# HIV Consumer Advocacy Project (HCAP) Annual Report, 2014-15 Contract Year

**The HIV Consumer Advocacy Project** (HCAP) assists people living with HIV/AIDS who experience difficulty accessing services from Ryan White Program-funded agencies located in San Francisco, San Mateo and Marin Counties, as well as from agencies funded by the San Francisco Department of Public Health's HIV Health Services.

To be eligible for HCAP's services, a client must:

- be diagnosed with HIV/AIDS;
- live in San Francisco, San Mateo, or Marin County; and
- face a dispute with any agency in San Francisco, San Mateo or Marin County that receives federal Ryan White Program funding or San Francisco Department of Public Health HIV Health Services funding.

Issues may involve barriers to enrollment, termination of services, disputes as to eligibility, miscommunication between consumers and staff and/or volunteers of an agency, and issues around cultural sensitivity and language competency.

HCAP is staffed by a full-time licensed attorney with experience in mediation and advocacy. The HCAP Staff Attorney is supervised by the executive director of the AIDS Legal Referral Panel.

For the final quarter of the 2014 contract year, HCAP had a new staff attorney, Gina Gemello. HCAP's previous attorney, Brian Brophy, remains at the AIDS Legal Referral Panel, in the Housing Advocacy Project (AHAP). Brian and Gina continue to work closely to ensure a smooth transition for both clients and service providers.

### **Clients Served**

From March 1, 2014 through February 28, 2015, HCAP served 73 unduplicated consumers.

# **Self-Reported Consumer Demographic Data<sup>2</sup>**

HCAP tracks demographic data of clients, as it is self-reported by consumers. Demographic information includes age, gender identity, race/ethnicity, sexual orientation, and income.

<sup>&</sup>lt;sup>1</sup> Although many HCAP clients have multiple matters, each consumer is counted only once per contract year. Beginning in contract year 2015, HCAP will tally both HCAP clients and HCAP matters, as this may provide richer insight into consumers' experiences with service providers.

<sup>&</sup>lt;sup>2</sup> Percentages may not add to 100 due to rounding.

### AGE

Age	Percentage of	Previous Age Ranges Used <sup>3</sup>	2013	2012
	Consumers	3		
0-20	0%			
21-30	8%			
31-40	15%	20-35	9%	9%
41-50	34%	36-50	40%	32%
51-60	32%	51+	52%	59%
61+	10%			
Decline to State	1%			

### **GENDER**

Gender	Percentage of Consumers	2013	2012
Male	81%	80%	81%
Female	15%	14%	13%
Transgender Male	0%	6%	6%
		(combined) 4	(combined)
Transgender Female	4%	-	-

## RACE/ETHNICITY

Race/Ethnicity	Percentage of Consumers 5	2013	2012
White	56%	37%	51%
African American/Black	19%	30%	32%
Latino/a	18%	19%	19%
Asian/Pacific Islander	1%	3%	3%
Native American	0%	4%	3%
Mixed	6%	6%	6%
Other/Unknown	10%	9%	8%
Decline to State	0%	0%	0%

### **SEXUAL ORIENTATION**

Sexual Orientation	Percentage of	2013	2012
	Consumers		
Gay/Lesbian	60%	66%	73%
Heterosexual	23%	21%	19%
Bisexual	10%	7%	6%
Other/Decline to State	7%	5%	2%

<sup>&</sup>lt;sup>3</sup> Beginning in 2014, HCAP is utilizing a more detailed breakdown of age ranges, in order to more effectively track trends in HIV and aging.

 $<sup>^4\,</sup>$  Beginning in 2014, HCAP began tracking transgender women and men in separate categories.

<sup>&</sup>lt;sup>5</sup> Some consumers identified themselves in multiple categories.

