
HIV CONSUMER RIGHTS

By Richard Bargetto¹

I. Introduction

One of the challenges in dealing with HIV/AIDS in San Francisco is navigating its complicated service delivery system. In San Francisco, there are approximately 60 Ryan White CARE funded agencies that provide a comprehensive array of services to the HIV/AIDS community. These services include Primary Medical, Case Management, Dental Care, Housing, Food Assistance, Mental Health Services, Legal Services, Transportation, Substance Use, Complementary Treatments and Home Health Care.

This process in accessing HIV services in any service category is sometimes filled with anxiety, power struggles and misinformation. Clients often feel confused about how to properly access the services they need. Even when the services are accessed, clients feel pressured into accepting a poor quality of care and do not know when the services fall below appropriate standards of care. Finally, if clients are terminated from service, sometimes they do not agree or understand the reasons for their termination or know what can be done to re-access services at a later date.

Fortunately, there are numerous federal and state laws that discuss consumer protection while accessing services. These include the Americans with Disabilities Act (ADA), the Occupational Safety and Health Act (OSHA), the Health Insurance Portability and Accountability Act of 1996 (HIPPA), Section 504 of the Rehabilitation Act of 1973, California Civil Code Sections 51 & 54, California Government Code Section 12900 *et seq.*)

In addition to these state and federal guidelines, San Francisco has developed standards of care for all Ryan White CARE funded agencies. These standards are designed to define minimally acceptable levels of service and to ensure consistency among service providers in San Francisco. While the discussion below talks in terms of “rights,” some of these rights could be more appropriately termed “expectations.” Either way, a client does have the right to expect services to be delivered in a client-centered service delivery system.

II. Rights in Accessing Service Delivery System

All agencies are required to provide services fairly and equitably while taking into account the client’s individual needs. Many of these rights were originally based on

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patients' rights in a medical model. Throughout the system of care, whenever a client decides to access the service delivery system, they have the following six rights:

1. Right to Access to Care:

- a. without discrimination;
- b. in a clean and comfortable environment, free from anticipated hazards;
- c. in a safe setting, free from abuse or harassment;
- d. to communicate with visitors with access to mail & telephone, unless clinically contraindicated;
- e. to be provided with a provider of their choice or given other options if they are dissatisfied; and the
- f. right to fair and consistent eligibility and admission standards.

2. Right to Considerate and Respectful Care:

- a. which optimizes patient's comfort and dignity;
- b. that acknowledges and reflects the client's desires;
- c. that notifies a family member, if requested;
- d. that has issues related to care at end of life addressed with sensitivity;
- e. that has access to pastoral and spiritual services;
- f. that has reasonable continuity of care and knowledge in advance of the time and location as well as identity of the persons providing the care;
- g. that is culturally sensitive; and
- h. that is competent.

3. Right to Knowledge & Information about Care:

- a. knowledge of the physician/provider who has primary responsibility for coordinating your care and the names and professional relationships of other caretakers who will be assisting you;
- b. to receive information about the illness, course of treatment, prospects for recovery in terms you can understand;
- c. to receive client rights in writing;
- d. to receive enough information for informed consent;
- e. to be advised about research and clinical trials;
- f. to refuse treatment;
- g. to be informed how to access protective services;
- h. to be informed of continuing health care upon discharge;
- i. to be informed about harm reduction principles and policies; and
- j. to be informed of risks, benefits and alternative treatments.

4. Right to Active Participation in Care:

- a. to participate actively in medical decisions regarding care;
- b. to participate actively with the provider in making ethical decisions regarding care;
- c. to appropriate assessment and management of pain;
- d. to be free of restraints or seclusion imposed as a means of coercion, discipline, convenience or retaliation;
- e. to formulate advance directives and designate a guardian or next of kin or legally authorized person to exercise to the extent permitted by law;
- f. to leave a program and withdraw from services; and
- g. to Informed Consent (Consent to share information, Treatment consent).

5. Right to Privacy and Confidentiality:

- a. to full consideration of privacy concerning care;
- b. to confidential treatment of all information, communications and records pertaining to care;
- c. to access to information when requested; and
- d. to be advised as to the reason for any presence of another person during care.

6. Respect for Client Rights:

- a. right to appoint a legal representative;
- b. right to be informed of client rights and responsibilities;
- c. right to be informed about confidentiality rights;
- d. right to express concerns or complain about care with the assurance that the complaint will not compromise the quality of the care or future access to care; and
- e. to access a grievance process (see below).

III. Minimum Standards of Care for Service Delivery

In addition to these general “patient rights,” San Francisco clients have specific rights regarding each particular service category. Within each of these service categories, clients have the right to expect a certain minimal level of professional service and care from HIV service providers. The following standards of care are minimum expectations for service delivery. If the service or care falls below these minimal levels, the San Francisco HIV Health Services Planning Council (C.A.R.E. Council) would consider it to be a breach of the standard of care for service delivery.

