

## **HIV Consumer Advocacy Project (HCAP) Annual Report 2016-17 Contract Year**

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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. HCAP was created by the HIV Health Services Planning Council in order to provide consumers an advocate who can help them navigate services, mediate disputes between consumers and providers, provide appropriate referrals to clients, and assist service providers by removing barriers to service.

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. Currently, HCAP is temporarily staffed with an interim person who holds a J.D. but is not a licensed attorney. HCAP's Staff Advocate continues to be supervised by the Executive Director of ALRP.

### **Clients Served**

From March 1, 2016 through February 28, 2017, HCAP served **77** unduplicated consumers (UDC) with a total of **89** HCAP matters (clients who have more than one HCAP issue in a given year are only counted as "unduplicated" once). HCAP served 86 UDC in 2015-16, 73 UDC in 2014-15 and 81 UDC in 2013-14.

There are two notable trends in HCAP clients served during the 2016-17 contract year. The first is age; as indicated in the data below, a majority of 2016-17 HCAP clients are over 50 years old. This is a shift from the 2015-16 report, where the majority were between 41 and 60 years old. A majority of HCAP clients are long-term survivors.

The second trend we have seen this year relates to clients' incomes. This presents its own challenges, as discussed under "Challenges" on page 6. The vast majority of HCAP clients are very-low income. A large number of HCAP clients rely primarily on Social Security Income and/or Social Security Disability. When income/poverty is combined with other stressors, such as substance abuse, mental health issues, or housing issues such as homelessness, the end result for the client can be devastating. This includes the loss of services such as dental, food, housing, or primary medical support.

## Self-Reported Consumer Data<sup>1</sup>

| GENDER                 | 2016-17 <sup>2</sup> | 2015-16  | 2014-15 | 2013-14                    |
|------------------------|----------------------|----------|---------|----------------------------|
| Male                   | <b>87% (67)</b>      | 83% (71) | 81%     | 80%                        |
| Female                 | <b>9% (7)</b>        | 3% (3)   | 15%     | 14%                        |
| Transgender Female     | <b>4% (3)</b>        | 12% (10) | 4%      | 6% (combined) <sup>3</sup> |
| Other/Decline to State | <b>0%</b>            | 2% (2)   | 0%      | 0%                         |
| Transgender Male       | <b>0%</b>            | 0% (0)   | 0%      | 6% (combined) <sup>4</sup> |

| AGE                      | 2016-17         | 2015-16  | 2014-15 <sup>5</sup> | 2013-14     |
|--------------------------|-----------------|----------|----------------------|-------------|
| 0-20                     | <b>0% (0)</b>   | 0% (0)   | 0%                   | Not Counted |
| 21-30                    | <b>5% (4)</b>   | 12% (10) | 8%                   | Not Counted |
| 31-40                    | <b>12% (9)</b>  | 12% (10) | 15%                  | 9%          |
| 41-50                    | <b>18% (14)</b> | 30% (26) | 34%                  | 40%         |
| 51-60                    | <b>44% (34)</b> | 30% (26) | 32%                  | 52%         |
| 61+                      | <b>21% (16)</b> | 14% (12) | 10%                  | Not Counted |
| Unknown/Decline to State | <b>0% (0)</b>   | 2% (2)   | 1%                   | Not Counted |

| RACE/ETHNICITY         | 2016-17 <sup>6</sup>      | 2015-16  | 2014-15 | 2013-14 |
|------------------------|---------------------------|----------|---------|---------|
| White                  | <b>51% (39)</b>           | 45% (39) | 56%     | 37%     |
| Latino/a               | <b>23% (18)</b>           | 14% (12) | 18%     | 19%     |
| African American/Black | <b>18% (14)</b>           | 26% (22) | 19%     | 30%     |
| Mixed Race             | <b>8% (6)<sup>7</sup></b> | 5% (4)   | 6%      | 6%      |
| Asian/Pacific Islander | <b>4% (3)</b>             | 3% (3)   | 1%      | 3%      |
| Native American        | <b>3% (2)</b>             | 0% (0)   | 0%      | 4%      |
| Other/Unknown          | <b>3% (2)</b>             | 9% (8)   | 10%     | 9%      |

