

HIV Consumer Advocacy Project (HCAP) Annual Report 2015-16 Contract Year

The HIV Consumer Advocacy Project (HCAP) assists people living with HIV/AIDS who experience difficulty accessing services from Ryan White-funded programs 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 (1) be diagnosed with HIV/AIDS; (2) live in San Francisco, San Mateo, or Marin County; and (3) 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 commonly 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.

Clients Served

From March 1, 2015 through February 29, 2016, HCAP served **86** unduplicated consumers (UDC) with a total of **107** HCAP matters (clients who have more than one HCAP issue in a given year are only counted as “unduplicated” once). HCAP served 73 UDC in 2014-15 and 81 UDC in 2013-14.

Self-Reported Consumer Data¹

GENDER	2015-16 ²	2014-15	2013-14
Male	83% (71)	81%	80%
Transgender Female	12% (10)	4%	6% (combined) ³
Female	3% (3)	15%	14%
Other/Decline to State	2% (2)	0%	0%
Transgender Male	0% (0)	0%	6% (combined) ⁴

¹ Percentages may not add up to 100 due to rounding.

² The actual number of clients who reported is noted in parentheses following the percentage.

³ Beginning in 2014, HCAP tracks transgender women and transgender men separately.

⁴ Beginning in 2014, HCAP tracks transgender women and transgender men separately.

AGE	2015-16	2014-15⁵	2013-14
0-20	0% (0)	0%	<i>Not Counted</i>
21-30	12% (10)	8%	<i>Not Counted</i>
31-40	12% (10)	15%	9%
41-50	30% (26)	34%	40%
51-60	30% (26)	32%	52%
61+	14% (12)	10%	<i>Not Counted</i>
Unknown/Decline to State	2% (2)	1%	<i>Not Counted</i>

RACE/ETHNICITY	2015-16⁶	2014-15	2013-14
White	45% (39)	56%	37%
African American/Black	26% (22)	19%	30%
Latino/a	14% (12)	18%	19%
Other/Unknown	9% (8)	10%	9%
Mixed Race	5% (4) ⁷	6%	6%
Asian/Pacific Islander	3% (3)	1%	3%
Native American	0% (0)	0%	4%

SEXUAL ORIENTATION	2015-16	2014-15	2013-14
Gay/Lesbian	64% (55)	60%	66%
Bisexual	16% (14)	10%	7%
Heterosexual	10% (9)	23%	21%
Other/Decline to State	9% (8)	7%	5%

ANNUAL INCOME	2015-16	2014-15	2013-14⁸
Under \$15,000	78% (67)	82%	97%
\$15,001 - \$26,000	10% (9)	12%	<i>Not counted</i>
\$26,0001 - \$30,000	1% (1)	0%	<i>Not counted</i>
\$30,001 - \$45,000	5% (4)	0%	<i>Not counted</i>
\$45,001 - \$50,000	0 (0)	3%	<i>Not counted</i>
Over \$50,000	1% (1)	0%	<i>Not counted</i>
Unknown/Decline to State	5% (4)	3%	<i>Not counted</i>

⁵ In 2014-15, HCAP began utilizing a more detailed breakdown of age ranges, in order to more effectively track trends in HIV and aging.

⁶ Some consumers identified themselves in multiple categories.

⁷ Clients identifying as “mixed race” reported their identities to be: Native American and African American (2), Native American and White (2).

⁸ Beginning in 2014, HCAP reports additional income brackets.

Service Categories

HCAP clients sought assistance across the spectrum of service categories, with the majority of cases in the housing, “request for assistance” (see page 4 for more information), case management, and primary medical care categories.

Notes on the most frequently occurring service categories:

- **Housing**

Issues related to housing include conflicts over house rules or policies, access issues (such as need for reasonable accommodation or need for in-home care), roommate/neighbor disputes, and termination/eviction. Depending on the situation, HCAP might meet with the client and the housing provider to resolve the conflict, utilize the formal grievance procedure, negotiate with the housing provider, or refer for formal legal representation.
- **Request for Assistance**

Service providers often contact HCAP for assistance with client issues that they are unable to resolve and which are directly affecting a client’s quality of life and/or ability to stay in care. Occasionally HCAP will simply make an appropriate referral, but more often than not it is most effective for HCAP to resolve the issue by working directly with the client. (See page 6, “Technical Assistance to Providers,” for a fuller discussion.)
- **Case Management**

Clients contact HCAP with a wide variety of issues involving case managers. Case managers may work independently with clients, be onsite in supportive housing locations, or be embedded in programs (such as substance use services). Several clients complained about case managers who they felt were non-responsive or not respectful. Other clients stated that their case managers were not providing the scope of services that clients felt they should.
- **Primary Medical Care**

Issues with primary care include confidentiality, termination or suspension from services, billing, and quality of care.
- **Dental Care**

Clients contact HCAP with a variety of complaints regarding dental care, including: wait times, internal procedures (such as check-in or appointments), billing, and quality of care. Many client issues (such as 3-hour appointment times, communication difficulties, and lack of continuity in care) stem from the fact that the largest provider of dental services is a teaching facility where providers are students supervised by dentists.

