necessary

Authorizing Signatures

Application must include two signatures: (Exec. Dir. & Board Pres. Or 2 Board Officers)

[Signature]
Signature

DAVID KILBORN
Name Printed

Executive Director
Title

[Signature]
Signature

LISA M. DEAN
Name Printed

Vice President
Title

Office Use Only

1. What demonstrated need in the LGBTQI community does the project address?

The demonstrated need in the LGBTQI community that this project addresses is the lack of HIV education and awareness of preventative medication available. After collecting responses from anonymous surveys, we found that the community could benefit from an educational outreach program that addresses HIV stigma and pre-exposure prophylaxis (PrEP). As an example to the question attached to the survey, “What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?”, the response was, “Education that the diagnosis is not terminal as it is believed” additionally, “A lesson explaining to HIV negative people in ALL of the myths people believe about how you can catch HIV”. According to these responses that pertain to the San Luis Community in specific one can determine that there is a need for a project that focuses its attention on HIV stigma and PrEP.

2. What is the implementation strategy for the program/project?

Implementation of an HIV outreach program that promotes an equal and safe environment for HIV positive and negative persons as well as awareness of preventative medicine and the importance of HIV testing.

This event, “Know Your Status,” will consist of a presentation on alleviating stigma from the HIV community and will demonstrate what other organizations such as *HIV Equal*, *HIV Ends with Me* and *HIV Stops with Me*, are doing in an effort to combat the stigmatization of HIV and the harmful effects due to stigma.

The presentation will also introduce two local guest speakers that have been trained to share their story and promote preventative methods for HIV negative people to be aware of. After the two guest speakers we will open the floor for discussion alongside a panel for HIV stigma to answer questions from the audience about HIV and the importance of working together as a community to alleviate stigma and normalize the conversation in regards to HIV. Participation will be incentivized with giveaways handed out to the audience by the AIDS Support Network that meet Cal Poly event guidelines.

We have acquired approval, through the Cross Cultural Centers to reserve UU 220, UU 218 and the UU Plaza Stage as the venues on May 21, 2015. To gain audience members a proposal for an extra credit opportunity will be sent out to different departments at Cal Poly, attached with a flyer with the date, times and locations. Mustang News will advertise for this event as well. This event will be open to the general public as well in an effort to reach the broader San Luis Obispo community.

Alleviating stigma from the HIV community also means alleviating the stigma that exists for HIV testing as well. In an effort to combat the stigma there will be free HIV testing offered as well. There is also going to be an Instagram photo campaign that will be labeled as “*#KNOWYOURSTATUSCP*” and photos will only be taken of students and community members who consent by signature on a form that describes the intended use of the photos and that they are being published to an online source. A 2 part presentation in the evening will focus on HIV stigma and PrEP. The Presentation and panel will focus on what PrEP is exactly and how to finance it.

This segment will be presented by an AIDS Support Network Volunteer and Cal Poly junior named Leah Campbell. We will also have a local Physician and a sponsored guest to present their knowledge and stories on the subject that will then segue into a Q&A on PrEP. An expected number of 15 volunteer staff members will be assigned to the event as help for facilitating the event during different shifts.

Timeline:

UU PLAZA 11:00 A.M. - 1:00 P.M.
(Instagram Photo campaign #KNOWYOURSTATUSCP)
UU 218 12:30 P.M. - 4:00 P.M. (Free HIV Testing)
UU 220 2:00 P.M. - 3:00 P.M. (Presentation & Slideshow)
UU 220 4:00 P.M. - 5:30 P.M. (HIV Stigma & Panel)
UU 220 5:30 P.M. - 6:00 P.M. (Dinner)
UU 220 6:00 P.M. - 7:00 P.M. (PrEP & Panel)

Our expectation is that students will learn about the stigma surrounding the HIV community, both internally and externally, and the offensive language that may be used when it comes to HIV in conversation. We also hope for HIV testing to become normalized and for students to develop a sense of how important it is to participate in routine testing. By the end of this event students' body of knowledge on HIV and the effects of stigmatization on a local level will be expanded.