| SEXUAL ORIENTATION     | 2016-17         | 2015-16  | 2014-15 | 2013-14 |
|------------------------|-----------------|----------|---------|---------|
| Gay/Lesbian            | <b>61% (47)</b> | 64% (55) | 60%     | 66%     |
| Heterosexual           | <b>16% (12)</b> | 10% (9)  | 23%     | 21%     |
| Bisexual               | <b>10% (8)</b>  | 16% (14) | 10%     | 7%      |
| Other/Decline to State | <b>8% (6)</b>   | 9% (8)   | 7%      | 5%      |

<sup>1</sup> Percentages may not add up to 100 due to rounding.

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

<sup>3</sup> Beginning in 2014, HCAP tracks transgender women and transgender men separately.

<sup>4</sup> Beginning in 2014, HCAP tracks transgender women and transgender men separately.

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

<sup>6</sup> Some consumers identified themselves in multiple categories.

<sup>7</sup> Clients identifying as “mixed race” reported their identities to be: African American and White (2), Native American and African American (1), Native American and White (3).

| ANNUAL INCOME            | 2016-17  | 2015-16  | 2014-15 | 2013-14 <sup>8</sup> |
|--------------------------|----------|----------|---------|----------------------|
| Under \$15,000           | 77% (59) | 78% (67) | 82%     | 97%                  |
| \$15,001 - \$26,000      | 6% (5)   | 10% (9)  | 12%     | Not counted          |
| \$26,001 - \$30,000      | 1% (1)   | 1% (1)   | 0%      | Not counted          |
| \$30,001 - \$45,000      | 8% (6)   | 5% (4)   | 0%      | Not counted          |
| \$45,001 - \$50,000      | 0% (0)   | 0 (0)    | 3%      | Not counted          |
| Over \$50,000            | 0% (0)   | 1% (1)   | 0%      | Not counted          |
| Unknown/Decline to State | 8% (6)   | 5% (4)   | 3%      | Not counted          |

**Service Categories**

HCAP clients sought assistance across the spectrum of service categories, with the majority of cases in housing, “request for assistance” (see page 7 for more information), primary medical care, and dental services.

*Notes on the most frequently occurring service categories:*

- **Housing**  
 Issues related to housing included conflicts between neighbors, access issues (such as need for reasonable accommodation, need for in-home care, or need for a subsidy), 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. These issues included assistance accessing other services, help with navigating the criminal justice system, and help filing appeals and grievances. Occasionally HCAP will simply make an appropriate referral, but more often 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).
- **Primary Medical Care**  
 Clients contacted HCAP with a wide variety of issues involving primary medical care. Five of the cases involved problems with the treatment of clients. These included (1) doctor missing a diagnosis; (2) client needing to see multiple doctors before being placed with a primary care physician; (3) staff allegedly treating patients disrespectfully; and (4) the office staff not

<sup>8</sup> Beginning in 2014, HCAP reports additional income brackets.

being responsive to clients. Four cases involved clients reporting that doctors refused to prescribe certain medications for various reasons. Two cases were due to problems with a prescription: one over prescribing, and one prescribing the wrong medication. The others included requesting a doctor sign a reasonable accommodation request, client being discharged while still under the influence of medication administered by the hospital, and discrimination based on veteran status.

- **Dental Care**

Clients contacted HCAP with a variety of complaints regarding dental care, including but not limited to: termination of services, internal procedures (such as check-in or appointments), and quality of care. Many client issues, such as long appointments, communication difficulties, limited availability in scheduling, 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. The three cases where care was terminated were because of behavioral issues and/or a challenging dental procedure beyond the service provider’s scope of services.