### INCOME

Annual Income	Percentage of Consumers	2013 <sup>6</sup>	2014
Under \$15,000	82%	95%	97%
\$15,001 - \$26,000	12%	Not counted	Not counted
\$26,0001 - \$30,000	0%	Not counted	Not counted
\$30,001 - \$45,000	0%	Not counted	Not counted
\$45,001 - \$50,000	3%	Not counted	Not counted
Over \$50,000	0%	Not counted	Not counted
Decline to State	3%	Not counted	Not counted

### **Service Categories**

HCAP clients sought assistance across the spectrum of service categories, with the majority of cases in the housing, case management, and primary medical categories.

### **SERVICE CATEGORY**

Service Category	Percentage of Cases <sup>7</sup>	2013	2012
Housing	32%	22%	29%
Case Management	27%	17%	12%
Primary Medical	15%	24%	9%
Mental Health	11%	7%	8%
Dental	8%	11%	19%
Food	7%	2%	8%
Social Support	7%	4%	0%
Emerg. Financial Assist.	6%	4%	7%
Benefits Counseling	3%	1%	0%
Substance Use	3%	2%	4%
Hospice	0%	1%	0%
Money Management	0%	4%	4%

*Notes on the most frequently occurring service categories:* 

### • Housing

 The housing crisis in the Bay Area continues to impact HCAP clients. Due to the limited options available for long-term housing, many clients remain in housing that is uninhabitable or otherwise unsuitable. Many HCAP clients are homeless. Several

<sup>&</sup>lt;sup>6</sup> Beginning in 2014, HCAP is reporting additional income brackets.

<sup>&</sup>lt;sup>7</sup> Some clients received assistance in more than one service category.

clients sought help from HCAP in securing a disability-based reasonable accommodation from a landlord or property manager.

### • Case Management

Clients contact HCAP with a wide variety of issues involving case managers. Very often, disputes can be resolved through clear communication. Some clients stated that their case managers were not providing the scope of services that clients felt they should. Several clients complained about case managers who they felt were non-responsive or not respectful.

### • Primary Medical

 Client issues with primary medical providers ranged from complaints about the quality of care to the perceived unresponsiveness or lack of availability of medical providers. Some clients sought assistance transferring to a new medical provider.

#### **Consumer Issues**

The following chart is an overview of the types of issues that consumers brought to HCAP. Many clients have more than one issue.

Type of Issue	Percentage of	2013	2012
	Cases		
Problematic Policy or Procedures	23%	17%	11%
Quality of Care	22%	16%	12%
Access	15%	11%	11%
Miscommunication	15%	13%	19%
Termination From Services	12%	6%	9%
Failure to Observe Procedures	10%	2%	4%
Eligibility	8%	4%	7%
Failed Negotiations with Regard	8%	2%	2%
to Grievance/Complaint			
Non-Engagement with Regard to	8%	2%	7%
Grievance/Complaint			
Assistance Sought by Provider	7%	4%	7%
Cultural Sensitivity	7%	3%	5%
Confidentiality	6%	2%	2%

#### **Outcomes**

The following summaries are examples of outcomes achieved for HCAP clients this year:

- **Dispute with Neighbor Resolved:** Client, a resident in supportive housing for people living with HIV, felt that his recovery and his well-being were threatened by his neighbor's behavior (repeated pounding on floor, angry yelling). Client also feared that a dispute with his neighbor would threaten his housing or cause the neighbor to react violently. HCAP had numerous meetings with client to determine possible outcomes, and discussed possible resolutions with the service provider. The service provider convened a meeting with the client, his neighbor, and a case manager, and the client's issue was resolved to his satisfaction.
- Housing Subsidy Maintained: Client, a resident in a supportive housing facility, was told by his case manager that his rental subsidy for the following month would not be approved because the client had not returned the case manager's calls. The client stated to HCAP that this was not true. The client did not want the case manager to know that he had sought assistance from HCAP, so HCAP ghostwrote a letter for the client and discussed how to present his case. The client then advocated for himself, and his rental subsidy was not terminated.
- Client Receives Refund from Service Provider: Client, a resident in a long-term shelter for women, believed that the shelter had not properly refunded her the money she had placed in the shelter's mandatory "savings account." HCAP met with client and service provider, and client was refunded the money in her account. HCAP later provided technical assistance to the shelter by creating a sample tally/accounting system to avoid confusion as to clients' deposits and balances.
- Temporary Apartment Transfer Secured: Client, a senior who uses a walker, lived in a building with an elevator that was about to be out of service for six weeks due to repairs. The client would not be able to access his apartment during the repair period. HCAP worked with the housing provider and determined that there were vacant apartments on first and second floors of building. The housing provider transferred the client to a new apartment for the duration of the repairs.
- Comprehensive Dental Health Provided: Client's mental health issues (anxiety and PTSD) interfered with his ability to seek dental care, due to the extensive amount of dental work needed and the client's concerns about pain, sedation, and the extent of the work to be performed. HCAP contacted the provider and explained client's concerns. At a meeting with the treating dentist, client, and HCAP, a treatment plan was agreed upon and the client's questions were answered. The service provider also followed up with the client's primary doctor to ensure that the client's mental and physical health needs were being addressed.