SERVICE CATEGORY	2015-16 ⁹	2014-15	2013-14
Housing	30% (32)	32%	22%
Request for Assistance	26% (28)	<i>Not counted</i>	<i>Not counted</i>
Case Management	18% (19)	27%	17%
Primary Medical	11% (12)	15%	24%
Dental	10% (11)	8%	11%
Food	5% (5)	7%	2%
Social Support	4% (4)	7%	4%
Residential Substance Use	4% (4)	3%	2%
Mental Health	3% (3)	11%	7%
Money Management	2% (2)	0%	4%
Hospice	2% (2)	0%	1%
Benefits Counseling	0% (0)	3%	1%
Emerg. Financial Assist.	0% (0)	6%	4%

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	2015-16	2014-15	2013-14
Quality of Care	34% (36)	22%	16%
Assistance Sought by Provider	26% (28)	7%	4%
Termination From Services	16% (17)	12%	6%
Problematic Policy or Procedures	14% (15)	23%	17%
Miscommunication	7% (8)	15%	13%
Eligibility	4% (4)	8%	4%
Non-Engagement with Regard to Grievance/Complaint	4% (4)	8%	2%
Confidentiality	4% (4)	6%	2%
Access	4% (4)	15%	11%
Cultural Sensitivity	3% (3)	7%	3%
Billing	2% (2)	<i>Not counted</i>	<i>Not counted</i>
Failure to Observe Procedures	1% (1)	10%	2%

⁹ Some clients received assistance in more than one service category.

Outcomes

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

- Client with significant cognitive issues was confused about his past and future dental treatment plan. The client was in need of significant dental work (approximately twelve appointments over a three-month period). HCAP worked with the service provider to create a treatment plan, which includes written summaries after each appointment for the client's care provider. HCAP accompanied client to meetings with service provider to establish the treatment plan.
- Service provider banned the IHSS worker of a client who uses a wheelchair and needs live-in care, due to verbal conflict between the IHSS worker and the front desk person. HCAP negotiated an agreement with the housing provider in which the IHSS worker is allowed in the building and will abide by certain behavioral restrictions. The IHSS worker is also taking anger management classes.
- Client was given a 30-day eviction notice from housing provider due to noise from client's singing practice and guests. HCAP, client, and housing provider met to discuss the respective needs of client and housing provider. A compromise was reached and client was not evicted.
- Client was unsatisfied with dental procedures that led to recurring infection and, eventually, surgery. Client had been billed approximately \$900 for services. HCAP filed a grievance on behalf of the client, who was refunded the money that he had paid.

Challenges

Although each client brings with them a unique set of challenges, there are a number of recurring themes among HCAP intakes.

- **Mental Health**

A large number of HCAP clients have mental health issues. The shortage of mental health providers generally, and those who provide ongoing talk therapy specifically, presents a significant, recurring challenge.

- **Housing**

The ever-worsening housing crisis directly affects clients' health and well-being. Clients who are homeless (whether on the streets or in temporary shelters) have difficulty keeping appointments, following up on their issues, and maintaining good health because their energy is consumed by the often futile effort at finding safe and consistent shelter.

Referrals

In addition to providing direct services to clients, HCAP provides clients with referrals to other agencies/organizations that may provide additional assistance. 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. In 2015-16, HCAP referred clients to the following agencies:

311	Equal Access to Healthcare Program (PRC)
A Woman’s Place, Access Center	HealthRIGHT 360
AIDS Emergency Fund	Native American Health Center (dental)
AIDS Housing Alliance	Openhouse
AIDS Legal Referral Panel	Pets Are Wonderful Support (PAWS)
Alliance Health Project	Positive Resource Center
Asian and Pacific Islander Wellness Center	Shanti
Baker Places	Southeast Health Center (dental)
Community United Against Violence (CUAV)	Tom Waddell (dental)
Consumer Credit Counseling of San Francisco	Tom Waddell (Primary)
Cooperative Restraining Order Clinic	Transgender Law Center
	Ward 86

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 resolve issues that are affecting client’s quality of life and making it more likely that they will fall out of care.

