

# Oakland Transitional Grant Area (TGA) 2015 HIV/AIDS Needs Assessment

Encompassing  
Alameda & Contra Costa Counties, California

Assessment conducted by



Richmond, CA

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All of the service providers and consumers who gave their time and insights in order to help all of us better understand the needs of people at risk for or living with HIV in the Oakland Transitional Grant Area in 2015.

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# CHAPTER ONE

## Introduction & Methods

### Background

In October of 2014, the Office of AIDS Administration of the Alameda County Public Health Department released a Request for Proposals on behalf of the Oakland Transitional Grant Area (TGA). Under the Part A funding category of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, areas of the United States that are disproportionately affected by the HIV epidemic can be designated as “Transitional Grant Areas” and can receive emergency relief grants to provide community-based HIV-related services.<sup>1</sup> The Oakland TGA encompasses both Alameda and Contra Costa Counties, a region of 1623.15 square miles with a population of approximately 2.6 million people.<sup>2</sup> Under the regulations of the Health Resources and Services Administration (HRSA) TGAs are required to use a community planning process, and are encouraged to establish a planning council that is representative of the community and assists in setting priorities for HIV services in the TGA, as well as allocating resources to address these priorities.<sup>1</sup> In the Oakland TGA, this group is the Collaborative Community Planning Council (CCPC), a 20-member body that meets monthly in entirety, in addition to smaller committee meetings.<sup>3</sup> The Request for Proposals released in late 2014 sought a qualified contractor to conduct a 2015 HIV/AIDS Needs Assessment in the Oakland TGA, and to produce a written report that could be used to guide the CCPC in determining HIV service priorities and allocations for Ryan White funds. In early 2015, Facente Consulting was hired to conduct this assessment.

### Focus of the Assessment

The 2015 HIV/AIDS Needs Assessment had 3 stated areas of focus:

1. Impact of health care reform on health care access, services, and cost for people living with HIV and AIDS (PLWHA) in the TGA
2. Incidence of hepatitis C among PLWHA in the TGA, current treatment status, and prognosis, and
3. Barriers and challenges to hepatitis C treatment by PLWHA, with proposed strategies for mitigation.

## Methods

This assessment was designed as a primarily qualitative effort to examine needs and underlying factors impacting these three topics. Qualitative research involves the exploration of chosen topics through unstructured data collection, primarily focus groups, in-depth interviews, facilitated group meetings, and analysis of existing written content (i.e. reports or published literature). Data are usually gathered through a combination of audio recordings, notes that were taken during discussions using loosely structured interview guides, and written observations recorded by the person responsible for data collection immediately after the close of each session. In this project, data were gathered in this way from service providers, community stakeholders, and directly from consumers to elicit stories and obtain a well-rounded perspective on the topic areas of the needs assessment. Data were then analyzed through a common process called immersion/crystallization,<sup>4</sup> whereby researchers immerse themselves in the data they've collected, reflect on the overall picture until the ideas crystallize and they can identify and describe meaningful themes and patterns in the data.

In this assessment, the qualitative research was paired with a quantitative survey of consumers, comprised of mostly closed-ended questions which could be summarized and counted in a way that was useful for the assessment. Overall, a team of three people worked on the assessment, together offering a comprehensive set of necessary skills, knowledge, and relationships within the TGA.

*Extensive efforts were made to solicit input from agencies, stakeholders, and individuals throughout the TGA. In all, data were collected from the following sources:*

#### 4 CLIENT/CONSUMER FOCUS GROUPS

held in partnership with Women Organized to Respond to Life-Threatening Diseases (WORLD), The HIV Education and Prevention Project of Alameda County (HEPPAC), and La Clínica de La Raza. These focus groups were for specific target populations relevant to the Needs Assessment areas of focus, including:

- Latino men (held in Spanish)
- Latina women (held in Spanish)
- People who inject drugs
- Women

#### 11 AGENCY-FOCUSED GROUP MEETINGS OR ONE-ON-ONE INTERVIEWS

held with a subset of service providers in key agencies at their service location. Agencies included:

- HEPPAC
- East Bay AIDS Center (EBAC)
- Kaiser Permanente – Oakland
- Highland Hospital
- AIDS Healthcare Foundation
- La Clínica de la Raza

#### 121 CONSUMER SURVEYS COLLECTED FROM AGENCIES THROUGHOUT THE TGA

these surveys were distributed on paper and collected from participating agencies after at least a 2-week period. Participating agencies were chosen to have a varied spread according to geography, service type, and target population. Consumer surveys are a small semi-representative sample of the larger population of PLWHA in the TGA and were not intended to be all-inclusive due to resource limitations. Surveys were distributed to:

- AIDS Healthcare Foundation
- AIDS Project East Bay
- Berkeley Free Clinic
- La Clínica de La Raza
- EBAC
- HEPPAC
- Highland Hospital
- Kaiser Permanente - Oakland
- Rainbow Community Center of Contra Costa County
- Tri-City Health Center
- WORLD

## Data Collection and Analysis

All qualitative sessions followed a loosely structured interview guide which changed slightly through the course of the assessment to focus on emerging themes or clarify discrepancies. Individual and group sessions were recorded when participants consented; if anyone objected, the recording was not made. Audio recordings were only used for transcription purposes and were not shared outside the assessment team. Team members took notes during sessions, and immediately afterward recorded observational notes of the session – i.e. what themes arose, what was challenging, what should be changed before the next session. The combination of assessment team member observations, session notes, and transcripts from each of the group and individual sessions was then analyzed and coded to identify themes, key quotations, and other information that informed the findings and recommendations presented in Chapters III – V of this report.

The consumer surveys were distributed on paper or via printable PDF (upon request) to 11 service agencies chosen for their diversity of location, services provided, and target populations. Paper surveys were distributed by hand in bulk to each agency, in both English and Spanish, with a request to have all clients living with HIV complete a survey during a two-week period. At the close of this period an assessment team member returned to the agency to pick up the surveys. Data from survey responses were entered into Microsoft Access and then analyzed for this report.

## Structure of this Report

Chapter II of this report provides a summary of the epidemiology of HIV/AIDS in the Oakland TGA. This is not intended to be a comprehensive epidemiological profile; rather, it is a summary intended to highlight the most relevant pieces of data recently analyzed and presented by staff at the Alameda and Contra Costa County health departments. This summary helps to set the stage for the findings and recommendations described in the following chapters of the report.

Chapters III – V each focus on one of the three topic areas of focus identified for this assessment. Each chapter presents any available data to describe the scope of the problem, highlights the findings of the assessment relevant to that topic, and presents a series of concrete recommendations.

Chapter VI presents a final summary of overarching themes regarding HIV/AIDS needs and service gaps in the Oakland TGA, and presents a series of recommendations for future work in this area.

## Limitations

This Needs Assessment was commissioned with limited resources; as a result the decision was made to focus primarily on service providers, with the assumption that those providers would be willing and able to speak as advocates for the needs of their clients. This information was then verified and supplemented through direct consumer assessment via focus groups and surveys.

The team succeeded in gathering a wealth of information that tells the story of needs and service gaps for the Oakland TGA in the chosen topics. However, it is important to keep in mind while reviewing and interpreting the findings and recommendations presented in this report that it was designed to be largely qualitative. Qualitative research is very well suited to provide information about human behavior, emotions, rationale, and contextual factors. However, because the numbers of people sampled in qualitative research tend to be small, those data cannot be summarized quantitatively. Additionally, although those surveyed for this Needs Assessment were chosen to reflect the diversity of the TGA, this was not a random sample and responses may not represent the experiences of everyone in the TGA.





# CHAPTER TWO

## A Summary of Epidemiology of HIV/AIDS in the Oakland TGA

The Oakland TGA is a multi-jurisdictional area encompassing a demographically diverse population across Contra Costa and Alameda Counties. Given such diversity, it is vital to understand the nuances of the epidemic within the TGA. Factors such as geographic sprawl of an area, density of the overall population in that particular location, and prevalence of HIV among those residents help to paint a very detailed picture of potential HIV need for the region. Layered upon that foundation is the greater detail about exactly who seems to be most at-risk for HIV infection in the TGA: in which groups is the disease spreading the fastest (what groups have higher incidence rates), and which people seem to be most disproportionately affected (what groups make up a greater proportion of HIV cases than their proportion of total people in the TGA). These epidemiological realities raise important questions about why certain people are more impacted by HIV, and offer critical information that should be used to fairly set priorities and determine funding allocations.

This chapter will first describe the HIV/AIDS epidemic in Contra Costa County and then provide an overview of the epidemic in Alameda County. The data summarized in this chapter were provided by the Alameda County and Contra Costa County health departments.

### Contra Costa County

Contra Costa County is a 732.6-square-mile area north of Alameda County, abutted by the San Francisco and San Pablo Bays on the west, Solano and Sacramento Counties on the north, and San Joaquin County on the east. Geographically, it is the ninth smallest county in California; however, in terms of population it is the ninth largest county in the state, with the US Census Bureau estimating 1,049,025 residents in the County in 2010.

Contra Costa County is generally divided into three zones for planning purposes: West County, Central County, and East County. The chart to the right shows the breakdown of towns, cities, and unincorporated areas within those zones.<sup>2,5</sup>

Figure 2.1 Contra Costa County Cities and Unincorporated Areas

West County		Central County		East County	
Incorporated Areas	2013 Population	Incorporated Areas	2013 Population	Incorporated Areas	2013 Population
Richmond	107,571	Concord	125,880	Antioch	107,100
San Pablo	29,685	Walnut Creek	66,900	Pittsburg	66,695
Hercules	24,848	San Ramon	74,513	Brentwood	55,000
El Cerrito	24,316	Danville	43,341	Oakley	38,194
Pinole	18,902	Martinez	37,165	<b>TOTAL</b>	<b>266,989</b>
<b>TOTAL</b>	<b>205,322</b>	Pleasant Hill	34,127	<b>Unincorporated Areas:</b> Bay Point Bethel Island Byron Discovery Bay Knightsen	
<b>Unincorporated Areas:</b> Bayview-Montalvin Crockett East Richmond Heights El Sobrante Kensington North Richmond Port Costa Rodeo Rollingwood Tara Hills		Lafayette	25,053		
		Orinda	18,681		
		Moraga	16,771		
		Clayton	11,505		
		<b>TOTAL</b>	<b>453,936</b>		
		<b>Unincorporated Areas:</b> Alamo Blackhawk-Camino Tassajara Canyon Clyde Diablo Mountain View Pacheco Vine Hill Waldon			

Approximately one out of four (23%) PLWHA in Contra Costa County live in Richmond, a city where 16% of residents were living in poverty in 2010. A substantial proportion are also living in Concord, Walnut Creek, Pittsburg, and Antioch.

Figure 2.2 shows a map of Contra Costa County, with the shading representing the distribution of PLWHA in the county by current residence; darker areas represent a higher density of PLWHA in a particular census tract. Each blue dot represents the location of an HIV/AIDS-related medical service.

Figure 2.2 Distribution of PLWHA and Medical HIV/AIDS Services, Contra Costa County, 2013

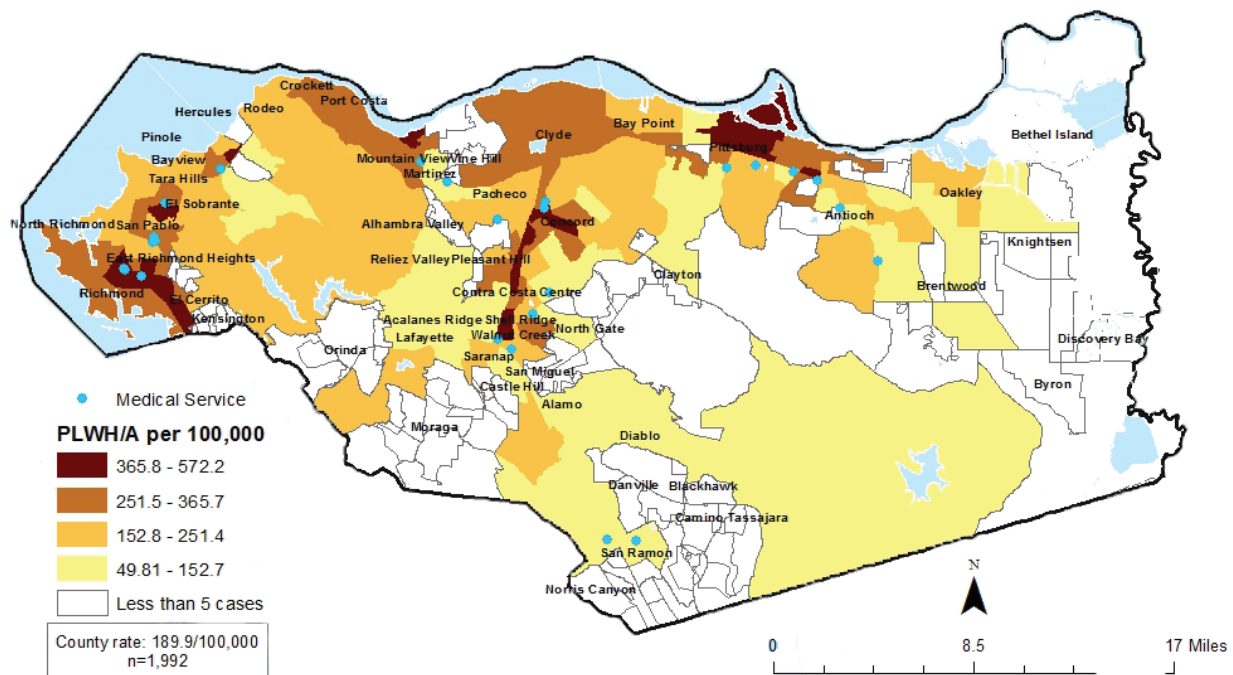
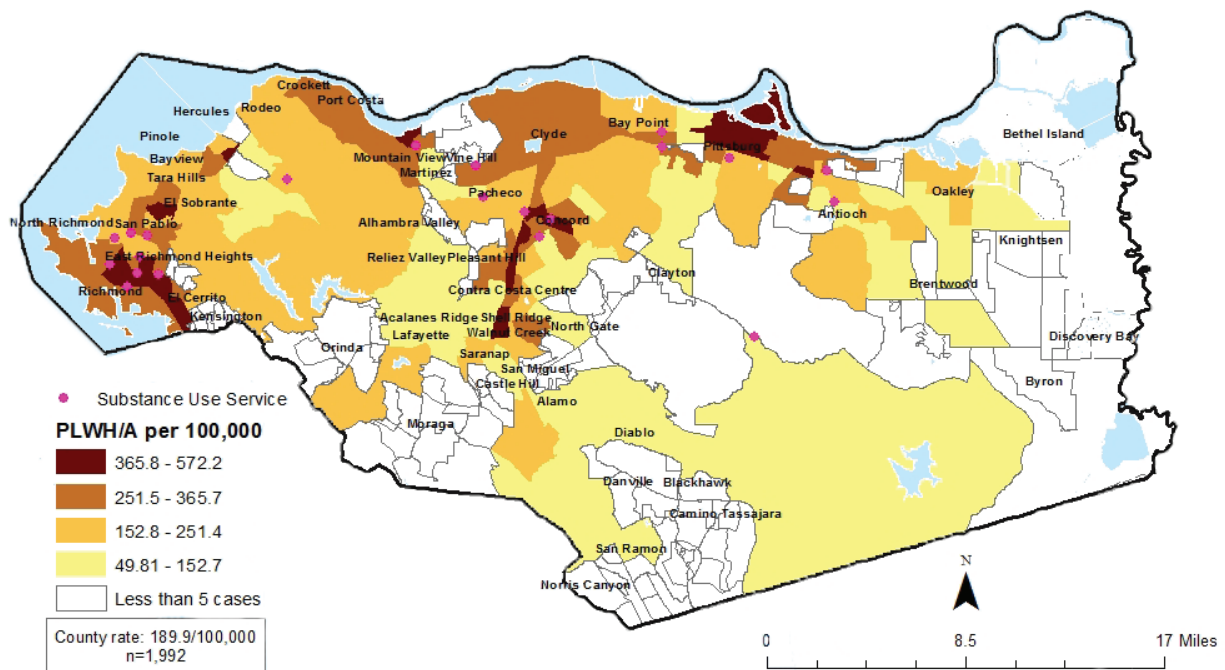


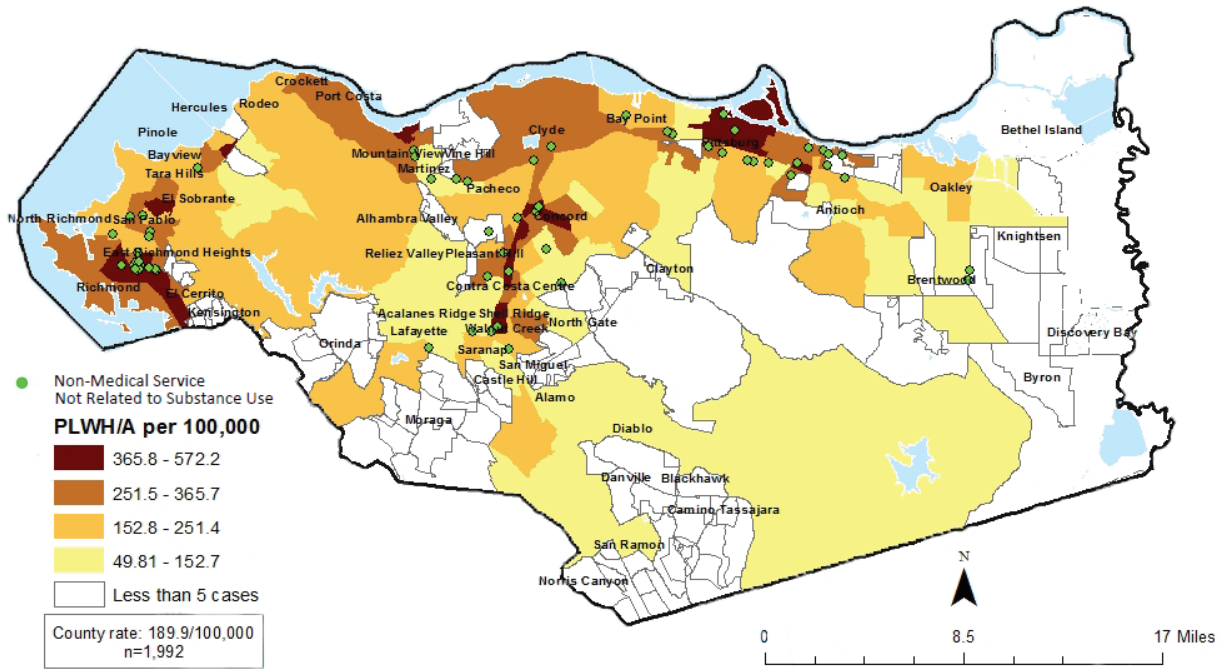
Figure 2.3 depicts the same map of Contra Costa County, with the pink dots representing the location of HIV/AIDS-related substance use services.