#### Challenges

Certain challenges affect HCAP's ability to fully respond to client's concerns. Some of the most common challenges are:

• **Communication:** Maintaining contact with clients – especially those who are homeless or marginally housed – can be difficult. Many clients change cell phone numbers and do not

contact HCAP for follow-up, resulting in HCAP being unable to communicate with them regarding their issue.

- Lack of affordable housing: Homelessness (and the threat of imminent homelessness) is a stressor that affects every aspect of HCAP clients' lives. Many clients have difficulty following up with HCAP when their housing situation is precarious because obtaining housing becomes their primary focus. Those clients who are unable to secure housing often lose touch with HCAP and may fall out of care.
- Mental health: Some HCAP clients have mental health issues that manifest in behaviors deemed "inappropriate" by service providers; in some cases, a service provider may be within its rights to terminate services and provide a referral to another provider. In such instances, HCAP seeks to ensure that clients understand why they were terminated from services and how to avoid the same outcome in the future. HCAP also provides clients with referrals to other agencies whenever possible.

#### Referrals

In addition to providing direct services to clients, HCAP provides clients with referrals to other agencies/organizations that may provide additional assistance to clients. In 2014, HCAP referred clients to the following agencies:

AIDS Emergency Fund, AIDS Legal Referral Panel, Alliance Health Project, Catholic Charities, Eviction Defense Collaborative, Lutheran Social Services, Openhouse, Positive Resource Center (Benefits Counseling and Employment Services), San Francisco AIDS Foundation, Southeast Health Center (Dental and Primary), St. Mary's Medical Center, Tenderloin Housing Clinic, Tom Waddell (Dental).

Whenever possible, HCAP strives to make a "warm referral" – that is, connecting the client directly with the service provider. HCAP also follows up with consumers and providers to ensure that the referral was both appropriate and effective.

#### **Technical Assistance to Service Providers**

HCAP also provides technical assistance to providers and receives direct referrals from service providers. HCAP works in conjunction with these service providers and/or directly with clients to assist clients in resolving their issues.

The following cases are a sample of "Requests for Assistance" made by service providers, and a description of the resolution achieved by HCAP.

• Client Debt Forgiven: Case manager at a transitional housing site for youth requested assistance from HCAP. The client was contacted by a collections agency regarding a bill for

emergency medical services that the client had not requested (the client's former employer, who knew client was HIV-positive, unnecessarily called 911 when the client had a nosebleed). The client, who was very low-income, was unable to pay the bill. HCAP negotiated with the collections agency and had the debt forgiven.