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

- Counselor in a harm reduction counseling program contacted HCAP on behalf of a homeless client with substance use issues who was experiencing extreme difficulty staying in care following the theft of his emotional support animal by an acquaintance. The police had declined to assist the client. HCAP and the service provider met with the client. HCAP contacted the acquaintance who had taken the dog, and acted as a mediator between the two parties to resolve their dispute. The acquaintance eventually drove three hours to San Francisco to return the emotional support animal to the client.

- Service provider requested assistance for a client who had a \$900+ energy bill due to another resident illegally siphoning energy from the building. HCAP contacted the utility provider and the Public Utilities Commission and had the charges removed. Another HIV-positive client in the building also contacted HCAP about the same issue. HCAP ensured that the charges for the entire building were removed.
- Service providers also request that HCAP work with clients whose mental health issues are preventing them from pursuing resolution of a particular issue due to the challenge of communicating with the individual or entities involved. Traditional legal services often simply refers a client to the agency without providing direct assistance in this circumstance. Examples include HCAP assisting clients in communication with a public defender regarding warrant clearing, and with the Department of Rehabilitation regarding a return-to-school plan.

Outreach to Consumers and Providers

HCAP conducts outreach to both consumers and service providers. During the 2015-16 year, HCAP conducted 24 outreach presentations, to the following organizations (some agencies hosted more than one outreach):

Assisted Care/After Care (AC/AC), Larkin Street Youth Services
 AIDS Emergency Fund
 Black Brothers Esteem
 Department of Public Health, Substance Use Research Unit
 “The Doctor Is In,” San Francisco AIDS Foundation
 Joy Luck Club (Asian and Pacific Islander Wellness Center)
 Larkin Street Youth Services staff
 Latino Programs, San Francisco AIDS Foundation
 Latino Service Providers’ Network
 Lutheran Social Services
 Project Open Hand
 Rita da Cascia
 San Mateo County CARE Council Meeting
 San Francisco AIDS Foundation
 Stonewall Project
 Tom Waddell Urban Health Clinic
 Tom Waddell Women’s Health Fair
 UCSF Positive Care 360
 University of the Pacific Dental School
 Westside Community Services

HCAP also participates in the Planning Council’s Community Outreach and Listening Activities (COLA) outreach presentations, which 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. This year, HCAP participated in COLAs targeted at: Marin County residents, previously incarcerated individuals, San Mateo County residents, and women.

Program Evaluation

HCAP distributes consumer satisfaction surveys by mail to clients. Each survey includes a pre-paid SASE for return. This year, HCAP received 10 completed surveys,¹⁰ a 12% response rate. It is an ongoing challenge to obtain feedback forms from consumers who are struggling with housing issues, income, mental health, and/or substance use.

Overall Satisfaction	<ul style="list-style-type: none"> • 3 out of 8 consumers (38%) gave HCAP the highest satisfaction rating. • 2 out of 8 consumers (25%) gave HCAP a 4 out of 5 satisfaction rating. • 3 out of 8 consumers (38%) rated HCAP 3 or below (out of 5). <p>Often, clients who respond that they are not satisfied are unsatisfied with the <i>outcome</i> of their issue, rather than with the services themselves. When consumers state that they are not satisfied, ALRP’s Executive Director contacts the individual to discuss their concerns. This year, the clients who rated HCAP a 3 or below either responded positively to follow-up from the Executive Director and resumed working with HCAP, or did not pursue their complaints further.</p>
Cultural Sensitivity of Staff	<ul style="list-style-type: none"> • 9 out of 10 (90%) consumers felt that staff was sensitive to their cultural identity and/or sexual orientation.
Consumers’ Stress/Worry About Their Issue	<ul style="list-style-type: none"> • 7 out of 10 consumers (70%) “felt better” (3 or above) after contacting HCAP. • 3 out of 10 consumers (30%) “felt worse” after contacting HCAP.
Comments	<ul style="list-style-type: none"> • “[HCAP staff] was a wonderful helper and knowledgeable person and I felt very comfortable.” • “The push I needed. Thanks.” • “[HCAP] was great. Felt very comfortable.”

¹⁰ Not all questions are answered on each form.

HCAP 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.

HCAP is also reviewed annually by the San Francisco Department of Health. For the 2014-15 contract year (the most current report), HCAP received 85 out of a possible 90 points, or 94%.