Figure 2.3 Distribution of PLWHA and Substance Use Services, Contra Costa County, 2013



And finally, Figure 2.4 shows the same distribution of HIV/AIDS cases in the county, but this time with green dots representing the locations of HIV/AIDS-related services that are neither medical nor related to substance use (i.e., psychosocial services such as mental health counseling, food, housing, case management, support groups, syringe exchange, etc.).

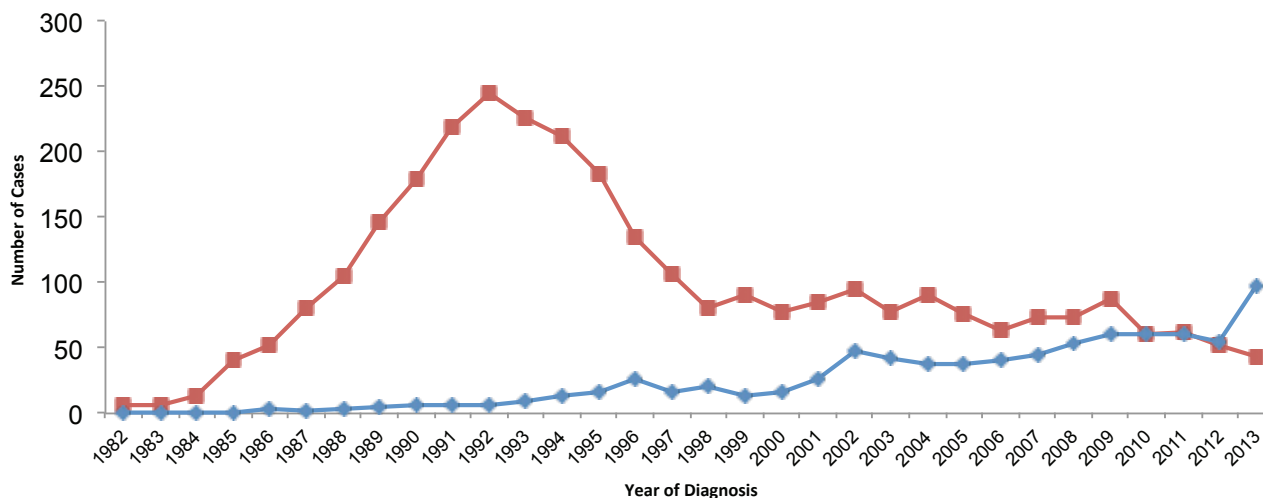
Figure 2.4 Distribution of PLWHA and Non-Medical HIV/AIDS Services Not Related to Substance Use, Contra Costa County, 2013



As of December 31, 2013, an estimated 2,025 people were living with HIV or AIDS in Contra Costa County. New AIDS diagnoses peaked at 245 in 1992, decreased over the subsequent five years, and have been gradually decreasing since 1997. However, new HIV diagnoses have increased gradually over time since the beginning of the epidemic, with incidence at its highest – 63-65 cases per year – during 2009-2011.

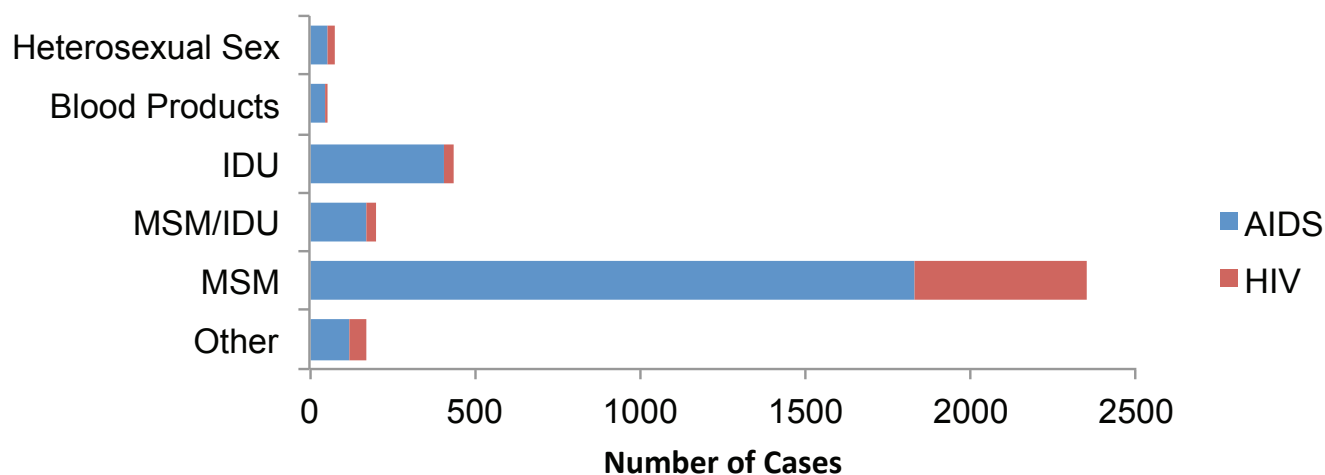
It is important to note that mandatory reporting of HIV infection (as opposed to AIDS, which has been a reportable disease since the early 80s) began in California in 2002. This had significant impact on the way non-AIDS HIV cases were counted and tracked, in both Contra Costa and Alameda Counties before and after that date.

Figure 2.5 New HIV/AIDS Diagnoses (N=3,839), Contra Costa County, 1982-2013



Historically, both HIV and AIDS cases among males in Contra Costa County have been concentrated among men who have sex with men (MSM), which reflects the profile of the wider HIV/AIDS epidemic in the western United States. However, unlike other areas of California, injection drug use (IDU) is a relatively common risk factor among males diagnosed with HIV/AIDS in Contra Costa County, contributing to 11% of diagnoses.

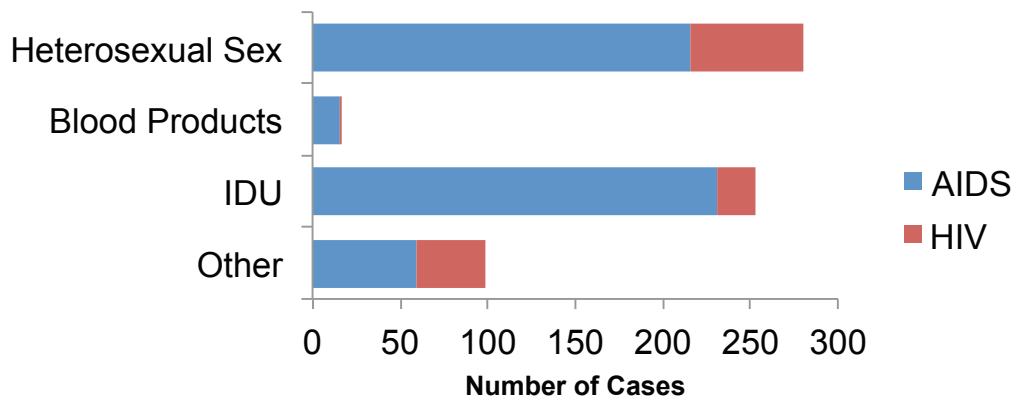
Figure 2.6 Risk Factors for Males Diagnosed with HIV/AIDS (N=3,200), Contra Costa County, 1982-2013





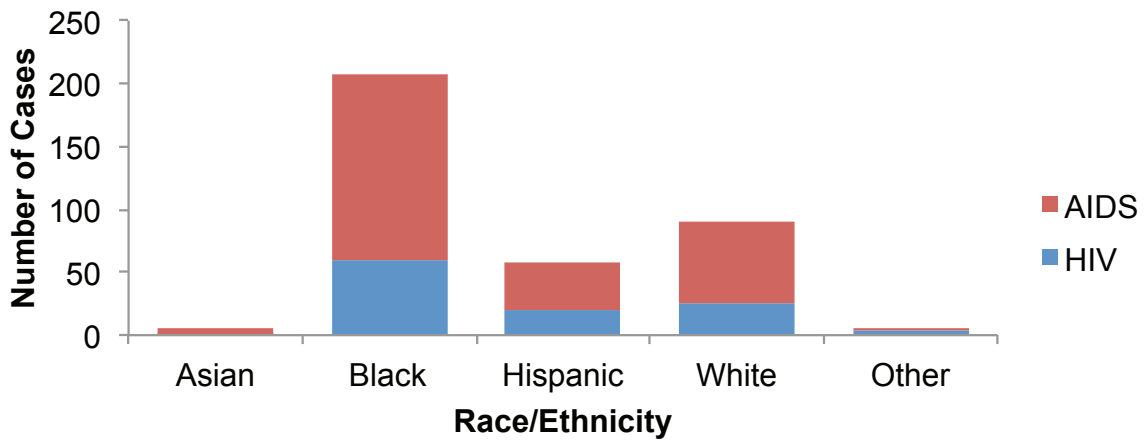
Of the total PLWHA in Contra Costa County as of December 31, 2013, 18% were women. Among women diagnosed with HIV/AIDS in the county during 1982-2013, the primary risk factors were heterosexual contact and IDU, accounting for 43% and 39% of cases, respectively.

Figure 2.7 Risk Factors for Females Diagnosed with HIV/AIDS (N=639),  
Contra Costa County, 1982-2013



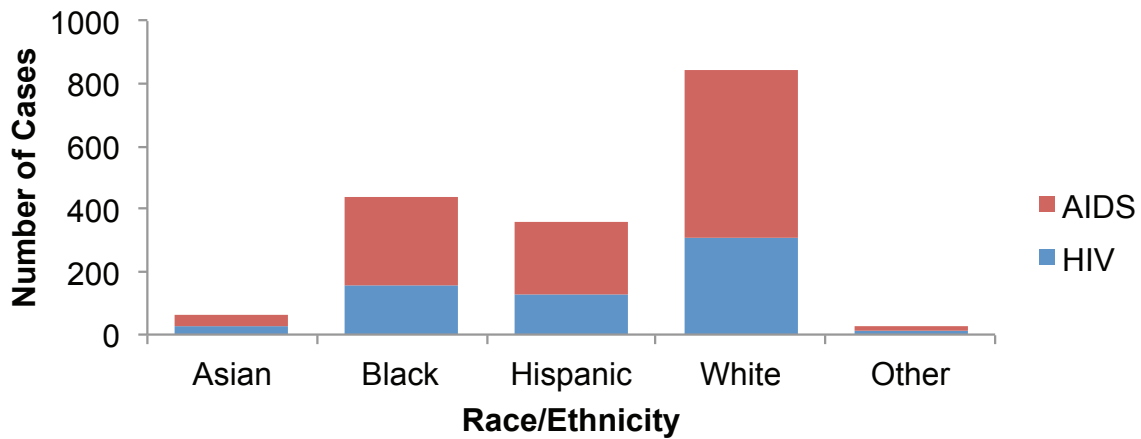
Among women, African Americans are disproportionately affected by HIV/AIDS in Contra Costa County. As of December 31, 2013, over half (57%) of female PLWHA were African American, compared to an overall 10% of county residents who are African American. There are half as many White women (25%) living with HIV/AIDS in the county.

Figure 2.8 Females Living with HIV/AIDS (N=364) by Race/Ethnicity, Contra Costa County, 2013



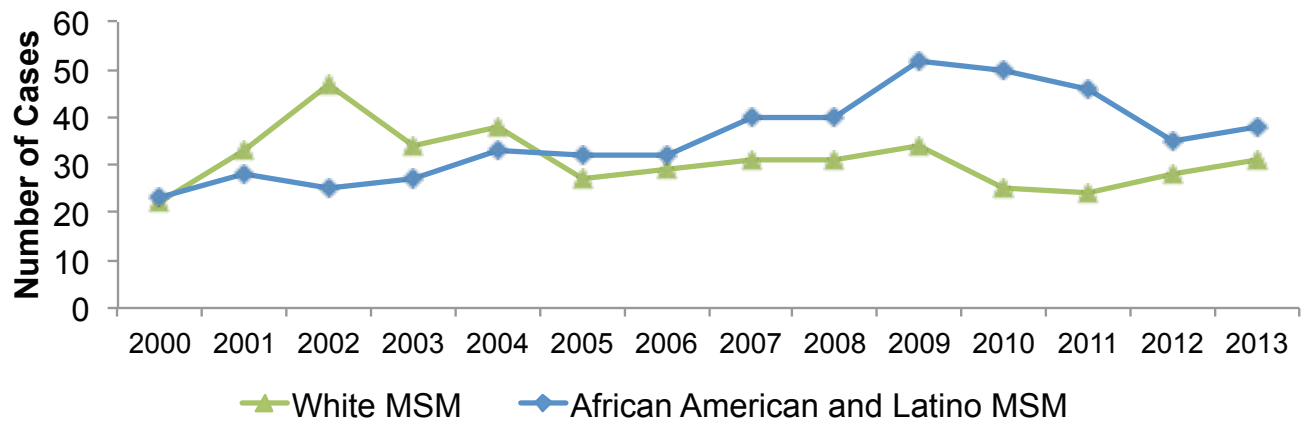
Among males in Contra Costa County, the epidemic also disproportionately affects African Americans. African Americans account for 25% of HIV/AIDS cases among males, compared to the overall 10% of county residents who are African American. On the other hand, 68% of county residents are White, while only 49% of male PLWHA in the county are White.

Figure 2.9 Males Living with HIV/AIDS (N=1,726) by Race/Ethnicity, Contra Costa County, 2013



As of 2000, there were no differences in HIV/AIDS diagnoses among White MSM compared to African American and Latino MSM in Contra Costa County. However, in the subsequent decade, HIV and AIDS diagnoses increased among African American and Latino MSM while decreasing among White MSM. Beginning in 2012, however, the gap began narrowing between the two groups, with 28 new HIV/AIDS diagnoses among White MSM compared with 35 among African American and Latino MSM.

Figure 2.10 HIV/AIDS Diagnoses Among MSM (N=886) by Race/Ethnicity, Contra Costa County, 2000-2013



## Alameda County

Alameda County is a 738-square-mile area bordered by Contra Costa County in the north, the San Francisco Bay on the west, Santa Clara County on the south, and San Joaquin County on the east. The 2010 population was estimated to be 1,510,271, making Alameda County the seventh most populated county in the State of California.