The availability of pre-exposure prophylaxis (PrEP) will also be a new concept for many students and members of the LGBTQTI community, as well as the broader community. After this event the attendees will be aware of the options available for financing PrEP as well as what

resources are available on campus and within San Luis Obispo. Moreover, attending this event will benefit students and faculty by engaging with physicians and professional guest speakers to answer any questions that are presented to them.

3. What are the measurable objectives and outcomes? How will they be measured and evaluated?

The Measurable objectives and outcomes will be an increase in students' breadth of knowledge in regards to HIV stigma, testing, contraction and knowledge about PrEP. This will be measured by pre-post questionnaires as well as a count of attendance that would measure the amount of interest the community has in attending future outreach events. The data presented will provide compelling responses from respondents in anonymous surveys that will produce emotional sensibility from the audience, enabling them to become aware of the effects of HIV stigma. An estimate of at least 50 attendees will be present for the presentations. Attendants will be measured by the number of questionnaires collected, signature counts for the photo campaign as well as the amount of people who participated in HIV testing (Adjusting for unique users).

4. What qualifications are possessed in order to successfully complete the program/project (both programmatic and administrative functions)? How will the program/project connect with other groups in the community?

The qualifications possessed in order to successfully complete this project are the AIDS Support networks' successful event history and my professional expertise in management and leadership. The AIDS Support Network as a fiscal agent has been the strongest collaborator for this project, with successful events such as, "Walk for Life," "Annual AIDS Update Symposium," and "Eat Out & Save Lives." Working with the AIDS Support Network has also enabled me to expand my organizational skills.

I have supervised up to 20 or more employees at a single time in my experience as a Shift Supervisor at Ross: Dress for Less and have acquired leadership skills through organizations such as Movimiento Estudiantil Xican@ de Aztlan (M.E.X.A.) and the PRISM Peer counseling program.

As an Alumnus of Cuesta College I have been contacted to speak on behalf of the Latino/a Leadership Network as a student panelist to empower and motivate prospective college students. My experience in management and as a student worker has provided me with the necessary administrative skills to organize and facilitate an event such as this one.

Campus organizations that have committed to participating in this event are as follows: Pride Center, Safer, Gender Equity Center, Multicultural Center, and Cal Poly Health Education's Peers Understanding Learning Supporting Educating (P.U.L.S.E.). Outside organizations that have committed to participating in this event are as follows: Community

Action Plan San Luis Obispo's (CAPSLO) The Center for Health and Prevention, and Planned Parenthood. Inviting these groups within the community to participate at this event it provides an opportunity for students and community members alike to interact with each other and network.

Line Item Budget

Please provide a detailed projected budget for your program/project.
 If additional space is needed, attach a maximum of one 8 1/2 by 11 in. sheet of paper

Budget Item and Description	Amount Requested from Community Foundation	Funds from Other Sources	Total
Graphics	135	Ø	135
Printing	180	Ø	180
Sponsored Guest	235	Ø	235
Food	450	Ø	450
Venue	Ø	100	100
Total	1000	100	1100

Appendix G: Press Release

Mario Espinoza

CONTACT

Mario Espinoza
AIDS Support Network
805-904-9225
mvespino@calpoly.edu

FOR IMMEDIATE RELEASE

Know Your Status: Educating SLO on HIV Stigma and Pre-Exposure Prophylaxis (PrEP)

May 21st, 2015

San Luis Obispo, CA, May 21, 2015— After collecting responses from anonymous surveys Mario Espinoza, Cal Poly junior, found that the community would benefit from an educational outreach program addressing HIV stigma and Pre-Exposure Prophylaxis (PrEP).

In his survey, Espinoza asked, "What do you feel is missing within the San Luis Obispo community that could be used as a resource for the HIV community?" One response, that clearly illustrated an overarching need, was providing "education that the diagnosis is not terminal as it is believed." Additionally, the SLO community expressed an interest in "a workshop explaining ALL of the myths people believe about how you can catch HIV."

Espinoza is working in partnership with Leah Campbell, a Cal Poly junior, the AIDS Support Network. All are collaboratively hosting the event, "Know Your Status" at Cal Poly on May 21, 2015. The event aims to alleviate stigma by raising awareness and educating the community on preventative medicine that can reduce the risks of contracting HIV. There will also be Free Rapid HIV testing for the students on Campus from 12:30 P.M. to 4:00 P.M. in CU 218. The informative panels will run from 4-7:30 P.M. and will include topics about HIV stigma and information on PrEP.