| SERVICE CATEGORY          | 2016-17 <sup>9</sup> | 2015-16  | 2014-15            | 2013-14            |
|---------------------------|----------------------|----------|--------------------|--------------------|
| Housing                   | <b>27% (24)</b>      | 30% (32) | 32%                | 22%                |
| Request for Assistance    | <b>20% (18)</b>      | 26% (28) | <i>Not counted</i> | <i>Not counted</i> |
| Primary Medical           | <b>18% (16)</b>      | 11% (12) | 15%                | 24%                |
| Dental                    | <b>12% (11)</b>      | 10% (11) | 8%                 | 11%                |
| Case Management           | <b>11% (10)</b>      | 18% (19) | 27%                | 17%                |
| Social Support            | <b>11% (10)</b>      | 4% (4)   | 7%                 | 4%                 |
| Benefits Counseling       | <b>7% (6)</b>        | 0% (0)   | 3%                 | 1%                 |
| Food                      | <b>6% (5)</b>        | 5% (5)   | 7%                 | 2%                 |
| Money Management          | <b>4% (4)</b>        | 2% (2)   | 0%                 | 4%                 |
| Emerg. Financial Assist.  | <b>4% (4)</b>        | 0% (0)   | 6%                 | 4%                 |
| Residential Substance Use | <b>3% (3)</b>        | 4% (4)   | 3%                 | 2%                 |
| Hospice                   | <b>1% (1)</b>        | 2% (2)   | 0%                 | 1%                 |
| Mental Health             | <b>0% (0)</b>        | 3% (3)   | 11%                | 7%                 |

### 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.

<sup>9</sup> Some clients received assistance in more than one service category.

| <b>TYPE OF ISSUE</b>                              | <b>2016-17<sup>10</sup></b> | <b>2015-16</b>  | <b>2014-15</b>     | <b>2013-14</b>     |
|---|-----------------------------|-----------------|--------------------|--------------------|
| Quality of Care                                   | <b>37% (33)</b>             | <b>34% (36)</b> | 22%                | 16%                |
| Assistance Sought by Provider                     | <b>20% (18)</b>             | <b>26% (28)</b> | 7%                 | 4%                 |
| Termination From Services                         | <b>11% (10)</b>             | <b>16% (17)</b> | 12%                | 6%                 |
| Access  | <b>10% (9)</b>              | <b>4% (4)</b>   | 15%                | 11%                |
| Problematic Policy or Procedures                  | <b>8% (7)</b>               | <b>14% (15)</b> | 23%                | 17%                |
| Eligibility                                       | <b>6% (5)</b>               | <b>4% (4)</b>   | 8%                 | 4%                 |
| Non-Engagement with Regard to Grievance/Complaint | <b>2% (2)</b>               | <b>4% (4)</b>   | 8%                 | 2%                 |
| Miscommunication                                  | <b>2% (2)</b>               | <b>7% (8)</b>   | 15%                | 13%                |
| Information and Referral                          | <b>2% (2)</b>               | <b>2% (2)</b>   | <i>Not counted</i> | <i>Not counted</i> |
| Failure to Observe Procedures                     | <b>1% (1)</b>               | <b>1% (1)</b>   | 10%                | 2%                 |
| Confidentiality                                   | <b>0% (0)</b>               | <b>4% (4)</b>   | 6%                 | 2%                 |
| Cultural Sensitivity                              | <b>0% (0)</b>               | <b>3% (3)</b>   | 7%                 | 3%                 |
| Billing   | <b>0% (0)</b>               | <b>2% (2)</b>   | <i>Not counted</i> | <i>Not counted</i> |

**Outcomes**

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

- Client was given a notice that his supportive housing was being terminated due to behavior issues. Leading up to this notice, client had been locked out of his home based on a 3 day suspension from the program, and left homeless for one night before the San Francisco Police Department stepped in. Because the police became involved and there was an additional issue between client and one of the managers, client was given approximately 36-hours notice that he would be discharged from the program and needed to vacate the premises. HCAP and client’s medical case manager both appealed the decision to discharge client. Client took responsibility for his actions. The program manager informed us that the previous manager, with whom the client had an on-going conflict, was no longer employed by the program. Client and the program manager made an agreement that client could stay in the program with a behavioral contract. Client was able to stay in his home and receive services through the supportive housing program.
- Client contacted HCAP because service provider was not following the restraining order that had been granted against client’s roommate. Service provider was allowing the roommate to enter client’s apartment and had not changed the locks. HCAP communicated the concern to service provider’s attorney. Service provider changed the locks and ensured that the roommate moved out immediately.
- Client contacted HCAP because her medical service provider had prescribed her a new medication. Client had never taken this medication and was not sure she should