Alameda County is generally divided into two zones for planning purposes: West County and East County (formerly known as the Livermore-Amador Valley), with running hills dividing the county in two.<sup>6</sup> The chart below shows the breakdown of towns, cities, and unincorporated areas within those zones.<sup>2,7</sup>

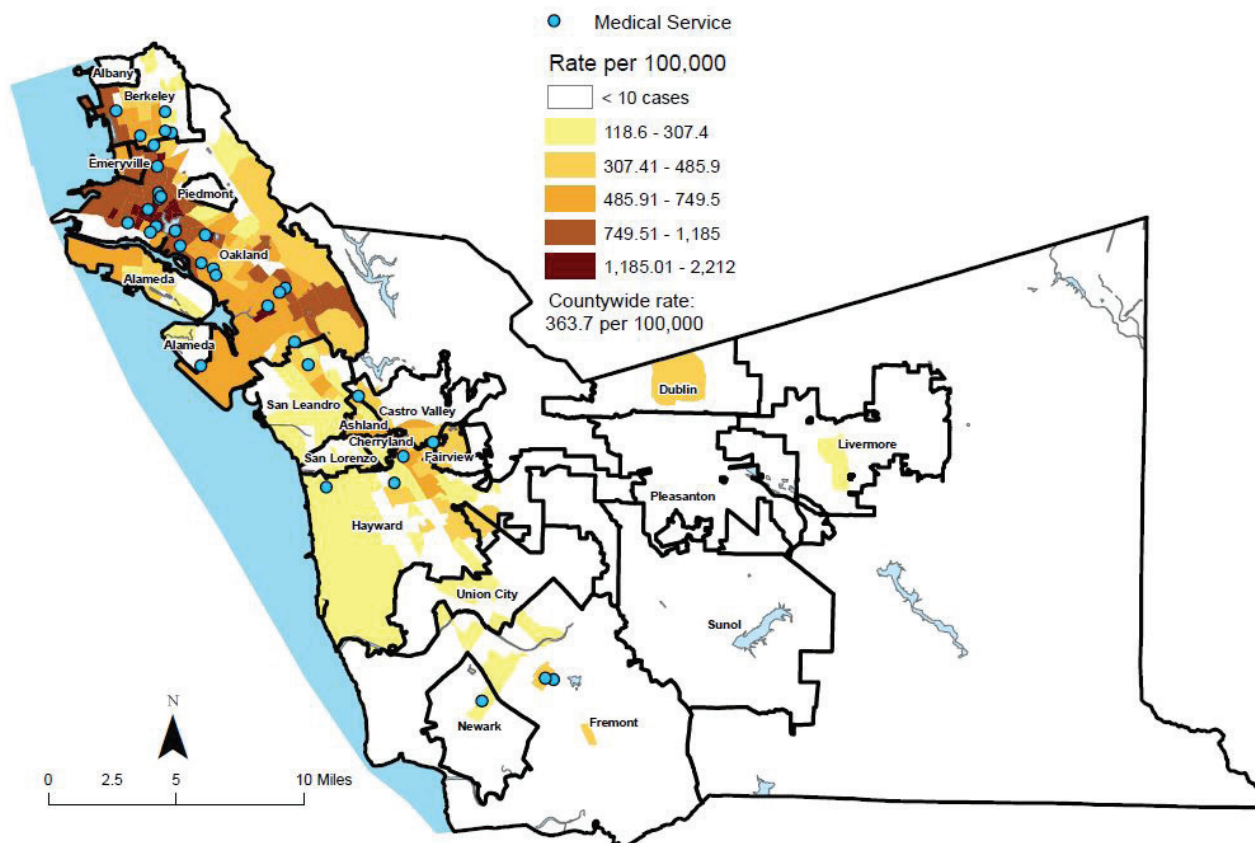
Figure 2.11 Alameda County Cities and Unincorporated Areas

Coastal Plain		Livermore-Amador Valley	
Incorporated Areas	2013 Population	Incorporated Areas	2013 Population
Alameda	76,419	Dublin	52,105
Albany	19,192	Livermore	85,156
Berkeley	116,768	Pleasanton	74,111
Emeryville	10,777	<b>TOTAL</b>	<b>211,372</b>
Fremont	224,922	<b>Unincorporated Areas:</b> Sunol	
Hayward	151,574		
Newark	44,096		
Oakland	406,253		
Piedmont	11,082		
San Leandro	87,965		
Union City	72,528		
<b>TOTAL</b>	<b>1,221,576</b>		
<b>Unincorporated Areas:</b> Ashland Castro Valley Cherryland Fairview San Lorenzo			

In Alameda County, the greatest burden of HIV cases is in the Oakland area. During 2011-2013, Oakland accounted for over half (58%) of new HIV diagnoses in Alameda County. Similar to the geographic distribution of cases in Contra Costa County, Oakland is characterized by a high prevalence of individuals living below the poverty line compared to the larger State of California (20% vs. 14% during 2007-2011).

Figure 2.12 shows a map of Alameda County, with all HIV/AIDS-related medical services locations represented by a blue dot. Behind those dots appears the distribution of PLWHA in the county by current residence. As can be seen by the map legend, the darker the shading of a particular census tract, the greater the concentration of PLWHA there.

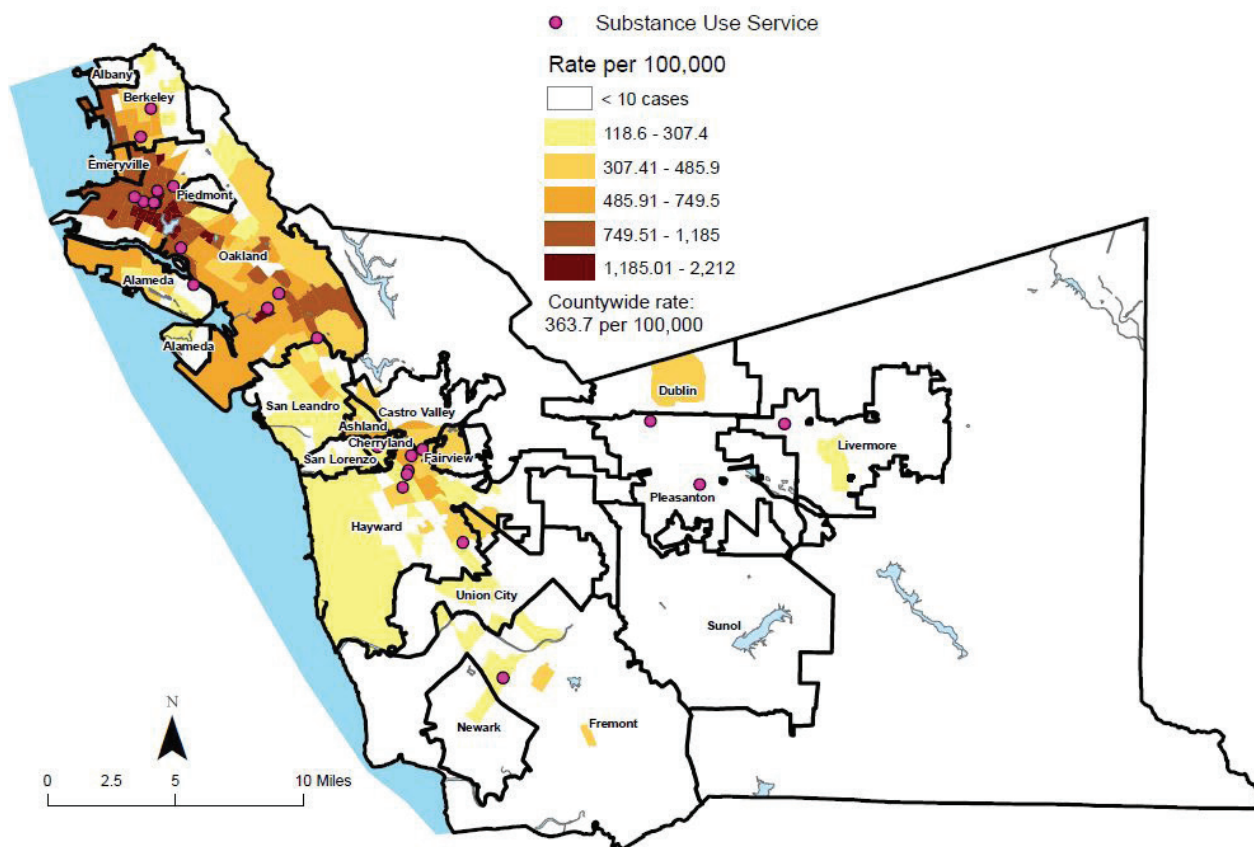
Figure 2.12 Distribution of PLWHA and Medical HIV/AIDS Services, Alameda County, 2014



Note: N=5077; an additional 572 (10.1% of all PLWHA) not represented due to missing or ungeocodable address data.  
 Source: CAPE (Community Assessment, Planning, Education, and Evaluation), with data from eHARS.

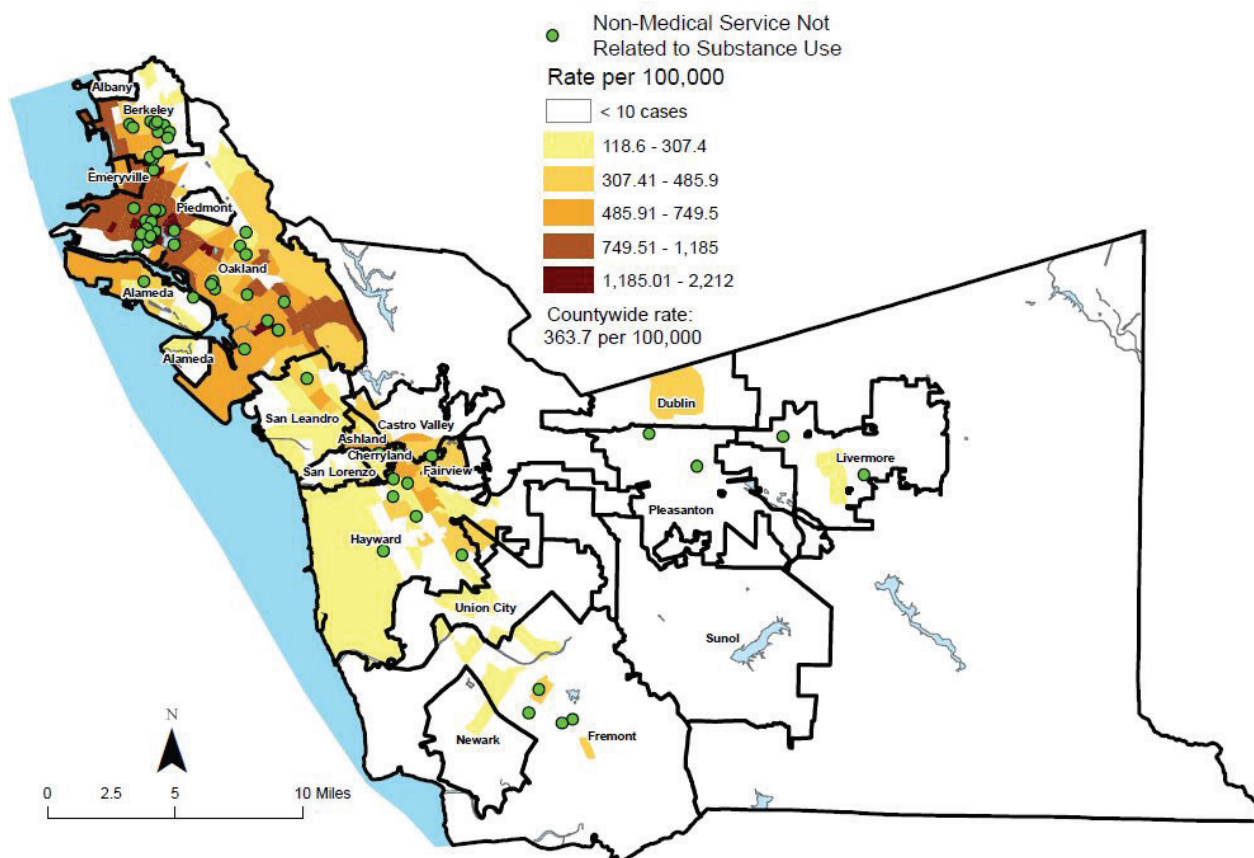
Figure 2.13 presents a nearly identical map of the county, except instead of HIV/AIDS-related medical services, the pink dots on this map denote substance use services.

Figure 2.13 Distribution of PLWHA and Substance Use Services, Alameda County, 2014



And finally, Figure 2.14 shows the same distribution of HIV/AIDS cases in the county, but this time with green dots denoting organizations that offer HIV-related services other than medical or substance use services (i.e., psychosocial services such as mental health counseling, food, housing, case management, support groups, syringe exchange, etc.). It is important to remember that the green dots on this map represent a very wide variety of services. The dots are not interchangeable; someone who specifically needs housing assistance, for example, will only be able to find services at a few dots on this map, regardless of where they live.

Figure 2.14 Distribution of PLWHA and Non-Medical HIV/AIDS Services Not Related to Substance Use, Alameda County, 2014



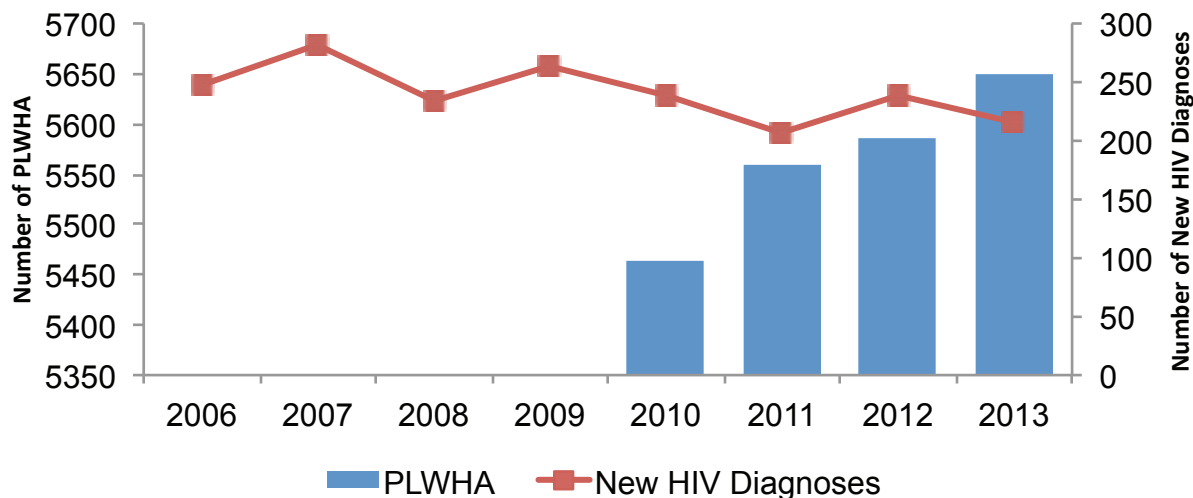
Note: N=5077; an additional 572 (10.1% of all PLWHA) not represented due to missing or ungeocodable address data.  
 Source: CAPE (Community Assessment, Planning, Education, and Evaluation), with data from eHARS.



As of December 31, 2013, an estimated 5,649 people were living with HIV infection in Alameda County, with 215 new HIV diagnoses in 2013. The average annual diagnosis rate for 2011-2013 was 14.3 new HIV cases per 100,000 population (95% confidence interval: 12.4-16.2).

The number of new HIV diagnoses per year has remained fairly stable since 2006, with 247 new cases in that year compared with the 215 in 2013. The number of PLWHA has increased as the number of deaths from AIDS has decreased due to improvements in antiretroviral therapy.

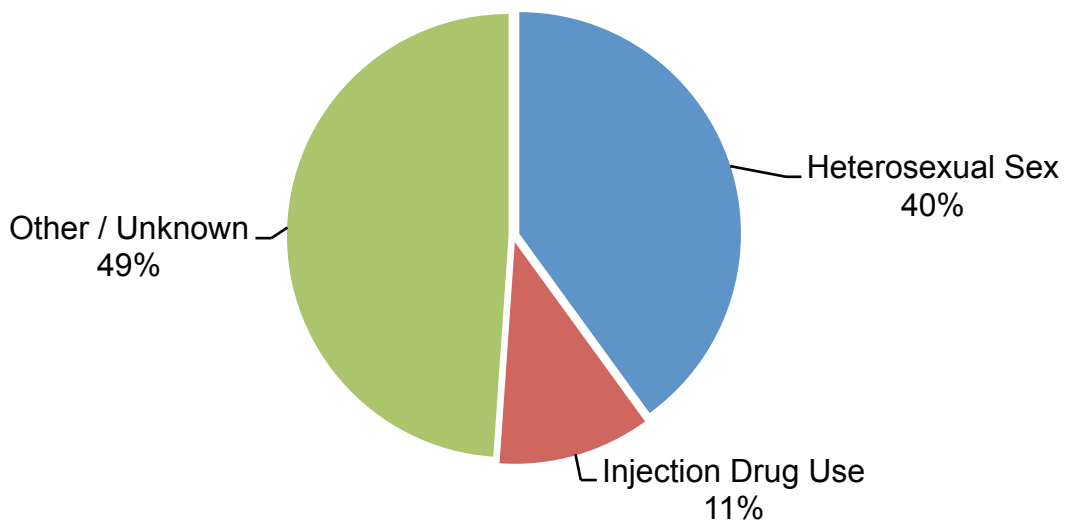
Figure 2.15 Newly Diagnosed HIV Cases and PLWHA, Alameda County, 2006-2013



NOTE: Numbers of PLWHA prior to 2010 were not estimable using most current methodology.

Demographically, the Alameda County epidemic largely parallels that of Contra Costa County. Among individuals newly diagnosed with HIV during 2011-2013 in Alameda County, 14% were female, compared to 12% female in Contra Costa County. Also similar to Contra Costa County, the primary risk factor for newly diagnosed HIV cases for women in Alameda County was heterosexual contact, accounting for 40% of cases.

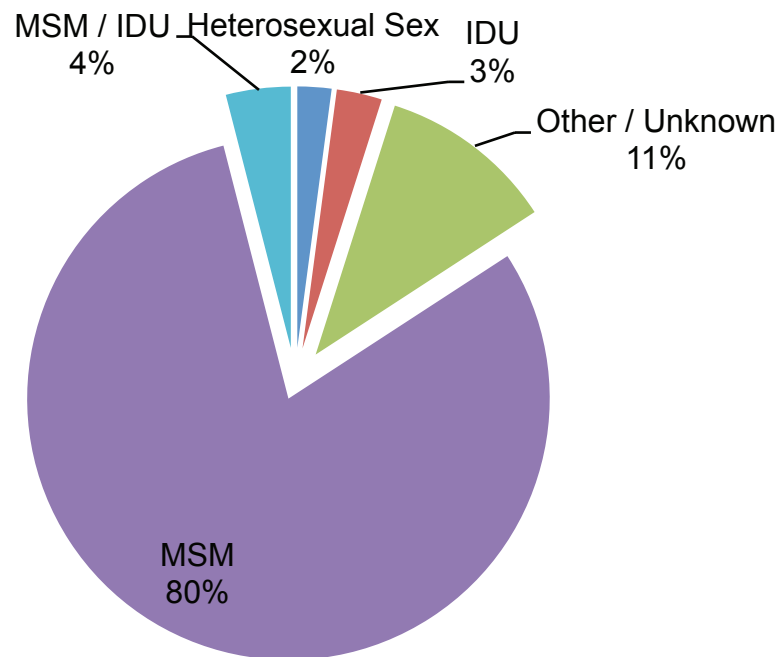
Figure 2.16 Female HIV Cases (N=90) by Mode of Transmission, Alameda County, 2011-2013



Note: N=5077; an additional 572 (10.1% of all PLWHA) not represented due to missing or ungeocodable address data.  
Source: CAPE (Community Assessment, Planning, Education, and Evaluation), with data from eHARS.