For more information please email mvespino@calpoly.edu or call the AIDS Support Network at 805-781-3660

###

Mario Espinoza • 805-904-9225 / mvespino@calpoly.edu • Cal Poly / AIDS Support Network

Appendix H: Timeline for the day of “Know your Status”

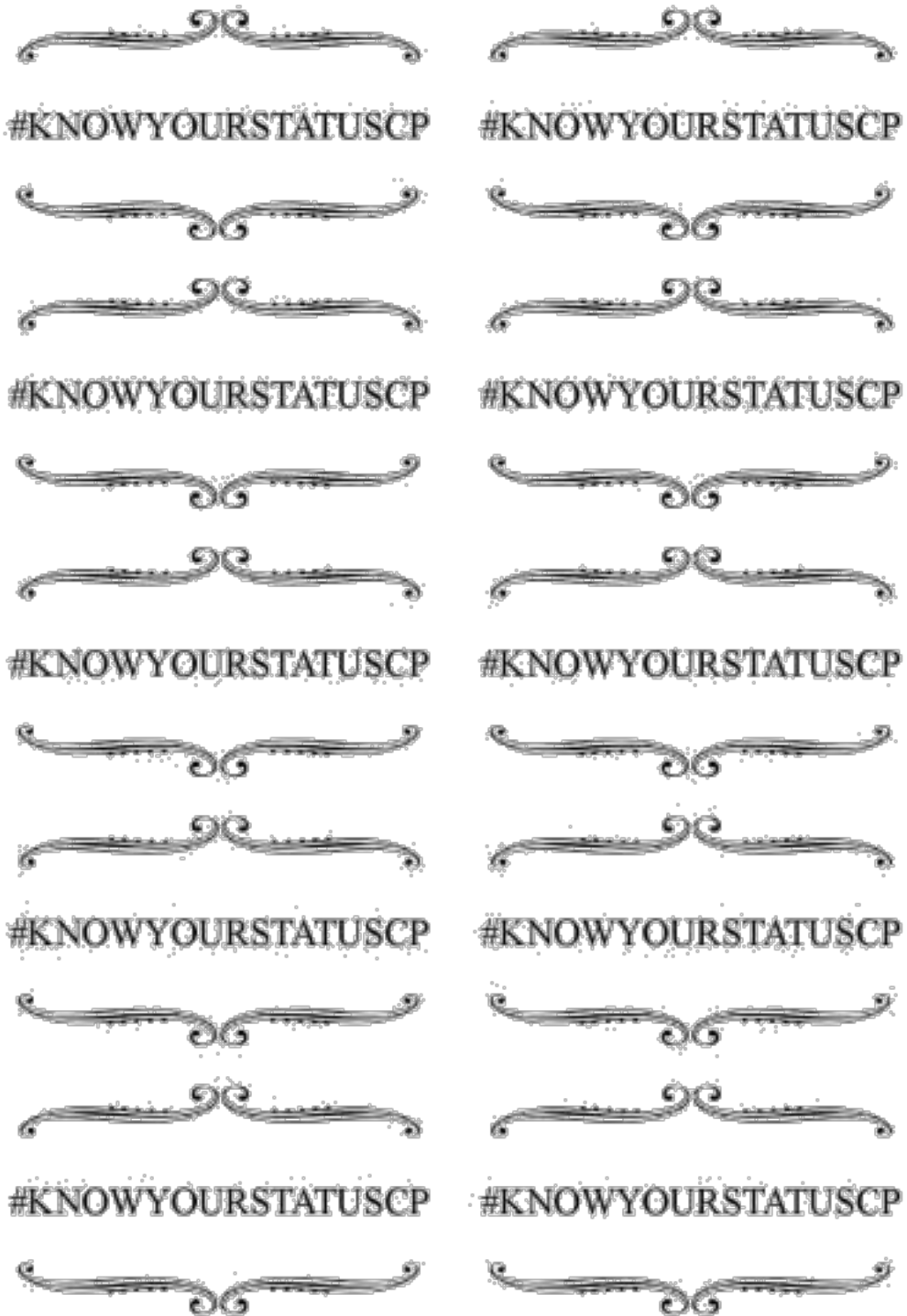
Know Your Status Schedule of Events

1. Remember to refer to this timeline to make sure you have a relaxed day and everyone is finished on time.
2. COMMUNICATION IS KEY; Feel free to contact me (Mario) at [REDACTED] to keep in contact throughout the day and with each other
3. This is going to be a long day, but we have help! Feel free to ask the volunteers to help out with any tasks necessary, this is why they are

4. Most importantly... HAVE FUN!

Time	Event	Notes
	Set-Up	
9:00 AM	Meet at UU 220	Mario and ASN Staff will be late because he has to pick up the boothing materials.
9:30 AM	Rally up with volunteers and prep for the day	
10:00 AM	Go get things down from the car	Horchata, Jar
	Boothing/ Photo Campaign	Have Media Release forms ready
11:00 AM	Be at the booths and round students up for pictures	Have Speaker Ready and Start Music
11:30 AM	Activities	Horchata, Games, Water
12:00 PM	Promote HIV testing at UU 218	Make sure to have a designated volunteer walk participants to Crisis Counseling as needed.
12:00 PM	Communicate with HIV Testing Counselors	Make sure everything is set and ready for testing
12:30 PM	Wrap-Up boothing event	
	Create Slide Show/ Prep for Presentation	Mario
1:00 PM	Save Pictures from Instagram	Mario
1:30 PM	Create slide show	Mario
	Prep for presentation	Mario
	Know Your Status Presentation	Mario
2:00 PM	Welcome Everyone	Mario
2:30 PM	End Presentation	Mario
	Begin resource fair	Mario
3:00 PM	Remind attendees of the upcoming HIV Stigma Panel	Mario
	Prep for HIV Stigma Panel	Mario
3:30 PM	Check In with volunteers and Coordinators	