<sup>10</sup> Some clients have more than one type of issue.

be taking it. HCAP contacted the service provider on behalf of the client and requested the service provider review the client's medications with her. In doing so, the service provider realized that an incorrect medication had been inadvertently prescribed. The medical service provider changed the prescription, and the client was placed on the correct medications.

- Client contacted HCAP because his treatment plan at a dental service provider was altered and would cause the client to go an extended period of time without teeth. Client had missed an appointment with a specialist while undergoing a complex treatment requiring twelve appointments over approximately four months. The service provider informed the client that, due to his missed appointment, the treatment would not be completed prior to the end of the year. This delay would require an additional six weeks without teeth due to the clinic being closed. HCAP contacted the service provider and requested that the client be placed on a cancellation list where the client would be contacted if an appointment opened up. HCAP also requested extra appointment reminders for client, who has cognitive disabilities. Service provider agreed to see client and to provide the extra reminder phone calls.
- Client was unable to access emergency financial assistance due to a prior incident. Client was at risk of losing his housing and the emergency financial assistance would allow client to remain in his home as it would pay for a cleaning service. HCAP reached out to the service provider and was able to secure emergency financial assistance for the client, by offering to deliver the check instead of the check going to the client. HCAP ensured the bill was delivered to the emergency financial assistance service provider, and followed up with the service provider to make sure the bill had been paid. Client was able to remain in his home.

## Challenges

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

- **Mental Health & Substance Abuse**

Mental health and substance abuse issues continue to be a challenge. A large number of HCAP clients have mental health issues. Additionally, many are currently struggling with substance abuse, or have prior substance abuse issues that have created barriers. The shortage of mental health providers presents a significant, recurring challenge. A client's mental health and substance abuse can also negatively impact the client's housing and dental services.

- **Housing & Homelessness**

The ongoing housing crisis in the Bay Area continues to be a challenge for HCAP clients. While the number of housing-related cases has gone down from last year, the ever-worsening housing crisis continues to directly affect HCAP clients. 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 efforts at finding safe and consistent shelter. Additionally,

clients who are not homeless face an increasing chance they may become homeless due to financial, mental health, addiction, or behavioral issues.

- **Dental Services**

The lack of dental service providers is a challenge for HCAP clients. In addition, there are a number of service challenges with the dental service providers. Clients find it difficult to find affordable comprehensive care that extends beyond the limited services offered at the dental schools. Due to the lack of service providers, the termination of services is a scary possibility for HCAP clients. If services are terminated at one of the providers, the client can be left without dental services.

**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 2016-17, HCAP referred clients to the following agencies:

- |                                 |   |
|---------------------------------|---|
| AIDS Emergency Fund             | Project Open Hand                                     |
| AIDS Legal Referral Panel       | San Francisco Bar Association Lawyer Referral Service |
| Bay Area Legal Aid              | Shanti  |
| Catholic Charities              | South Van Ness Behavioral Health                      |
| Conard House                    | St. Joseph Healthcare Fund                            |
| Disability Rights California    | Swords to Plowshares                                  |
| HIV Integrated Services (HIVIS) | Ward 86   |
| Homeless Advocacy Project (HAP) | Westside Community Services                           |
| Instituto Familiar de la Raza   |   |
| Prison Law Office               |   |

**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 the client’s quality of life, 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.

- A client advocate contacted HCAP on behalf of a client who was at risk of losing access to SF Paratransit taxi services. The advocate had been able to schedule an appeal for the client, but wanted assistance with possible representation at the hearing. HCAP reached out to SF Paratransit and asked for the client to be put on a behavioral stipulation. This request was denied, but HCAP was permitted to attend the appeal with the client. HCAP provided support for the client during the appeal hearing. After the appeal, the panel made the decision to allow the client to remain in services with a behavioral stipulation.