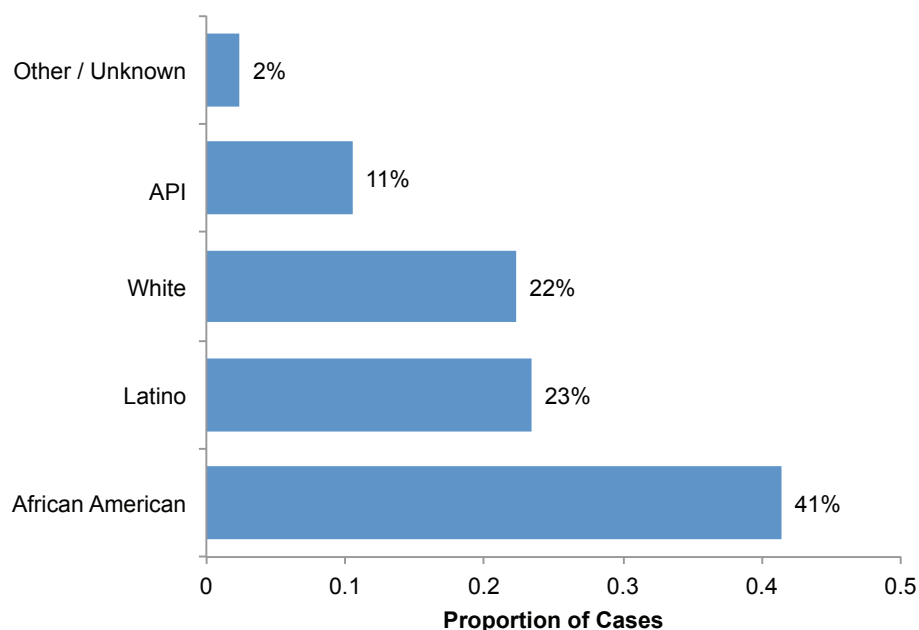
As reflected in the wider HIV/AIDS epidemic in the State of California, the burden of the epidemic in Alameda County lies among men. Of the males newly diagnosed with HIV during 2011-2013, the large majority (80%) were MSM, with IDU and heterosexual sex only contributing to 3% and 2% of the cases, respectively.

Figure 2.17 Male HIV Cases (N=569) by Mode of Transmission, Alameda County, 2011-2013



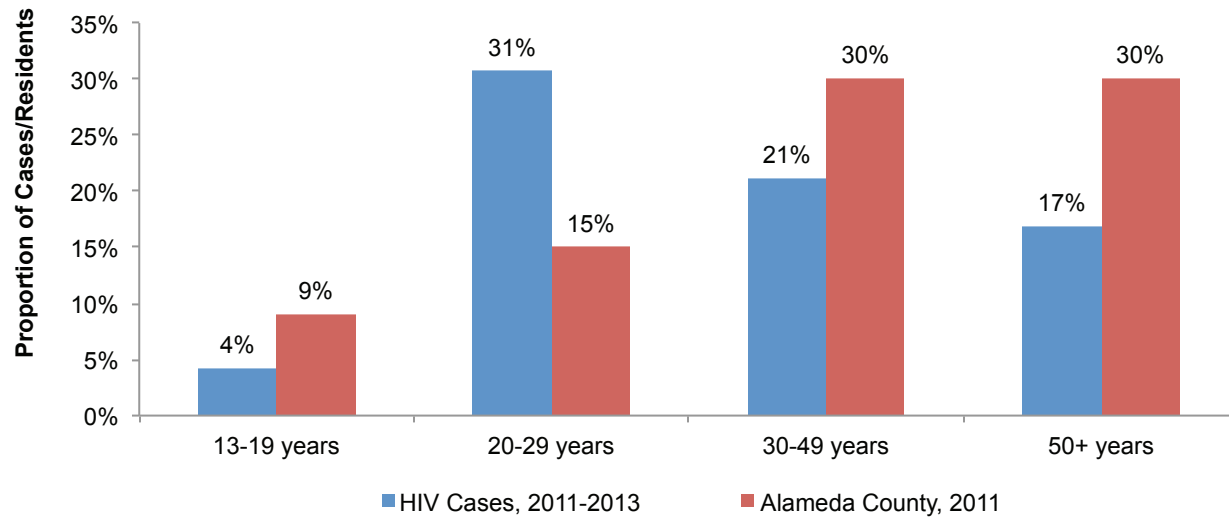
As seen in Contra Costa County, new HIV diagnoses in Alameda County in both males and females are disproportionately concentrated in African Americans. Overall, 41% of new HIV cases during 2011-2013 were among African Americans, while African Americans make up only 12% of the county population.

Figure 2.18 Newly Diagnosed HIV Cases by Race/Ethnicity, Alameda County, 2010-2012



Compared to the overall age distribution in Alameda County, newly diagnosed HIV cases in the county are disproportionately concentrated in younger adults. The majority (79%) of HIV cases are diagnosed among individuals between the ages of 20 and 49, while adults aged 20-49 are only 45% of the total county population.

Figure 2.19 Comparison of Newly Diagnosed HIV Cases and County Residents by Age, Alameda County, 2011-2013



Overall, the HIV/AIDS epidemic in both Contra Costa and Alameda Counties is concentrated in males, African Americans, MSM, and young adults. Males account for the vast majority of new HIV diagnoses in both counties, with MSM contributing to the majority of those cases. In both males and females, African Americans are disproportionately affected by HIV/AIDS compared with the overall demographic profile of these counties. Adults aged 20-49 also carry a disproportionate burden of the epidemic in both counties.

In the following chapters, this Needs Assessment focuses on three specific topic areas of concern. Although this HIV/AIDS overview is not comprehensive, having a broad understanding of the overall demographic profile of the epidemic in these counties provides a context for these topic areas and findings of this assessment.

# CHAPTER THREE

## Impact of the Affordable Care Act on PLWHA

### Background about the Affordable Care Act and Insurance Options

The 2010 passage of the Patient Protection and Affordable Care Act (known as the ACA)<sup>8</sup> was a landmark event for health care in the United States. Since its inception, more than 16 million people who were once uninsured have gained access to reliable medical care that previously seemed out of reach.<sup>9</sup> Primarily, this has happened through:

1. The creation of the Health Insurance Marketplace: “exchanges” – which in California are included under the umbrella of “Covered California”, and
2. Medicaid Expansion: As of January 1, 2014, Medicaid (“Medi-Cal” in California) was available to all Americans under age 65 whose family income is at or below 133% of the Federal Poverty Level (\$11,770 for an individual and \$24,250 for a family of 4 in 2015). This has resulted in more than 12 million people being added to state Medicaid programs since October 2013.

While this is a significant increase in health insurance coverage for Americans, the ACA does not result in universal health care access.<sup>10</sup> In the fourth quarter of 2014, 12.9% of adults in the United States were still uninsured,<sup>11</sup> including undocumented immigrants and those who choose not to purchase health insurance.<sup>12</sup>

People otherwise uninsured in the Oakland TGA still have options for health care, however: in Alameda County, residents who have a gross monthly income at or below 200% of the Federal Poverty Level, are not enrolled in private or employer-based insurance, and are not eligible for full-scope Medi-Cal can enroll in HealthPAC,<sup>13</sup> which allows them to access care through a contracted network of health care providers including the Alameda Health System and community-based organizations offering primary care. It is important to note that HealthPAC is the only insurance coverage option for undocumented people in Alameda County (they are excluded from Medi-Cal and other Covered California options); by all reports during this assessment, it is working well – undocumented people have streamlined access to high-quality, affordable care.

In Contra Costa County, uninsured residents can receive care through the Contra Costa Regional Medical Center (CCRMC, a program of the health department). Care for uninsured PLWHA is paid for by the County using funds supplied through the Ryan White HIV/AIDS Program, as long as they are enrolled in Medical Case Management, complete the recertification process every 6 months, and receive HIV services through CCRMC – this is true for both documented and undocumented people.<sup>14</sup> Additionally, PLWHA who live in the TGA and are 18 years or older, have a Modified Adjusted Gross Income of not more than 500% of the Federal Poverty Level (\$58,850 for a single individual in 2015), and do not have insurance that will cover the cost of their HIV medications are eligible for the AIDS Drug Assistance Program (ADAP),<sup>15</sup> and may receive medications through ADAP at no cost.

PLWHA who are able to access insurance through Covered California but have difficulty meeting their premiums or co-pays can apply for financial assistance through the Office of AIDS Health Insurance Premium Payment (OA-HIPP) Program. OA-HIPP will pay premiums for health, dental, and vision insurance for California residents living with HIV/AIDS who are enrolled in ADAP, are at least 18 years of age, are not enrolled in Medicare or Medi-Cal, and have a Modified Adjusted Gross Income (MAGI) that does not exceed 500% of the Federal Poverty Level.<sup>16</sup> Currently, there is no backlog of applications to be processed by OA-HIPP staff; however, all applications must be complete before they are processed.

While in general Medi-Cal Expansion may be the most impactful part of the ACA for PLWHA in the TGA, it is not without its challenges. Due largely to the significant increase in people applying for Medi-Cal through the Expansion program, the Medi-Cal offices have a substantial backlog of submitted applications; however, once approved, Medi-Cal applies retroactively back to the date of application. While everyone interviewed for this assessment agrees that this retroactive payment is excellent, the 9-12 month lag between submission and approval dates creates an administrative burden for safety net programs. For example, in Contra Costa County any PLWHA waiting

for their Medi-Cal application to be processed can receive care through the health department, paid for by Ryan White funds. However, the Ryan White HIV/AIDS Program requires that these funds may only be used as a payer of last resort; if Medi-Cal is retroactively applicable, the Ryan White charges must be reversed and Medi-Cal must be billed instead. The process of amending past invoices and payments for ambulatory medical care paid with Ryan White funds is very time consuming for County staff, given the numbers of patients with this backlog.

A similar challenge exists for PLWHA on Medi-Cal who receive health care through Kaiser. Those who apply for Medi-Cal often receive word that they have been accepted, but their insurance status has not officially been changed in the system that Kaiser can see. If that patient tries to seek services at Kaiser they will be told that Medi-Cal will not cover their expenses and they must pay out of pocket; this bureaucratic snafu occurs frequently and often takes multiple tries to resolve. In the meantime, says Dr. Sally Slome, the Chief of Infectious Disease at Kaiser-Oakland, the patients are missing appointments and not taking medications.

Dr. Slome summed up the major shifts nicely:

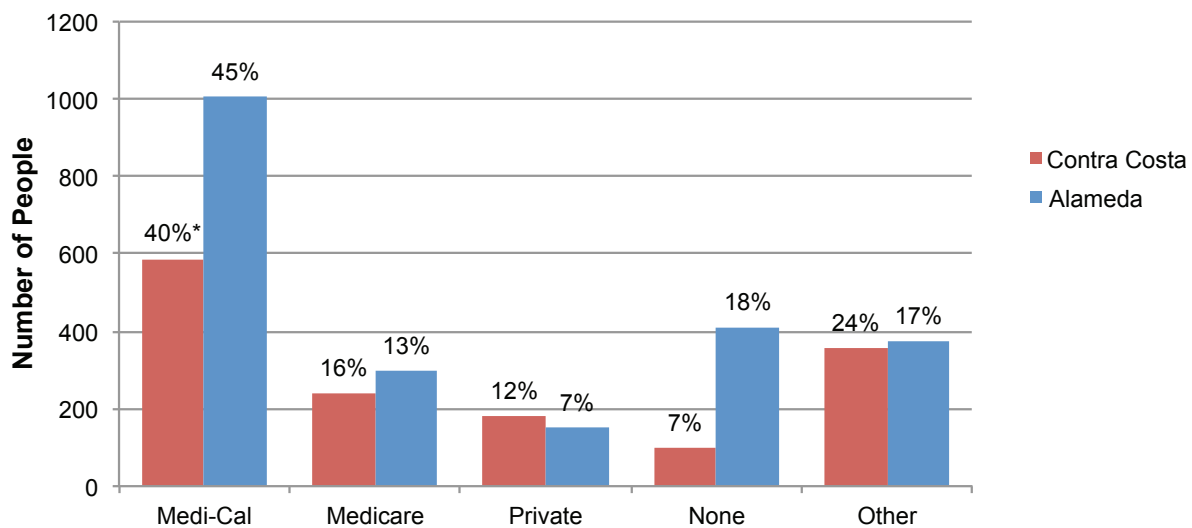
*"Members are extremely appreciative of the opportunity to have insurance. Many have stated that without it, they would be uninsured. Kaiser has been able to access the Office of AIDS Health Insurance Premium Payment Program to pay their premiums, and more clients have qualified through Medi-Cal Expansion. All this is evident by the decrease in referrals to free or Ryan White-funded clinics like the Magic Johnson Clinic, Tri-City Clinic, and AIDS Project East Bay."*

As described above, health care reform has dramatically impacted many Americans. However, for a lot of PLWHA in the Oakland TGA there has actually been little to no change in their health coverage. About 60% of PLWHA in Contra Costa County are insured through Medi-Cal, with about 25% having Medicare (there is some overlap between these categories). Some of those have been able to access Medi-Cal as a result of the Medi-Cal Expansion provisions of the ACA, but others were on Medi-Cal before and have essentially experienced no change. Approximately 1 in 5



(18%) have private insurance, and around 10% are served through the Covered California exchange. The remainder (10%) are uninsured, with care paid for with Ryan White funds. In Alameda County, about 45% are insured through Medi-Cal, with about 10% having Medicare. Approximately 7% have private insurance and 17% are served through the Covered California exchange or HealthPAC. Almost 1 in 5 (18%) remain uninsured, with care paid for with Ryan White funds.

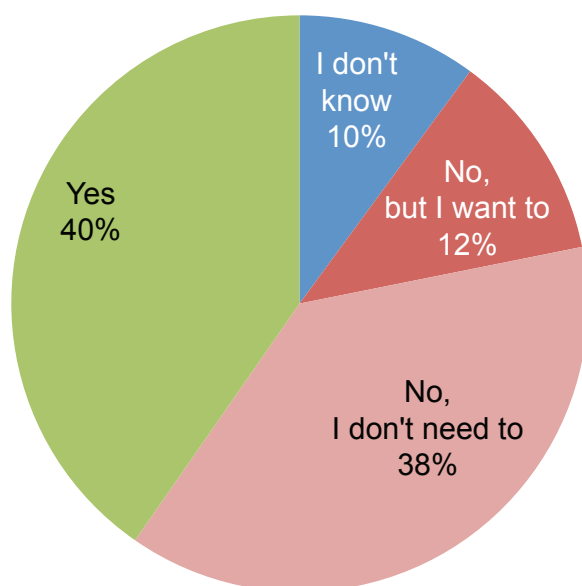
Figure 3.1 Insurance Status of PLWHA, 2014



\*Note that percentages equal percent of total in that county, excluding those with unknown insurance status.

Of the 119 consumers who responded to the first question of the consumer survey for this assessment, 40% said their current health insurance was through Covered California, though it is unknown whether this is part of the exchange, or Medi-Cal through the Medi-Cal Expansion program. More than 1 in 3 said they did not have insurance through Covered California, nor did they need it; these are likely to be people who either already had Medi-Cal prior to passage of the ACA, or those who are privately insured through an employer. The remaining 22% either wanted insurance through Covered California or were unsure of their insurance status (red and blue pie slices in Figure 3.2): these are the PLWHA of greatest concern for this assessment, as those are the people who are currently “falling through the cracks” post-ACA.

Figure 3.2 Do you currently have health insurance through Covered California?

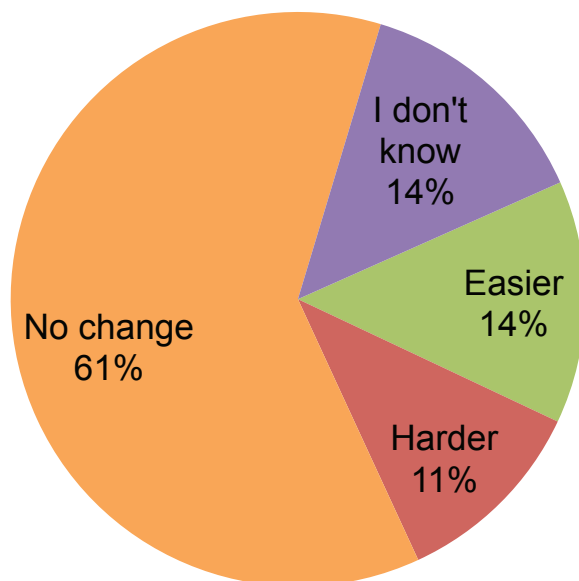


The 22% of PLWHA who either wanted insurance through Covered California or were unsure of their insurance status were split evenly with respect to gender (exactly 50% female and 50% male); 1/4 were African American and 3/4 were Latino, with no Whites or Asians in these slices of the pie.