	Make sure speakers are ready	
4:00 PM	Coordinators arrive	
4:30 PM	Go to Costco and pick up food	Kris and who ever else is available to help
5:00 PM	Pick Up Food at Olive Garden	Luis
	Refreshments	Napkins, Plates, Cups, Silverware, Salad Bowl
5:30 PM	Announce Refreshments	
6:00 PM	Wrap-up refreshments	
	Begin PrEP panelists introductions	
6:30 PM	Begin Discussion for PrEP panelists	
	Ask Questions	
7:00 PM	Say Thank You/ End KYS	
7:30 PM	Clean-Up	

Appendix I: Business Cards





Appendix J: Flier



KNOW YOUR STATUS

PRESENTED BY MARIO ESPINOZA & THE AIDS SUPPORT NETWORK

"Know Your Status" is an educational outreach program designed to incorporate fun activities with educational outcomes. Help alleviate stigma from the HIV community by participating and educating yourself on topics of awareness and prevention by attending our panels.

*Attendance for all events is not mandatory

MAY 21 SCHEDULE

INSTAGRAM PHOTO CAMPAIGN #KNOWYOURSTATUSCP	UU PLAZA	11AM-1PM
FREE HIV TESTING	UU 218	12:30PM-4:30PM
KNOW YOUR STATUS presentation	UU 220	2PM-3PM
HIV STIGMA panel	UU 220	4PM-5:30PM
REFRESHMENTS	UU 220	5:30PM-6PM
PrEP panel	UU 220	6PM-7PM

PANEL: HIV STIGMA

What's behind the stigma of HIV and what other organizations are doing to normalize the conversation on the topic of HIV and testing. This event will feature local guest speakers and allies who will be speaking to the audience about their experiences and knowledge about HIV.

PANEL: PrEP

A focus on preventative medicine that is available and how to finance for PrEP. This event will feature professional guest panelists, local guest speakers and chances to win prizes.

*Contact your professor for details about extra credit opportunities.

For more information contact m.espinoza@calpoly.edu or call the AIDS Support Network at (805) 731-3430.



Appendix K: Instagram Photo Campaign #KNOWYOURSTATUSCP