- A social worker contacted HCAP on behalf of a client who was at risk of losing services with a food services provider due to not having an identification card. The client had never had an ID. When the social worker and the client tried to get an ID, they were denied because there was an error on the client's birth certificate. HCAP assisted the client in getting a corrected birth certificate, which allowed the client to get an ID and retain services. HCAP was also able to work with the service provider to allow the client to retain services throughout the process of getting his ID.
- A service provider contacted HCAP for a client with substance use and memory issues, who was denied placement in supportive housing for seniors. The case manager requested that HCAP assist in determining the options available to the client. HCAP reviewed the client's file and determined the process for requesting a fair hearing. HCAP met with the client and referred him to a local legal services organization for representation at the hearing.

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

HCAP conducts outreach to both consumers and service providers. During the 2016-17 year, HCAP conducted 6 outreach presentations, to the following organizations:

Catholic Charities (Peter Claver Community)  
 Central City SRO Collaborative  
 Family and Children's Law Center  
 Marin CARE Council  
 Positive Resource Center  
 UCSF 360 Positive Care Center

HCAP was unable to meet its goals for outreach to consumers and providers during the 2016-17 contract year. Due to the HCAP Staff Attorney going on an extended medical leave during the contract year, the position was staffed temporarily by another attorney at ALRP. Due to the attorney's case load, efforts were directed solely toward assisting clients. An interim HCAP Staff Advocate has been hired and is in the process of conducting and scheduling consumer and provider outreaches for the 2017-18 contract year.

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 COLA, 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 to: San Francisco residents who are Latina women, and San Francisco residents who are undocumented immigrants.

### **Program Evaluation**

HCAP distributes consumer satisfaction surveys by mail to clients. Each survey includes a pre-paid SASE for return. This year, HCAP sent out 17 satisfaction surveys and received 3



completed surveys back,<sup>11</sup> a 17.6% response rate. It is an ongoing challenge to obtain feedback forms from consumers who are struggling with housing issues, poverty, mental health, and/or substance use issues. HCAP is currently in the process of sending consumer satisfaction surveys by mail to the remaining 60 unduplicated clients for the 2016-17 contract year.

|  |   |
|--|---|
| <b>Overall Satisfaction</b>                      | <ul style="list-style-type: none"> <li>• 2 out of 3 consumers (66.7%) gave HCAP a 4 out of 5 satisfaction rating.</li> <li>• 1 out of 3 consumers (33.3%) rated HCAP 3 or below (out of 5).</li> </ul>  |
| <b>Cultural Sensitivity of Staff</b>             | <ul style="list-style-type: none"> <li>• 2 out of 3 (66.7%) consumers felt that staff was sensitive to their cultural identity and/or sexual orientation.</li> </ul>  |
| <b>Consumers' Stress/Worry About Their Issue</b> | <ul style="list-style-type: none"> <li>• 2 out of 3 consumers (66.7%) "felt better" (3 or above) after contacting HCAP.</li> <li>• 1 out of 3 consumers (33.3%) "felt worse" after contacting HCAP.</li> </ul>  |
| <b>Comments</b>                                  | <ul style="list-style-type: none"> <li>• <i>"Thank you [HCAP staff] and all at ALRP. Keep doing us (HIV survivors) proud. It lifted that troubling situation out of my way and life. [HCAP staff]'s representation at a meeting gave me strength and support which made it a worthwhile experience."</i></li> </ul> |

HCAP provides monthly reports to the staff of the Department of Public Health's HIV Health Services, and presents a monthly report at the HIV Health Community Services Planning Council's Community Engagement Committee meetings. A goal of these reports is to maintain awareness regarding challenges faced by consumers and ways in which services may be improved. For example, during the contract year, HCAP was able to produce information regarding dental service issues to the Community Engagement Committee upon their request. 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 Public Health. For the 2015-2016 contract year (the most current report), HCAP received 90 out of a possible 90 points, or 100%.

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<sup>11</sup> Not all questions are answered on each form.