Four percent of respondents in these categories had known they were HIV positive for less than a year; 16% had known for 1-3 years, 21% had known for 3-10 years, and 58% had known for more than 10 years that they were living with HIV. This corresponds closely to age: 12% of respondents in these categories were ages 18-24, 44% were ages 35-44, 40% were ages 45-54, and 4% were age 60 or older.

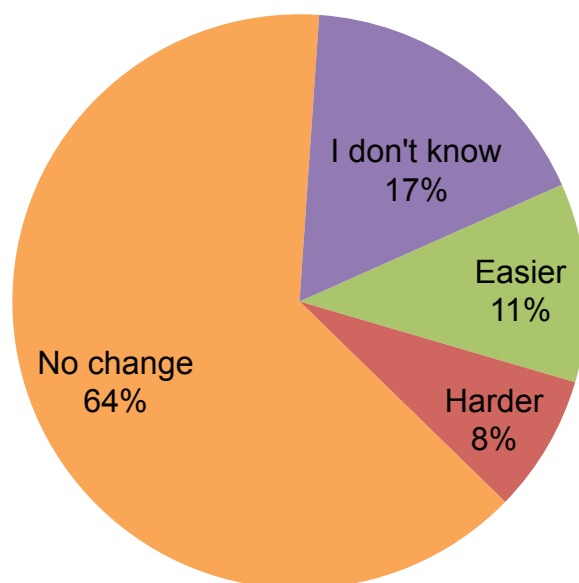
While 14% of responding consumers thought health care reform had made it easier for them to get health care for their HIV and 11% thought it had made it harder, almost 2 out of every 3 respondents said it had made no change for them. This is likely because they were privately insured or had Medi-Cal already, and had no change in insurance status.

Figure 3.3 Health care reform has made getting health care for my HIV...



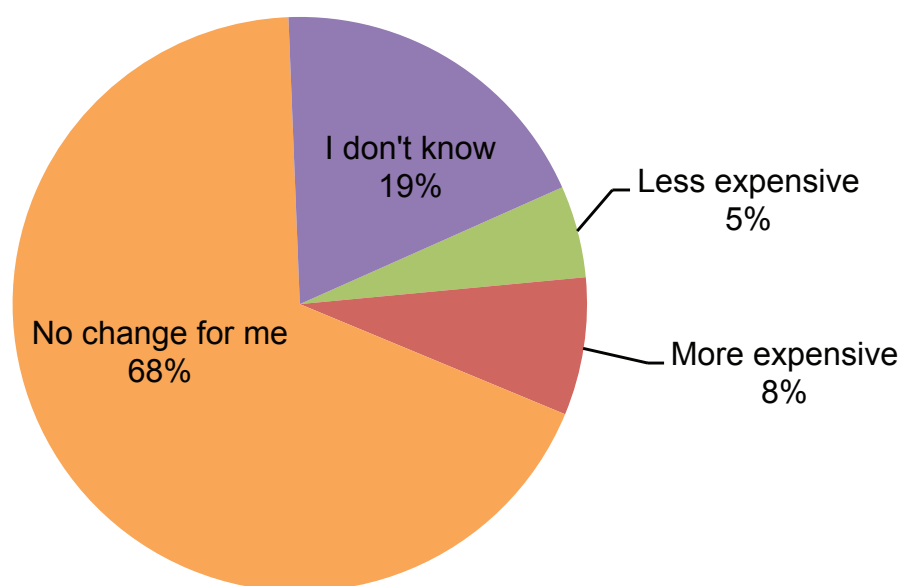
Similar figures were seen when asked about the impact that health care reform had had on their ability to get primary health care (not necessarily HIV related): in this case, more people were unsure about the impact it had, and a few more people said they saw no change.

Figure 3.4 Health care reform has made getting primary health care...



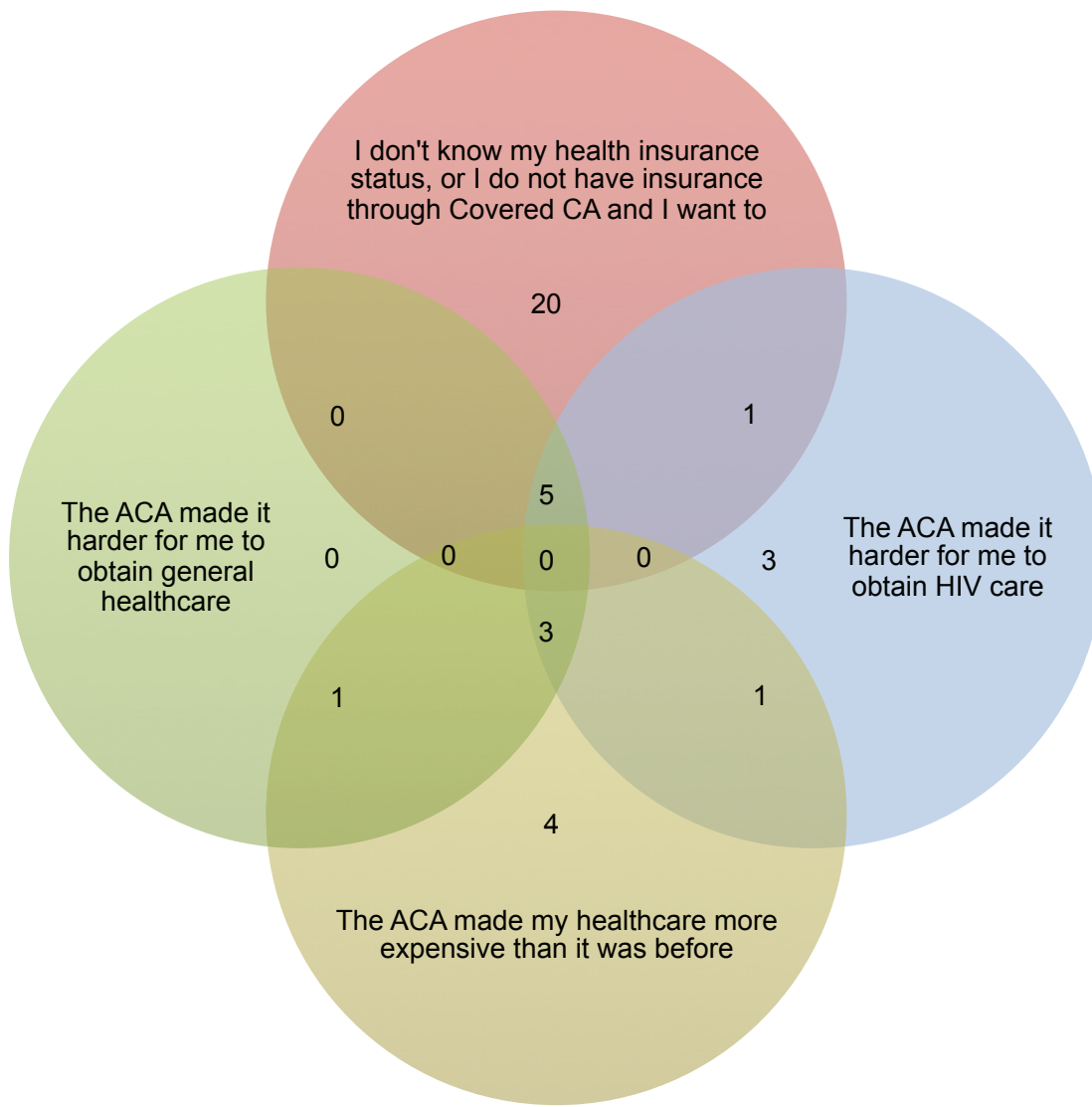
And finally, while 5% of people thought health care reform made their health care less expensive and 8% thought it made it more expensive, more than 2/3 of respondents said it had made no difference in their cost of health care.

Figure 3.5 Health care reform has made my cost of health care...



In the same way that the highest-priority PLWHA are those who answered they were unsure about their healthcare status or didn't have insurance through Covered California and wanted to (22%; Figure 3.2), those who said that the ACA had made it harder for them to get HIV care (11%, Figure 3.3), harder to get general healthcare (8%, Figure 3.4), or more expensive to obtain healthcare (8%; Figure 3.5) are also higher priority. Figure 3.6 demonstrates the overlap of respondents in these various "high-priority categories." While there is some overlap, 27 of the 38 respondents who answered with at least one high-priority answer did not have overlap in the other areas.

**Figure 3.6** Overlap Between Survey Respondents With 'High-Priority' Answers to Health Reform Questions



## Understanding of Health Care Options by Providers and Consumers

Through this assessment there were three main categories of consumers when it comes to health care reform:

- A. People for whom everything is basically working great, often like it's always been
- B. People feeling stuck between changing doctors or not getting good coverage / paying a fine, and
- C. People who are totally confused.

It was a general theme among service providers that the roll-out of health care reform has been exceedingly confusing, both for them and for their patients/clients. Support group moderators, health educators, and even some social workers – who, more than anyone, have been tasked with supporting patients/clients in navigating the changes – described the lack of training or segmented training. Multiple providers noted the “trial and error” way they’ve learned the ropes of health care reform, with one saying, *“Everything I’ve learned about how it works has been through all the problems and crises I’ve faced with my patients.”* Specifically, those who received training from Covered California explained that trainings were provided as it was rolling out, which sounded good but in actuality meant they were continuously receiving disjointed and sometimes conflicting information. This simply exacerbated the confusion. A provider from AIDS Healthcare Foundation explained,

*“Two years after Covered California was implemented, they are still sending ‘updates,’ creating more confusion. Even the people who’ve come to give presentations to the service providers have not always received the most updated information.”*

This contributes not just to a general sense of confusion, but also has concrete impacts: bureaucratic errors by service providers due to misunderstanding, outdated training, and general lack of awareness of the rules often create red tape that takes months to resolve. As a provider from Highland Hospital noted, *“Often by the time these situations have been solved, patients have lost weeks or even months of treatment.”*

The benefits counselor at EBAC said she thought there was significant patient confusion about the different plan offerings, provider network, and scope of benefits available to them after health care reform. She explained, *"Most understand they need to enroll in something, but have limited knowledge and experience with the process, requirements, and results."* This was echoed strongly in each of the focus groups, exemplified by one participant who said,

*"At first it was SO confusing. I never had a co-pay before, and now I have to pay for my healthcare. Some don't have to pay, and some do. Why? I don't know. They deliver my meds to me with a bill."*

"That's not right!" exclaimed another participant; uproar ensued in the group after that, with people comparing notes about what insurance they had and who had to pay or not pay.

Another focus group participant said,

*"Highland made everybody change to Blue Shield. They didn't know what to do, and then they were telling us to do this and that – it wasn't even the right stuff. It got all screwed up. It's still kind of confusing. I always thought, 'Well, at least I still have Medicare,' but then I found out my card was outdated and I didn't even know. So I had to come back and do everything over. I'm still not clear on things."*

Across focus groups, there were very mixed feelings about whether medical providers were knowledgeable and helpful about health care reform or whether they simply added to the confusion. Though not always true, those who had Alameda Alliance for Health had typically positive things to say; same with those who sought care at Magic Johnson Clinic (run by AIDS Healthcare Foundation) or EBAC. Those who received care at Highland Hospital were often very frustrated with their experience; this may be partially explained by the fact that, according to providers interviewed during the assessment, Highland Hospital does not currently have contracts with any insurance providers participating in the health exchange through Covered California, limiting their ability to provide care to people enrolled through the exchange.

Beyond confusion about the technical aspects of insurance coverage and health care access after passage of the ACA, for some there is the added misunderstanding of the paradigm shift that



health care reform is trying to achieve: a greater focus on regular primary care visits, and establishment of a medical home for all people. As a provider at HEPPAC explained,

*“People are getting enrolled, but they don’t really understand how that benefits them. They’re not really establishing a relationship with a medical home. They’re used to the idea that if you have to go to the doctor, you have to pay right then. If you go to the ER, they’re going to mail you something – and if you don’t have the money, you don’t have the money. You still got the care. Whether it’s true or not, people worry about that.”*

Resistance to attending regular medical visits was a strong theme in the assessment, with the fears described here by HEPPAC staff confirmed by those who now experience expensive co-pays every time they go to the doctor. This will be discussed in greater detail later in the chapter.

In sum, more training is needed to ensure that providers have up-to-date information about the options available to patients under the ACA, and have the tools to adequately communicate those options to their patients/clients. But importantly, there is also a need for more of what EBAC described they were preparing to do internally: trainings for enrollees/recipients of coverage through the ACA, bringing them up to speed with current developments and being sure they understand how to maximize the benefits available to them.

## Benefits of Health Care Reform for PLWHA

The benefits of health care reform are clear, especially for people who were unable to access affordable health insurance before the passage of the ACA. Providers and consumers alike spoke at length about the positive aspects of the ACA and often had to be prompted to come up with negative impacts of it, other than general confusion and need for more training about health care options.

Benefits that providers highlighted during this assessment, other than those already discussed in the previous section, include:

1. More people able to access health coverage, which means greater access to preventative and life-improving care with minimal financial burden.
2. More flexibility with insurance carriers. Provisions of the ACA that standardize insurance – including prohibiting restrictions based on pre-existing conditions and requiring that insurance policies meet minimum standards for service coverage – as well as establishment of the Health Insurance Marketplace (exchanges) have all increased the number of high-quality insurance options available to many PLWHA.
3. Medi-Cal Expansion has meant that a significantly increased number of PLWHA have qualified and been successfully enrolled in Medi-Cal, giving them very low to no-cost access to HIV care and medications.
4. For those low-income individuals who find it challenging to pay for insurance coverage at the rates available to them through the ACA, there are a variety of subsidies that can help. These include the Advanced Premium Tax Credit (APTC; also known as Premium Assistance) and Cost Sharing Reduction (CSR) subsidies. Any individual can potentially qualify for either or both of these cost-reducing measures during Covered California enrollment. In California, legal residents who make between 138% and 400% of the Federal Poverty Level and are not eligible for any other type of coverage (such as Medi-Cal) can qualify for APTC; it is available on a sliding scale and reduces the cost of premiums by sending a supplemental check to the insurance provider each month for the amount of APTC for which an individual has qualified. Then the individual only needs to send a check for the remainder of the premium. APTC is available to qualifying individuals regardless of the plan that they choose through the Health Insurance Marketplace. It is worth noting that, as previously discussed, PLWHA in California can often qualify for full premium remission through OA-HIPP, so may not require this program. CSR subsidies are for any legal resident who makes between 138-400% of the Federal Poverty Level and enrolls in a Silver-level plan through Covered California; these subsidies reduce the out-of-pocket costs (co-pays) for a plan. The Medical Benefits counselor at EBAC explained that she has worked with quite a number of patients who had enrolled in lower tier plans to save premium costs, but had higher out-of-pocket expenses, and the majority of

these patients stopped seeking regular care when they realized the cost to them. She works with them to upgrade them to the highest tier plan available to reduce their out-of-pocket costs and encourage regular care, or the Silver plan so they can qualify for CSR subsidies. In the end, with some support from a knowledgeable benefits counselor, PLWHA are able to qualify for care at very low or no cost – a benefit for everyone.

5. HIV and other medications can be requested by medical providers up to 3 months in advance, where before that was not possible. This is especially beneficial for patients who travel for long periods and may not easily be able to obtain refills while abroad.

6. More coverage is available for dental and vision than was available before. In the consumer focus groups, this was repeatedly raised as a major improvement people had experienced since the ACA had passed; as one person said, *"I'm getting new teeth now. Before, they just always wanted to pull my bad teeth out and that was it."*

7. Mental health care is now an “essential” service meaning that all health plans are now required to provide it as part of primary care. There are significantly expanded options for mental health care now, for those PLWHA who need it.

8. Similarly, substance use treatment is also now an “essential service”. As multiple medical providers noted during this assessment, the bottom line here is that methadone – and other options - are now available to patients/clients in a way they simply weren't before.

## Challenges Posed by Health Care Reform for PLWHA

Almost every service provider interviewed in this assessment agreed that for those PLWHA who qualify for Medi-Cal or are already enrolled in State or County-funded programs, the ACA has led to more options and essentially no financial burden. However, this is not the same for those who enroll in plans through Covered California, and struggle with large co-payments. As one provider explained,

*“People who are truly eligible [for reduced-cost insurance] need help getting through the process the first time. They may have sticker shock as they start to go through it, but there are resources: OA-HIPP, premium payment programs, medical case workers...people who finally get their health care covered are generally very happy. They just have to get there.”*

It’s the “getting there” that seems to be a problem for so many PLWHA. There are resources available, but most of the PLWHA who participated in focus groups for this assessment were unaware of them. The challenges of co-payments were repeatedly discussed. *“I did not have to pay co-payments before, but now I can’t afford to go to the doctor,”* said one person. *“The co-payments for medicines and doctor visits are so high! I can’t afford that,”* said another. *“I prefer not to go see the doctor unless it is strictly necessary. I can’t afford paying co-payments so often,”* said a third. Providers repeatedly underscored the importance of this, with several noting that they had seen drop-offs in attendance at regular medical appointments for some of their patients living with HIV, since they found it to be unaffordable to seek care that is non-emergency. *“If they’re not feeling very ill, there are other ways they are going to choose to use their limited money. We just won’t see them,”* said one provider.

This is especially important given that some PLWHA already are unused to seeking preventative or routine medical care, as discussed earlier; the ACA is attempting to change patients’ orientation to primary care services, but cannot do this if regular primary care support appears to be financially out of reach. The good news is that the resources exist to make medical visits and medications affordable; patients simply need navigation assistance to tap into them.