- Client's Legal Documents Drafted: Social worker sought assistance for her client, who was six months pregnant, HIV+, and hospitalized for the remaining three months of her pregnancy. The client had questions pertaining to the care and/or guardianship of her child should the client become ill after the birth, and wanted to draw up guardianship papers. The client also had questions about life insurance. HCAP connected the client and social worker with an insurance broker who specializes in policies for HIV+ individuals, and arranged for a volunteer attorney to create guardianship papers for the client.
- Client's Warrant Dismissed: Case manager at transitional housing site for youth contacted HCAP on behalf of 22-year-old client (a resident of San Francisco) who had received a bench warrant from Alameda County Superior Court that she did not understand. HCAP determined that the warrant stemmed from a 2010 citation for driving without a license. HCAP submitted a letter of support from the client's case manager and arranged for an attorney from a nonprofit legal services agency in the East Bay to appear in court on behalf of the client. The client's warrant was dismissed.

### **Outreach to Consumers and Providers**

HCAP conducted outreach presentations to approximately 280 consumers and service providers in 2014. Presentations were conducted at Alliance Health Project, Asian Pacific Islander Wellness Center, Black Brothers Esteem, Black Coalition on AIDS, Castro Country Club, Project Open Hand, Rita de Cascia, San Francisco AIDS Foundation, Shanti Project, Southeast Health Center, Tom Waddell Urban Health, UCSF Positive Care 360, University of the Pacific, Ward 86, Westside Community Services, and the "We've Got This" community event.

HCAP also participates in the Planning Council's Community Outreach and Listening Activities (COLA) outreach presentations, which seek to solicit community feedback from various demographic groups. Through COLAs, HCAP can reach potential clients who are not already accessing the system of care and hear from consumers regarding satisfaction with services (what service areas are working well, where consumers feel there are gaps, where consumers feel that more resources are needed).

### **Program Evaluation**

HCAP distributes consumer satisfaction surveys by mail to clients. Each survey includes a pre-paid SASE for return. This year, HCAP received 9 completed surveys, a 12% response rate (for contract year 2013, the response rate was 11%).

The survey results indicated:

Overall Satisfaction	<ul> <li>6 consumers (67%) gave HCAP the highest satisfaction rating.</li> <li>1 consumer (11%) HCAP a 4 out of 5 satisfaction rating.</li> <li>2 consumers (22%) stated that they were "not satisfied" with services.</li> <li>When consumers state that they are not satisfied, ALRP's Executive Director (or a staffmember who is not the HCAP advocate) contacts the individual to discuss his or her concerns/complaints. Often, clients are not satisfied with the outcome of their issue, rather than with the services themselves.</li> </ul>
Cultural Sensitivity of Staff	100% of consumers felt that staff was sensitive to their cultural identity and/or sexual orientation. (One consumer marked that the question was "not applicable.")
Consumers' Stress/Worry About Their Issue	<ul> <li>7 out of 9 consumers (78%) "felt better" after contacting HCAP</li> <li>2 out of 9 consumers (22%) "felt worse" after contacting HCAP</li> <li>The 2 consumers who stated that they "felt worse" after contacting HCAP were the same consumers who were "not satisfied" with services.</li> </ul>
Consumer Comments	<ul> <li>Thanks for every thing [you] are doing. Nice etc.</li> <li>I would just like to thank [HCAP] I was very happy with the outcome of the case.</li> <li>It's great [HCAP] played a huge role But I am just fine now, and very grateful.</li> <li>I always fall apart emotionally, at first and then when I receive your help it's always worked out very well in [my] favor, you are a huge resource to me.</li> <li>[My life is] much more peaceful and enjoyable.</li> <li>Reliable.</li> <li>I'm very appreciative.</li> </ul>

HCAP is also reviewed annually by the San Francisco Department of Health. For the 2013-14 contract year (the most current report), HCAP was given the highest rating ("Commendable/Exceeds Standards"). HCAP received 90 out of a possible 90 points.

HCAP also provides monthly reports to the staff of the Department of Public Health's HIV Services, and presents a monthly report at the HIV Health Services Planning Council's Committee on Consumer and Community Affairs (CCA) meetings. A goal of these reports is to maintain awareness regarding challenges faced by consumers and ways in which services may be improved. Additionally, communication between HCAP and these bodies facilitates collaboration between HCAP and CCA members, as well as with staff at the Department of Public Health.