Another challenge that was repeatedly mentioned was restrictions on access to providers for non-emergency care. For example, one provider noted,

*“A lot of our clients lean toward the Chinese Community Health Plan because co-payments are very affordable – but only 2 out of 50 providers in the San Lorenzo area take that plan. So this hinders patients from receiving care, because the only providers who take the plan are either too far away, or not experienced with HIV.”*

The Medical Benefits counselor at EBAC noted that the only real negative impacts that the ACA has had on PLWHA in the TGA are that a limited network of health care providers have contracted with Covered California plans, and those who have Covered California contracts often only contract with a single plan, not the majority of options. This impacts patient choice, because if they want to stay with their current provider they can only select that plan option within the Covered California exchange, regardless of whether it is the best plan for them. This often happens because providers do not like the reimbursement rates available to them with plans in the exchange, so choose not to accept those plans. Patients who have been seeking care from them for years are then faced with the choice of changing providers, or not taking advantage of the plan options now available to them as a result of the ACA.

Highland Hospital was repeatedly mentioned as a place where this challenge was acutely felt; providers and consumers alike explained that they do not have any contracts with Covered California plans, so dozens of patients living with HIV have been forced to seek non-emergency care elsewhere if they wish to reduce their medical costs through the exchange. It isn't a problem unique to Highland, however, or to Covered California. The changing landscape of Covered California, private insurance, Medi-Cal, and Ryan White funding for HIV specialty care is leaving patients with confusion and gaps in coverage, unless they change providers. One focus group participant explained the problem well:

*"I have to apply for Obamacare, but I'm afraid I'm going to get shut down, because I can get insurance through my job. If I take the insurance through my job, then I can't go to the doctor that I want to go to, because they don't take that plan. My doctor says they're not going to take Ryan White anymore, so I'll have to pay \$100 out of pocket every time I go, unless I get into an Obamacare plan. Or they'll assign me to another provider, like EBAC. I think I can't get into the Obamacare plan. But I love my provider. So I don't know what I'll do."*

HIV, like other life-threatening, nuanced diseases, is one where people work hard to find a specialty provider with whom they feel comfortable. Most are not satisfied with a run-of-the-mill primary care provider treating their HIV – they want a specialist who knows their

personal challenges and is well-versed in the constantly changing landscape of HIV antiretroviral therapies. *“They need to keep it open. It’s important for us to maintain our same doctor, and that’s really hard with Obamacare,”* explained one focus group participant. *“It’s supposed to be helping us, and sometimes I think it’s great, but other times I’m just not so sure.”*

The last major complaint with health care reform as it relates to PLWHA has to do with mail-order pharmacies and county-based pharmacy restrictions that are now in place as part of the ACA. This challenge was consistently mentioned by both providers and consumers. Many insurance companies are now requiring patients to buy their medicines by mail, rather than allowing them to go to physical pharmacies. This strategy reduces costs for insurance companies, but is detrimental to patients because sometimes they miss their dates for re-order, or medicines are out of stock – causing them to not take medications for days or even weeks, with a negative impact on health. It also causes care to be increasingly disjointed; as a provider at EBAC noted, instead of being a “one-stop” shop for their patients, now they are often not allowed to dispense medications to their patients and must instead write prescriptions and have patients go home and wait for them to come in the mail before they can begin treatment.

Even for those who are not restricted to mail-order pharmacies, many people who receive health coverage through Covered California are finding themselves having to change pharmacies, just like some are finding a requirement to change doctors. Since medications are such an important part of every-day life for most PLWHA, these changes can have a real impact on them. As one focus group participant said,

*“I used to get my medicines from CVS or Walgreens, wherever. With my new health plan, they made me pick from a list, so now I go to Rite-Aid, and my HIV medicines come from San Francisco. Sometimes there’s a wait because of that. My plan doesn’t let me be flexible anymore.”*

And finally, one challenge that some consumers described when asked about negative impacts of the ACA on their access to health care came from the focus group for IDUs, conducted at a syringe exchange site in Oakland. A number of consumers in this group described a recent shift in access, where in the beginning of health care reform providers were very excited about increasing

access to those who needed it, but as time went on they realized that “people like us” (IDUs, people who are homeless or unstably housed, etc.) are expensive and difficult to treat. One summed it up,

*“They are really trying to take people off Obamacare now. It started off good, but now they’re cutting out the major programs that are helping the people who can’t afford it. They realized we’re expensive! And sometimes we can be a pain – we don’t show up for appointments, or we don’t always do what the doctor says. So they don’t want to waste time with us anymore. They’re trying to charge people on Medi-Cal \$12 a day to get methadone. They’re saying there are no available appointments. So many people are on Obamacare now, it’s hard for people like us to get access to what they need – and sometimes I think they do that on purpose.”*

Other consumers described urine screenings to qualify for HIV medications, receptionists who are hostile or unhelpful in scheduling appointments, and inflated charges for the sole purpose of making care less available for those who are most underserved. These types of claims were not substantiated by providers, though there was widespread agreement in the room of consumers that this was an increasing problem.

In the end, many of the challenges experienced by PLWHA in relation to health care reform are logistical challenges related to requirements imposed by insurance companies or medical providers; these are unlikely to be easily addressed by anyone at the County level. However, there are still a few things that can be done to mitigate other challenges explained here, including:



## RECOMMENDATIONS

**1. INCREASING SUPPORT FOR NAVIGATION TO EXISTING RESOURCES TO HELP WITH OUT-OF-POCKET EXPENSES FOR PEOPLE ENROLLED IN COVERED CALIFORNIA; ALTERNATIVELY, ESTABLISH NEW MECHANISMS WITHIN THE TGA TO IMPROVE CO-PAY SUPPORT FOR PLWHA.** It is clear that resources exist to ensure that PLWHA can have affordable access to medications and regular doctor's visits – most providers were aware of those resources, and yet many consumers who participated in this assessment spoke of limiting their doctor's visits to avoid large co-pays. More must be done to address this situation and help patients understand and access the financial support they need, to free them from financial burden and encourage regular medical care.

[Relevant to Ryan White Part A Core Service Category Medical Case Management]

**2. PROVIDING MORE TRAINING TO ENSURE THAT PROVIDERS HAVE UP-TO-DATE INFORMATION ABOUT THE OPTIONS AVAILABLE TO PATIENTS UNDER THE ACA, AND HAVE THE TOOLS TO ADEQUATELY COMMUNICATE THOSE OPTIONS TO THEIR PATIENTS/CLIENTS.** One of the most common themes during this assessment was that providers were frequently confused about Medi-Cal Expansion or Covered California, or did not have updated information. As health care reform continues to mature, the flow of information should start to be more standard and less contradictory. This presents a good opportunity for clarifications and refresher trainings for providers who serve PLWHA, either by providing medical care or assisting with benefits navigation. One way to do this may be through cross-training for medical case managers and eligibility counselors within the TGA, to improve chances that a consumer will interact with a knowledgeable provider who has the skills to help them get the financial support they need.

[Relevant to Ryan White Part A Core Service Category Medical Case Management]

**3. PROVIDING TRAINING OPPORTUNITIES AND/OR EDUCATIONAL MATERIALS AND SOCIAL MARKETING CAMPAIGNS GEARED TOWARD CONSUMERS, TO PROVIDE INFORMATION ABOUT BENEFITS AND RESOURCE AVAILABLE TO THEM AS A RESULT OF HEALTH CARE REFORM.** Consult with EBAC to learn more about the training they are developing for their patients in this regard; it may be a useful model for the TGA as a whole. In general, even when providers are clear about coverage options and resource for PLWHA, most consumers who participated in this assessment shared widespread confusion and skepticism about the information they heard about how health care reform could benefit them.

[Relevant to Ryan White Part A Support Service Category Psychosocial Support Services]



#### 4. PROVIDING INCENTIVES TO HIV SPECIALTY PROVIDERS TO CONTINUE SERVING LOW-INCOME PATIENTS.

Medical providers are frequently squeezed in our health care system, looking for ways to provide care to the greatest number of people in limited time. This is complicated by low reimbursement rates for many of the least expensive plans, and a patient population with high need, chaotic lives, and little success with bureaucratic systems. Any efforts to incentivize the high-quality, sensitive provision of care to those PLWHA who are most underserved would benefit those who are most vulnerable and currently finding the benefits of health care reform to be limited.

[Relevant to Ryan White Part A Core Service Category Early Intervention Services]

#### 5. CONTINUING TO BUOY THE RYAN WHITE CARE SYSTEM, LEVERAGING SPECIALTY CARE FOR PLWHA WHO ARE CHRONICALLY UNDERSERVED, INCLUDING PLWHA WHO USE SUBSTANCES AND THOSE WHO ARE HOMELESS OR UNSTABLY HOUSED.

Though the ACA is designed to encourage connection to a primary care medical home for all healthcare needs, some PLWHA are simply not well-served in a general primary care setting. This is especially true for those with housing, mental health, and substance use co-morbidities, and those who are transgender or even gay or bisexual. These individuals have an increased chance of encountering a healthcare provider who is not culturally competent, or worse, treats them poorly. As one focus group participant noted, "We need more providers who have been trained to see us as human beings. More interactions with people who really care." Though they are not all perfect, HIV specialty providers tend to have more experience with these more vulnerable populations than general primary care providers. Multiple consumers from these particular groups spoke directly to the importance of maintaining HIV specialty care options, leveraging Ryan White funding to improve quality of care for these higher-need populations.

[Relevant to Ryan White Part A Core Service Categories Ambulatory/Outpatient Medical Care and Early Intervention Services, and Support Service Category Medical Transportation]

# CHAPTER FOUR

## Incidence and Treatment of Hepatitis C in California and the Oakland TGA

As a leading cause of liver disease, liver cancer, and liver transplants, chronic infection with hepatitis C virus (HCV) is an important public health problem in California and nationwide. Chronic HCV infection is nearly five times as prevalent as HIV infection, affecting 3-5 million people in the U.S. and surpassing HIV as a cause of death in this country.<sup>17,18</sup> In 2011, HCV infection was the second most commonly reported communicable disease in California (after chlamydia).<sup>19</sup> Most people with HCV infection remain asymptomatic for decades, such that the majority of HCV-infected individuals are unaware of their infection even as liver disease progresses to cirrhosis.

Prior to routine screening of the blood supply in 1992, HCV was primarily transmitted through blood transfusions and organ transplants. Now, however, HCV is mainly transmitted through sharing of needles or other equipment during injection drug use. More rarely, HCV is transmitted through needlesticks, birth to an HCV-infected mother, or sexual contact with an HCV-infected individual.

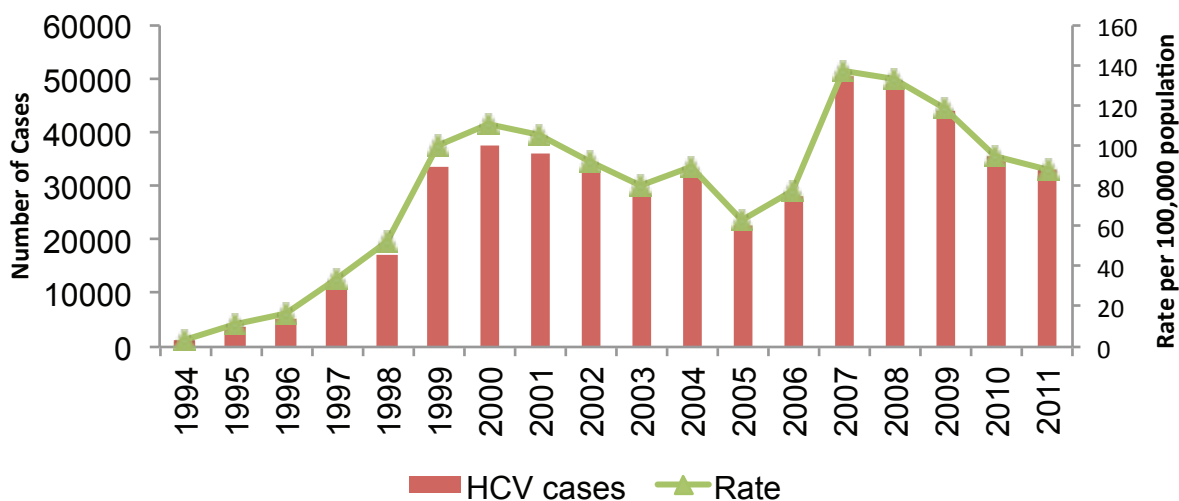
The health impacts of HCV infection are especially severe in PLWHA, in whom HCV-associated liver disease is the leading cause of non-AIDS-related death.<sup>20</sup> HIV/HCV coinfection has also been linked to an increased risk of non-liver-related health outcomes, including cardiovascular<sup>21</sup> and kidney disease,<sup>22</sup> and may accelerate the progression of HIV.<sup>23</sup> Among PLWHA, an estimated 1-12% of men who have sex with men (MSM) and 72-95% of injection drug users are coinfecting with HCV.<sup>24</sup> Of the 121 PLWHA surveyed as part of this needs assessment, 11 (9%) said they were co-infected with chronic hepatitis C, and another 24 (20%) said they were unsure. Of the 11 who self-identified as co-infected, only two had been or were currently on treatment.

This chapter will provide a broad overview of the HCV and HIV/HCV epidemic in California. There is typically a two-year delay in the reporting of HCV data, and the most recent data were only available through 2011. Data on HCV are particularly limited for specific local health jurisdictions, but will be described where available for Contra Costa County and Alameda County. Most data presented in this chapter were collected and disseminated by the California Department of Public Health.<sup>19</sup>

### HCV Epidemic in California

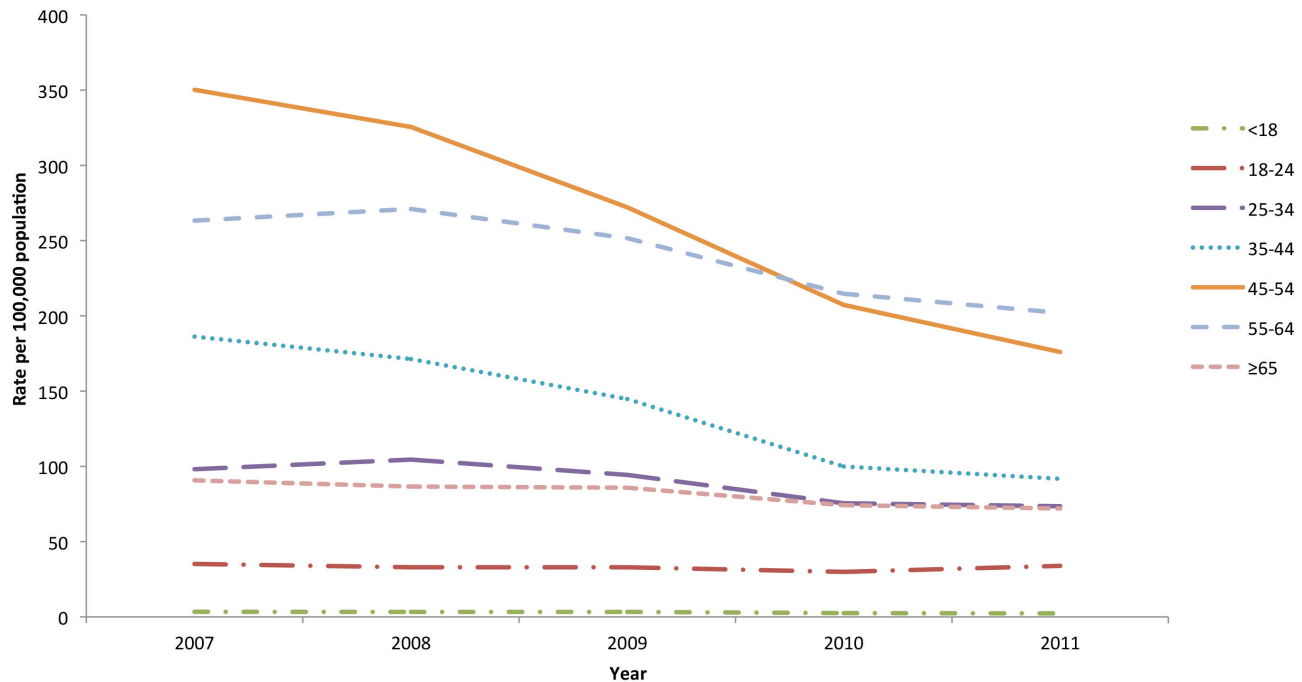
From 1994 through 2011, a total of 501,664 chronic hepatitis C cases were newly reported in California. In 2011, 33,190 new cases were reported, for a rate of 88 cases per 100,000 population. The rate of newly reported cases peaked in 2007, when the reporting of HCV cases by laboratories was implemented in California.

Figure 4.1 HCV Cases and Rates of Newly Reported Cases, California, 1994-2011



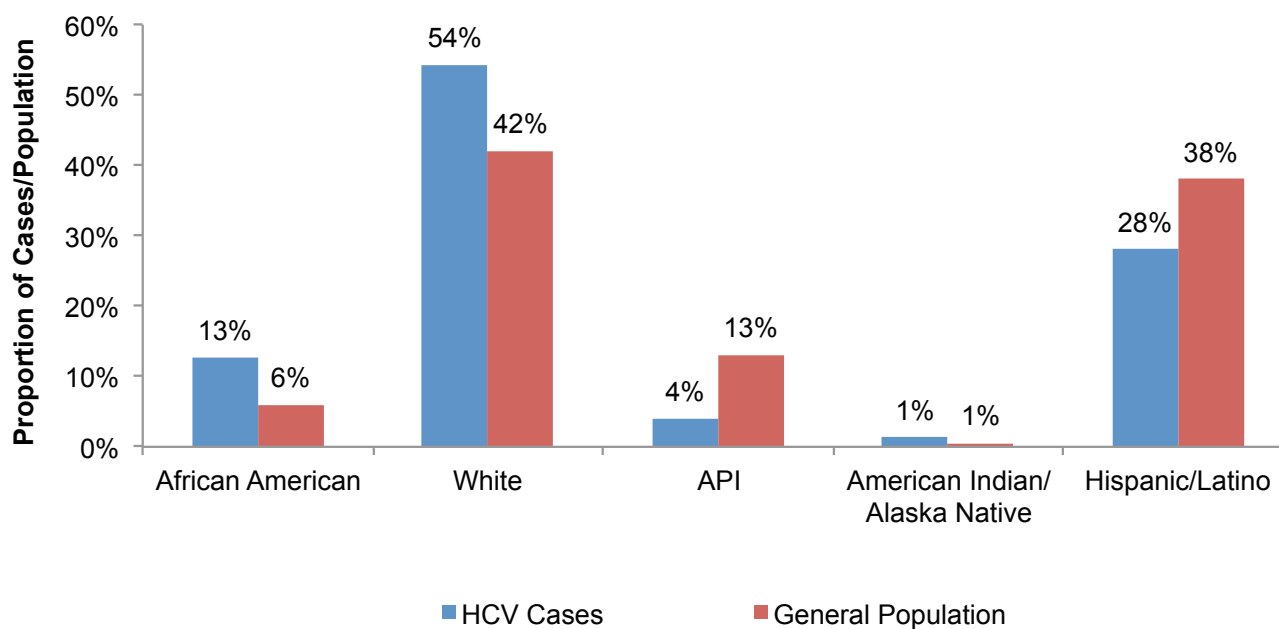
In 2011, the median age of HCV cases was 51, an increase of two years of age from the median of 49 in 2007. The highest rates of newly reported HCV cases have shifted from 45-54-year-olds in 2007 to 50-59-year-olds in 2011. Over half of newly reported HCV cases (56% in 2011) were in individuals born during 1945-1965, reflecting the epidemiology of HCV in the broader U.S.

Figure 4.2 Rates of Newly Reported HCV Cases by Age, California, 2007-2011



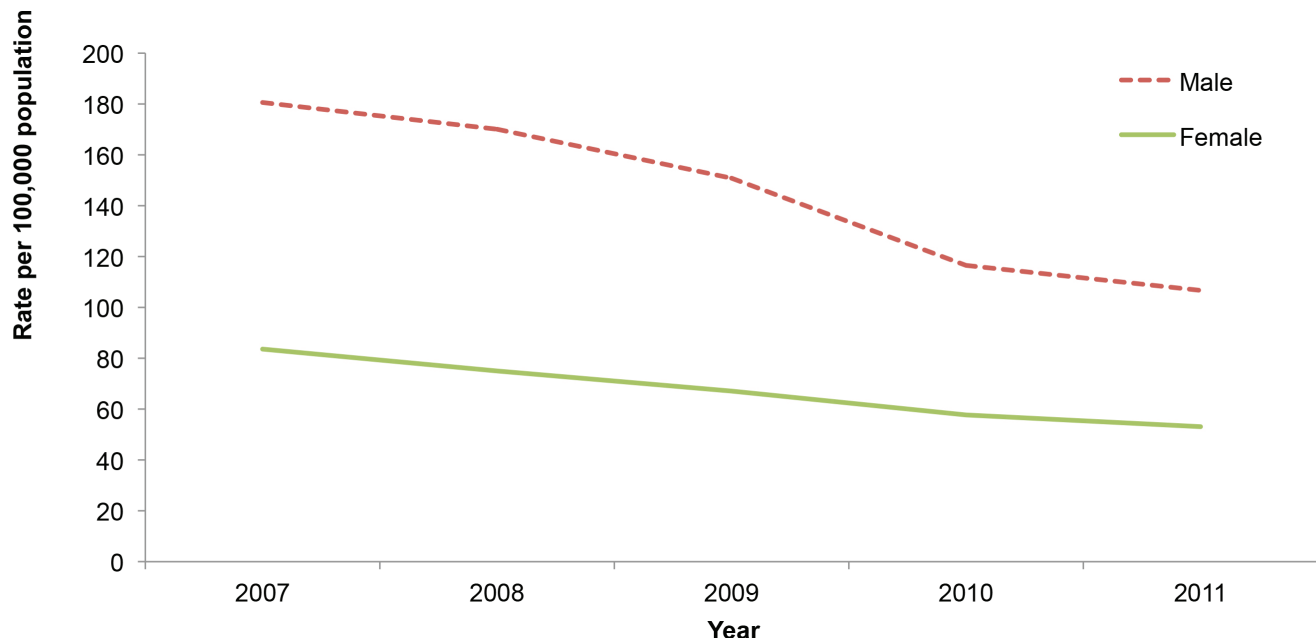
Compared with the general population in California, HCV disproportionately affects White and African American individuals. In 2011, Whites comprised 42% of the general population in California while making up 54% of newly reported HCV cases. Similarly, African Americans comprised 6% of the general population in California but 13% of HCV cases.

Figure 4.3 Comparison of Newly Diagnosed HCV Cases and General Population by Race/Ethnicity, California, 2011



The burden of HCV infection in California, as in the broader U.S. population, lies mainly among males. During 2007-2011, two-thirds of new HCV cases in California were male, and the rate of new HCV cases among males was twice the rate among females.

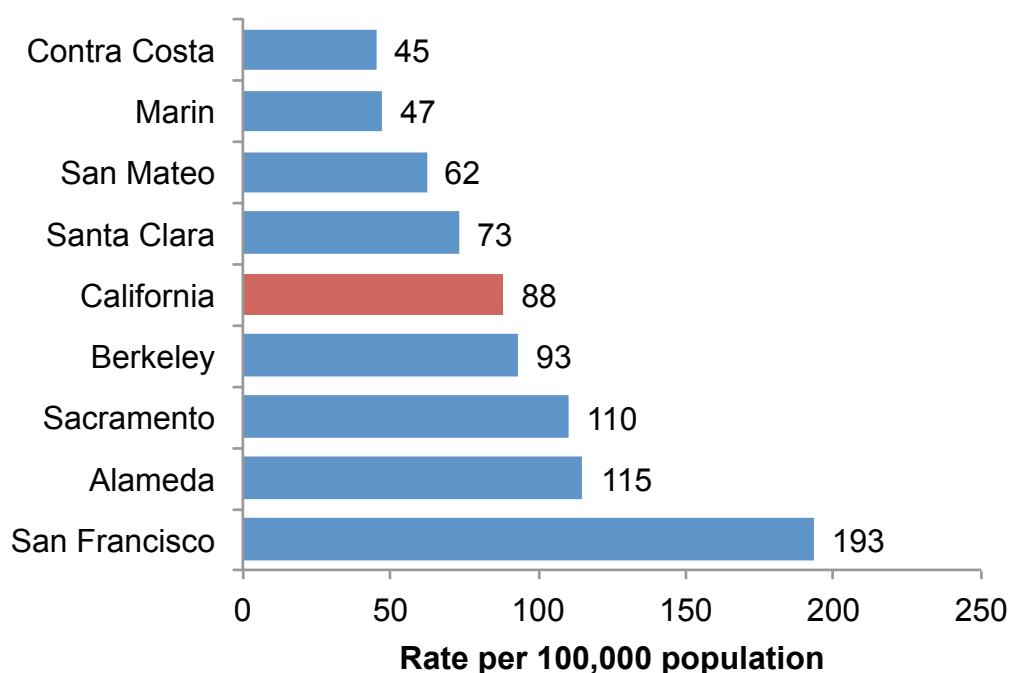
Figure 4.4 Rates of Newly Reported HCV Cases by Gender, California, 2011



NOTE: Rates were not available for transgender individuals because information on transgender identity was not systematically collected until 2011.

Among populous local health jurisdictions in California (with  $\geq 100,000$  population), Alameda County had the fifth highest rate of newly reported chronic HCV cases in 2011, with a rate of 115 cases per 100,000 population, compared with a statewide rate of 88 cases per 100,000 population. Alameda County had the second highest rate among local health jurisdictions in the Bay Area, with San Francisco County having the highest rate of newly reported HCV cases in this region. Contra Costa County had half the rate of the overall California population, with 45 cases per 100,000 population.

**Figure 4.5 Rate of Newly Reported HCV Cases in Selected Local Health Jurisdictions, California, 2011**



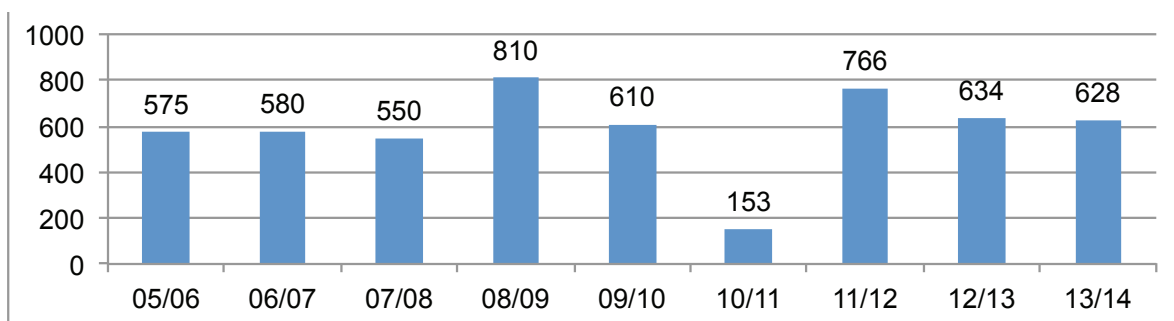
NOTE: Rates exclude cases in the incarcerated population.

## HIV/HCV Epidemic in California

HIV/HCV coinfection is not itself reportable in California; thus, data on this high-risk population are limited. To address this gap, the California Department of Public Health matched data in 2011 between the statewide HCV and HIV registries to assess the burden of HIV/HCV coinfection in California.<sup>25</sup> This study identified 120,921 known PLWHA at the end of 2011, of whom 14% were coinfecting with HCV. Similar to the age distribution of the overall HCV population in California, HIV/HCV-coinfected individuals were older than HIV-monoinfected individuals, with more HIV/HCV-coinfected individuals in the 45-64-year-old age group. Among male PLWHA, HIV/HCV-coinfected individuals were over five times more likely to report IDU as an HIV risk factor. Similarly, HIV/HCV-coinfected females were over four times more likely to report IDU as an HIV risk factor than HIV-monoinfected females.

In summary, HIV/HCV coinfection is prevalent among PLWHA, with approximately 1 in 7 HIV-infected individuals in California having been diagnosed with HCV infection. Data on HIV/HCV coinfection were not available for specific local health jurisdictions, including Alameda and Contra Costa counties. However, a general sense of the likelihood of co-infection can be gathered by looking at overall HCV rates in the jurisdictions, as well as rates of IDU among PLWHA (the group at highest risk of being co-infected; the CDPH Office of Viral Hepatitis estimates that at least 60% of HCV infections in the state are associated with IDU). Alameda County has one of the highest rates of newly reported HCV cases in California, with a higher rate than the overall statewide population. Contra Costa County, on the other hand, has a much lower rate of new HCV cases, with half the rate of statewide population. With a high of 1,400 reported cases of chronic HCV in 1999, the rate has declined to roughly half that and stayed relatively stable each year for the last decade.<sup>26</sup>

Figure 4.6 Reported Cases of Chronic Hepatitis C By Year, Contra Costa County





Within the TGA as a whole, there were an estimated 703 PLWHA in 2013 who were infected through IDU; 5.9% of the people living with HIV that year, and 10.6% of the people living with AIDS. This compares to 15% of PLWHA in California as a whole who had identified their risk for HIV as IDU as of 2012.

During this assessment, 9% of the 121 consumers surveyed knew they were co-infected with HIV and HCV. In the consumer focus groups, approximately 10% of the participants were co-infected. Providers who were interviewed were generally not able to speak to co-infection among their client/patient populations, unless they specialized to some extent in HCV among their patients. For those who were knowledgeable, however, their proportion of co-infected client/patients ranged considerably depending on their specialty. Kaiser estimates that approximately 10% of their patients living with HIV are co-infected with HCV, in line with county figures overall. HEPPAC, which focuses in serving the IDU population, believes their proportion is closer to 1 in 3. The EBAC provider explained,

*“When we look at national estimates, we expect that 20-30% of our HIV-positive patients probably have HCV co-infection. But since we started using the Ryan White database to track this, we are only seeing 5-10% of our 2000 patients end up on the HCV treatment candidate list. We need to do a more aggressive job of screening people who are appropriate for HCV testing, so we really know the answer.”*

# CHAPTER FIVE

## Barriers and Challenges to Hepatitis C Treatment for PLWHA

### Availability of Hepatitis C Treatment in California

Until the FDA approval of Sovaldi® (sofosbuvir) in December 2013, diagnosis of HCV provided little more than incentive to care for one's liver and avoid transmission of the virus to others. Once screening was available in 1992, the most common treatment was pegylated interferon – a chemotherapy treatment that usually lasted for 11 months, required daily injections, caused severe side effects including “brain fog”, depression, and suicidality, and had limited success. Sovaldi® marked the beginning of a new class of HCV drugs called “direct acting antivirals” (DAAs) that have revolutionized treatment for people living with HCV. Currently used drugs are Sovaldi®, Harvoni® (ledipasvir and sofosbuvir), and Viekira Pak™ (ombitasvir-paritaprevir-ritonavir with dasabuvir), with more options coming down the pipeline every year. While these are sometimes still combined with interferon or ribavirin for certain patients, most people experience short courses of treatment with few side effects and an extremely high cure rate. The problem now is that accessing these medications is extremely difficult, with drug costs rising near \$100,000 per course of treatment and insurance providers working steadily to limit the utilization of these medications.

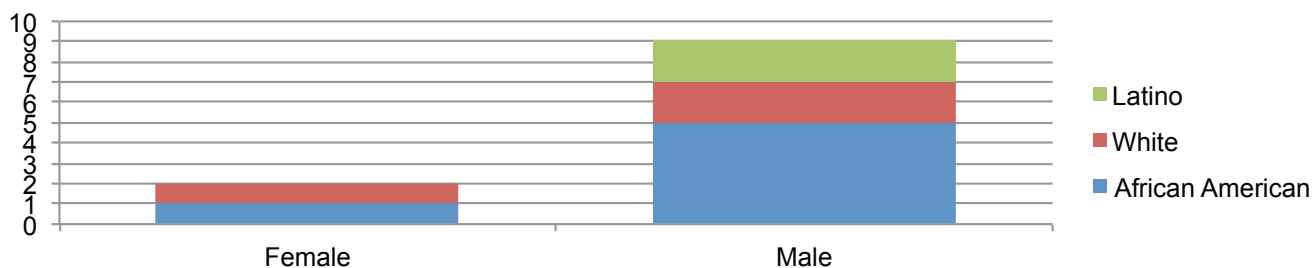
While Medi-Cal is required to provide any FDA-approved medication within their formulary, they can set restrictions on these provisions through treatment and utilization policies released by the California Department of Health Care Services (DHCS). Until July 1, 2015, most patients required documented advanced fibrosis or cirrhosis (stage 3 or 4) and were excluded based on active substance use or many mental health conditions.<sup>27</sup> Patients co-infected with HIV and HCV were only considered optimal for treatment if they were on a stable HIV antiretroviral regimen and had a suppressed viral load for at least 8 weeks. Furthermore, HCV medications were only available through the AIDS Drug Assistance Program (ADAP) formulary for ADAP clients with more advanced liver disease (stage 3 or 4) or other symptoms of advanced liver disease. Even for those eligible for treatment, available medications have been slow to add to the ADAP formulary, with

the now-outdated drug Olysio™ (simeprevir) and Solvaldi® being added in July 2014<sup>28</sup> and Harvoni® and Viekira Pak™ being recently added in May 2015, with a restriction that ADAP clients must be treated with Viekira Pak™ unless preauthorized with clinical justification.<sup>29</sup>

The great news is that a new, dramatically improved DHCS treatment policy is in effect as of July 1, 2015,<sup>30</sup> which will allow treatment for anyone in California with evidence of stage 2 or greater hepatic fibrosis/cirrhosis, active injection drug use, or co-infection with HIV. In line with this revised policy, the ADAP treatment policy has also been revised to make HCV medications available to all ADAP clients who are co-infected, though still with a restriction for the provision of Viekira Pak™ without preauthorized clinical justification.<sup>31</sup> While these new policy changes are a giant step forward, around 75% of Medi-Cal patients receive their care through a managed care plan, most of which have a history of creatively interpreting DHCS policies to contain costs. It remains to be seen how the various managed care plans will revise their own treatment policies to comply with the new DHCS rules.

During this assessment, 11 of the 121 PLWHA surveyed were co-infected with HCV; they came from 4 different organizations throughout both counties in the TGA. The gender and ethnic breakdown of these co-infected consumers is presented in Figure 5.1.

Figure 5.1 Surveyed Consumers Co-Infected with HIV/HCV, by Gender and Ethnicity



Importantly, 24 (almost 20%) of those surveyed said they did not know if they were co-infected with HCV. Of those respondents who did self-identify as co-infected, 2 responded that they were currently taking HCV treatment. Two said they did not know whether they were being treated for their HCV. Of the 7 who knew their HCV was untreated, 1 planned treatment but hadn't started yet, 2 said no one had offered them treatment, 1 said treatment was prohibitively expensive, and 2 said they didn't want to go on treatment – which, given the general ease and effectiveness of the new treatments, is most likely a reflection of these people being unaware of the current treatment options.

With one exception, no one in the consumer focus groups was aware of the new HCV treatments available. In fact, no one in either of the Spanish-speaking focus groups was even clear about what HCV was at all. Within the IDU and women's focus groups, most who knew about HCV treatment had only heard of the old treatments with severe side effects and limited effectiveness. The general consensus within the IDU focus group was that their providers were more focused on managing other conditions, with one explaining, *"I've had hep C for a long time, and it hasn't hurt me yet. I've got other things to worry about, like my HIV and my diabetes."* One woman in the focus group held at WORLD was co-infected and aware of the new treatments, though was unsure about eligibility and access, explaining:

*"My HCV was dormant, but with the new medicine that's out, I had to go through a questionnaire to see if I was eligible. I think I passed, because they called me and want me to come in tomorrow and take a urine test, a blood test, some other test, and a hep A shot. Tomorrow I'll find out if I passed the test, and see if it's being paid for. So we'll see."*

Ultimately, this is right in line with what providers described as the main barriers to HCV treatment for the patients/clients living with HIV. The general sense among providers was that HCV medication was too expensive, not everyone qualifies, and the only people who end up getting treated are those who are extremely sick or extremely high-functioning and savvy. One provider at HEPPAC noted, *"The clients we deal with don't look like the people on that Harvoni® commercial."* Another pointed out,

*"Some of our clients just can't get the meds because they're perceived as unstable. Especially with housing. If you live under a bridge, they're not going to give you an \$18,000 bottle of pills. They probably won't even do that if you're in transitional housing. So lots of our people are out."*

This type of thing was repeatedly mentioned by providers in all areas, who said that many of their patients either were ruled out for treatment or believed they would be, so didn't work very hard to pursue it as an option. Hopefully, with the change in the DHCS/ADAP treatment policies and more time for HCV treatment success stories to spread in the community, this will begin to change.

For those whose providers are actively recommending HCV treatment, it seems to work best when they are referred to clinics with experience negotiating the significant barriers to insurance approval. According to providers in this assessment, the best options include Dr. Sylvestre at the OASIS Clinic, the GI Liver Clinic at Highland Hospital, Dr. Greensberg at LifeLong Medical, and Dr. Peterson at Roots Community Health Center. HEPPAC is also beginning to work with the East Bay Community Recovery Project, where clients can get HIV and HCV testing along with treatment, mental health services, and substance use support. In Contra Costa County, most co-infected people access care for both their HCV and their HIV through the health department. For any Kaiser patients, HCV treatments are available but are currently placed in the Specialty Tier, which means that depending on their specific coverage, many patients must pay thousands of dollars out of pocket to receive treatment. The Kaiser HCV Treatment Team works with patients to explore options for coverage, and there is currently action within the organization to move HCV treatments into the Brand Name Tier and make it more accessible.

Despite the challenges, the fact remains that all clinicians in this assessment were clear that their patients co-infected with HIV and HCV have done exceedingly well on HCV treatment, when they have been able to access it. It's the access that is the main challenge. Proposed strategies for mitigation of these challenges to treatment include:

## RECOMMENDATIONS

**1. WORK TO INCREASE INFORMATION AND AWARENESS ABOUT HCV TREATMENT OPTIONS FOR PLWHA AND THEIR PROVIDERS IN THE OAKLAND TGA.** Simply put, PLWHA have a generally low awareness of HCV transmission, current HCV treatments, and options for accessing that treatment if they are co-infected with HIV and HCV. Recent treatment advances have changed the game for people living with chronic HCV, but they are largely underutilized, especially among PLWHA. Policies will only continue to change and improve access to medications if consumers and providers are aware of the potential benefits and strongly advocate for increased access, and this requires training and social marketing to increase awareness in the community overall.

[Relevant to Ryan White Part A Core Service Category Ambulatory/Outpatient Medical Care]

**2. SUPPORT INCREASED STAFFING IN MEDICAL CLINICS TO MANAGE THE BUREAUCRATIC PROCESS FOR TREATMENT APPROVAL FOR THEIR PATIENTS.** One of the biggest barriers to treatment for people infected with HCV is the lengthy process of denials and appeals required for most people to obtain treatment approval. For many this process can take 4-6 months. For patients, this is a psychologically stressful process – especially for those uncomfortable with bureaucracy, receiving a 6-page denial letter (or multiple letters) can be overwhelming and disheartening. For providers, however, this also represents a challenge, as this process is extremely time-consuming. Clinics able to hire a medical social worker with a main task of managing the treatment access process for patients with HCV generally have higher rates of patients on HCV treatment. In other cases, some clinics simply do not offer treatment to those unlikely to gain quick approval, because they don't have time to engage in this process – one possible explanation for the extremely low awareness of treatment options among consumers in this assessment.

[Relevant to Ryan White Part A Core Service Category Medical Case Management]

**3. TRAIN HIV SPECIALTY PROVIDERS ON HCV TREATMENT PROTOCOLS AND ACCESS STRATEGIES.** Within Contra Costa Health Services, there is a current effort to train physicians in the Positive Health Program to integrate HCV treatment into their work for all co-infected patients. This will be even more important as a strategy now that the revised DHCS policies prioritize treatment for people co-infected with HIV and HCV. Clinicians who specialize in HIV have experience with nuanced treatment regimens, genotyping, discussions of risk factors, and prevention of ongoing transmission (or in the case of HCV, re-infection prevention, a critical step). They are well-suited to add HCV treatment into the regimens of their existing patients, rather than expecting hepatitis or liver specialists to take on this burden, segmenting patient care. This is a model that can be adopted throughout the TGA, to improve care coordination and reduce backlog for HCV treatment.

[Relevant to Ryan White Part A Core Service Category Ambulatory/Outpatient Medical Care]

**4. INCREASE OPTIONS FOR SUBSTANCE USE TREATMENT, PARTICULARLY THOSE THAT ARE INTEGRATED WITH OTHER SERVICES IN A "ONE-STOP SHOP" MODEL.** While not directly related to HCV, increasing options in the TGA for substance use treatment serves two important purposes: it helps people who are HCV-uninfected to reduce their risk for HCV, and it improves access to treatment for those who already have chronic HCV. Even though the revised DHCS policy allows people who are active injection drug users to obtain HCV treatment, it is left to a provider's discretion, including whether s/he thinks a patient is stable enough to succeed in an expensive treatment regimen. For this reason, people with active, chaotic substance use may require harm reduction services or other substance use treatment programs in order to be offered treatment for their HCV. Multiple providers in this assessment noted that increased options for this type of substance use support within the TGA would be a significant improvement for their co-infected patients/clients – especially those that do not stand alone, but rather are integrated with other valuable services.

[Relevant to Ryan White Part A Core Service Category Substance Abuse Services]

**5. CONTINUE TO ADVOCATE FOR INCREASED FINANCIAL SUPPORT AND IMPROVED TREATMENT ACCESS FOR PLWHA IN CALIFORNIA.** While the July 2015 DHCS policy change represents a massive improvement in access to HCV treatment for PLWHA in the TGA and the state as a whole, there is still more progress to be made. Mail-order pharmacy restrictions, a lengthy process of denials and appeals with managed care companies, and other limitations continue to restrict the ability of people with HCV to succeed at a cure. Any opportunity to support people who are co-infected with HIV and HCV to access services that should be available to them, and advocate for changes that will reduce these barriers, should be taken whenever possible.

[Relevant to Ryan White Part A Support Service Categories Emergency Financial Assistance and Legal Services]

# CHAPTER SIX

## Implications of Findings & Suggestions for Further Research

This report summarizes almost one hundred hours of information-sharing on the part of PLWHA in the Oakland TGA, service providers, and members of the assessment team. The assessment focused on three main topics that had been pre-selected by the CCPC; this is not a comprehensive look at needs related to HIV/AIDS overall. Particularly, all consumers involved in this assessment were connected to the assessment team through HIV service providers. PLWHA who are not active consumers of HIV care in the Oakland TGA are largely invisible in these findings; reaching this population is extremely difficult and only really achievable through an assessment specifically designed to reach out to this population, with resources designated to this accordingly (as was true in the 2013 HIV/AIDS Needs Assessment).

### Implications for Ryan White Allocation Planning

The CCPC is charged with helping to set priorities related to allocation of funding under Ryan White Part A, Core and Support services. With that in mind, the following is a summary of implications of the findings of this needs assessment for the most relevant service categories:

#### **CORE SERVICES (75% OF FUNDS)**

##### *Ambulatory/Outpatient Medical Care:*

- Services specifically designed to provide HIV specialty care are critical for many members of the most vulnerable populations, especially including those who are homeless or unstably housed, use substances, have a mental health diagnosis, or are transgender. HIV specialty providers funded through Ryan White tended to be more highly rated as culturally competent by members of these groups than other more general primary care providers. Continuing to look for opportunities to support HIV specialty care geared toward these populations will improve the lives of PLWHA in the Oakland TGA.



- For those co-infected with HIV and HCV, it is critical that additional work be done to increase information and awareness about HCV treatment options for PLWHA and their providers in the Oakland TGA, as very few consumers in this assessment were aware of the new and improved treatments.
- Many HCV care specialists are overwhelmed, with long waits for services now that effective treatment is available. Many primary care providers are not well-prepared to support people who are co-infected with HIV and HCV in navigating the nuances of HCV treatment. Given that, it would be valuable to follow the lead of Contra Costa Health Services, and work to train HIV specialty providers on HCV treatment protocols and access strategies. This type of comprehensive cross-training will help ensure that people co-infected with HIV and HCV receive high-quality, culturally competent, streamlined care for both diseases.

#### *Medical Case Management:*

- More support is needed for navigation to existing resources for PLWHA to be enrolled in Covered California if needed, or to be enrolled in OA-HIPP and/or a different insurance plan to help with out-of-pocket expenses.
- Significant confusion about health care options and strategies for access was reported by both providers and consumers; more training is needed to ensure that providers have up-to-date information about the options available to patients under the ACA, and have the tools to adequately communicate those options to their patients/clients.
- For those who work with patients co-infected with HIV and HCV, increased staffing is needed for medical case managers to manage the bureaucratic process for HCV treatment approval for their patients.

### *Early Intervention Services:*

- As described above in the Ambulatory/Outpatient Medical Care category, more attention should be paid to supporting HIV specialty services, even as the ACA strives to consolidate health care in general primary care settings. These needs are acutely felt by those who are newly diagnosed or need assistance becoming re-engaged in care, which Early Intervention Services settings are best-suited to support.
- It would be valuable to enhance requirements or design incentives for HIV Early Intervention Services providers to continue serving low-income patients (to accept as many plans as possible through the Covered California exchange), which currently is a challenge experienced by many consumers in this assessment.

### *Substance Abuse Services:*

- Multiple providers in this assessment noted that increased options for this type of substance use support within the TGA would be a significant improvement for their co-infected patients/clients – especially those that do not stand alone, but rather are integrated with other valuable services. While not directly related to HIV or HCV, increasing options in the TGA for substance use treatment serves two important purposes: it helps reduce risk of transmission for PLWHA and those living with or at risk for HCV, and it improves access to treatment for those who already have chronic HCV.

## **SUPPORT SERVICES (25% OF FUNDS)**

### *Medical Transportation:*

- Though not a focus of this assessment, multiple consumers mentioned the availability of transportation as a major facilitator or barrier to accessing regular medical care for their HIV and/or HCV. Especially for those who live in non-central areas of the TGA, medical transportation is a critical services (See Figures 2.2-2.4 and 2.12-2.14 of this assessment report for maps illustrating residential parts of the two counties where HIV-related services are sparse). For those PLWHA who do not own cars, public transportation is frequently insufficient to support regular access to HIV and other medical providers.

### *Housing Assistance:*

- At the end of every provider or consumer interaction, a member of the assessment team asked those being interviewed whether they had anything else they wanted the health department to know. Almost invariably, those that had something to add wanted to talk about the challenges of housing for PLWHA in the TGA. Though housing assistance was not a focus area of this assessment, housing certainly impacts access to health care and especially treatment for HCV, in addition to HIV. People who are worried about the stability of their housing situation are often not able to pay attention to medication adherence for their HIV or HCV; furthermore, many medical providers are reluctant to prescribe treatment to someone who is homeless or unstably housed. Increased resources for housing assistance would drastically improve the lives of many PLWHA in the Oakland TGA.

### *Psychosocial Support Services:*

- When it comes to health care reform, one of the biggest barriers to increased health care access for PLWHA is general confusion about options. This can be mitigated by providing training opportunities and/or educational materials and social marketing campaigns geared toward consumers, to provide information about benefits and resources available to them as a result of health care reform.
- When it comes to treatment for HCV, one of the biggest barriers for PLWHA also living with HCV is the lengthy process of denials and appeals required for most people to obtain treatment approval. For many this process can take 4-6 months, though this will hopefully improve after the July 1, 2015 DHCS policy change. For patients, the repeated denials are a psychologically stressful process – especially for those uncomfortable with bureaucracy. Offering psychosocial support services that aid people who are co-infected with HIV and HCV in persevering through the lengthy process to obtain HCV treatment would significantly improve treatment uptake for people living with HCV in the TGA.

### *Emergency Financial Assistance:*

- Though the Emergency Financial Assistance category is typically used for financial support for utilities, food, etc., it can also be used for medication when other resources are not available. Though most PLWHA with financial need can access medications through ADAP, in some cases high co-pays or other financial issues may prevent PLWHA from filling prescriptions for HIV medications and using them on a regular basis. In those cases, exploring the use of Emergency Financial Assistance funds for this purpose may be warranted.

## Suggestions for Future Assessments

Future assessments should be carefully planned to maximize the use of limited resources within the TGA for this type of endeavor. Above all, this requires thoughtful selection of topics of focus in order to ensure that findings are relevant and likely to result in actual changes within the jurisdiction. Ultimately, priorities need to be formed within the TGA through reviewing the epidemiological profile of the HIV/AIDS epidemic, and matching the relative money and attention that various target populations receive to that hard data.

Particular suggestions for further research and exploration within the TGA include:

- More in-depth exploration of the nuances between people's use and understanding of private insurance accessed through the Covered California exchange, and Medi-Cal Expansion accessed through the Covered California website. Many people throughout this assessment defined each of these pieces as being under the ACA umbrella, and many thought of the ACA simply as the Covered California exchange. It wasn't until late in the assessment data collection process that the many pieces of the ACA puzzle started to fit together – and more time and resources would be needed to revisit the information collected earlier from providers and consumers, given this full picture.
- Greater examination of provider motivations for failing to contract with Covered California plans, therefore limiting the access that some PLWHA have with that provider. This was an issue that both consumers and providers described as a challenge, and warrants further exploration.

- More detailed probing of the reasons that some consumers wanted to enroll in insurance through Covered California but had not yet done so at the time of the assessment survey, as well as reasons that some consumers thought the ACA had made it more difficult or more expensive to seek healthcare. In order to quickly distribute and retrieve the maximum number of completed surveys, the assessment consumer survey was designed to be extremely simple and quick to complete, with limited to no support. As a result, some of the answers to questions (particularly those detailed in Figures 3.2 – 3.5) are difficult to interpret. Qualitative data gathered via focus groups and insights from interviewed providers offer the best opportunity to guess at possible reasons for these answers, but with more time and resources it would be interesting to explore these barriers and perceptions more clearly.
- Assessment of the impact that the July 1, 2015 California DHCS HCV treatment and utilization policy change will have on access to treatment for people living with HCV in the TGA. All data collection for this assessment occurred before this policy change and at the time of report writing, the real-life impact of this major shift in policy is still unrealized.

Finally, timing of future assessments should be discussed before launch. In this case, a deadline for funding allocations existed on one end, and a series of slow bureaucratic processes squeezed from the other end, compressing the available period for data collection in a very large TGA, both geographically and demographically. This, combined with that data collection period falling near the end of the fiscal year, when monitoring and grant reports were coming due in large number, meant that involvement was very difficult or even impossible for some service providers. Our assessment team struggled to engage many providers throughout the jurisdiction, and this limits the generalizability of the findings contained within this report.

Regardless, recommendations presented here were intended to be concrete and feasible, if prioritized by the CCPC and county health departments. They are respectfully submitted for consideration and action by those bodies.

# APPENDIX A

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# APPENDIX B

## GLOSSARY

<b>ACA</b>	Affordable Care Act
<b>ADAP</b>	AIDS Drug Assistance Program
<b>APTC</b>	Advanced Premium Tax Credit
<b>CARE</b>	Comprehensive AIDS Resources Emergency
<b>CCPC</b>	Collaborative Community Planning Council
<b>CSR</b>	Cost Sharing Reductio
<b>DAA</b>	Direct-Acting Antivirals
<b>DHCS</b>	California Department of Health Care Services
<b>EBAC</b>	East Bay AIDS Center
<b>HCV</b>	Hepatitis C Virus
<b>HEPPAC</b>	HIV Education and Prevention Project of Alameda County
<b>HIV</b>	Human Immunodeficiency Virus
<b>HRSA</b>	Health Resources and Services Administration
<b>IDU</b>	Injection Drug Use
<b>MAGI</b>	Modified Adjusted Gross Income
<b>MSM</b>	Men who have Sex with Men
<b>OA-HIPP</b>	Office of AIDS Health Insurance Premium Payment Program
<b>PLWHA</b>	People Living with HIV/AIDS
<b>TGA</b>	Transitional Grant Area
<b>WORLD</b>	Women Organized to Respond to Life-threatening Diseases