1. Primary Medical Care:

- a. right to a comprehensible treatment plan;
- b. right to clinicians who are familiar with the most recent HIV/AIDS & STD guidelines that are relevant to the population the provider serves;
- c. right to a provider of their choice or given the option to transfer their care if dissatisfied;
- d. right to be assisted in determining how to deal with “after-hours” medical needs;
- e. right to be educated about the disease, treatment, maintenance and transmission;
- f. right to child-care or referrals to child-care;
- g. right to HIV transmission prevention education; and
- h. right to coordinated services and referrals, if appropriate.

2. Mental Health:

- a. right to mental health services provided by licensed professionals in accordance with CMHS standards;
- b. right to mental health services provided with harm reduction principles;
- c. right to full continuum of services that include: intake & assessment, treatment planning, crisis intervention, psychotherapy, coordination & referral and discharge planning;
- d. right to counseling that includes current life issues, not just past issues/history;
- e. right that assessment is performed pursuant to the CMHS requirements;
- f. right that all clients complete intake within 30 days of first visit;
- g. right to the provider of choice and options given if dissatisfied;
- h. right that client and provider sign the treatment plan;
- i. right that services are provided in a timely fashion; and
- j. right that services are culturally and linguistically appropriate.

3. Substance Use:

- a. right to services in harm reduction principles and abstinence models;
- b. right to private, confidential space to meet with program staff;
- c. right to full continuum of services that include: intake and assessment, treatment planning, crisis intervention, group and substance use counseling, coordination and referral, and discharge planning;

- d. right to a comprehensive treatment plan that is prepared, reviewed and modified in accordance with requirements outlined by the substance use services of the SF Department of Public Health; and
- e. right to a treatment plan that includes secondary prevention education, harm reduction, substance use behavior change plans and adherence to HIV medications.

4. Dental Care:

- a. right to a completed treatment plan that includes oral examinations, emergency and non-emergency care and triage care;
- b. right to a full mouth radiograph/Panorex every three years or as needed;
- c. right to Bitewing radiographs (four films) every six months or as needed;
- d. right to dental prophylaxis (teeth cleaning), home care instructions and occlusal sealants;
- e. right to silver fillings for posterior teeth (premolars and molars) and composite resin (tooth colored) fillings for anterior teeth (cuspid to cuspid);
- f. right to anterior single unit crowns, posterior single unit crowns, fixed prosthetics (bridgework), periodontal (gum) treatment and endodontics (root canal therapy);
- g. right to surgery for extractions, incision and drainage;
- h. right to surgery of impacted wisdom teeth; and
- i. right to a night guard.

5. Case Management:

- a. right to case management services that include respect and dignity of each client where the emphasis is placed on encouraging client autonomy and independence in daily living;
- b. right to have all communications remain confidential and limited in scope to client care;
- c. right to a release of information signed annually by the client;
- d. right to a Care Plan that includes identification of all services needed by the client, identification of agencies that have the capacity to provide the needed service, a plan as to how client will access those services, and a monitoring follow-up mechanism;
- e. right to a Care Plan that includes the assessment of basic needs, physical health and health care, mental health and substance use; and
- f. right to meet with case manager once a month.

6. Housing:

- a. right to housing that is clean and safe, well maintained, hygienic and compliant with all state and federal housing guidelines;
- b. right to be placed on a housing wait list if no housing is currently available;
- c. right to be informed orally and in writing of the reasons for denial to housing, unless deemed clinically inappropriate;
- d. right to be informed verbally and in writing with explicit information/criteria for reapplication and reevaluation unless deemed clinically inappropriate;
- e. right to request an extension of housing services; and
- f. right to be linked with other non-housing services.

7. Complementary Therapies:

- a. right to the full continuum of care that includes acupuncture, therapeutic massage and herbal therapies;
- b. see Primary Care above.

8. Peer Advocacy:

- a. right to have peer advocacy services received by a certified Community Health Outreach Worker, who also is CSTEP (Treatment A) trained and TEP (Level I, II, III) certified; and
- b. right to a client needs assessment that includes the client's limitations in daily activities, information and referrals, practical support provided, emotional support provided, coordination with multidisciplinary team and assistance in the development of education, and employment and social programs.

9. Treatment Advocacy:

- a. Right to a written certification that client was given information on available treatments, coordination with multidisciplinary team, informed about treatment options, progress on adherence strategies, success against barriers and clinical trials participation

Please note: Rights for Food, Legal, Transportation & Home Health Care have not yet been developed by the San Francisco HIV Health Services Planning Council (C.A.R.E. Council).

IV. Other Rights

1. Right to be Protected from Discrimination:

If a client believes that s/he has been discriminated against on the basis of race, color, national origin, disability, age, and in some cases sex or religion by an entity that

receives federal financial assistance from the U.S. Department of Health and Human Services (DHHS), the client may file a complaint with the Office of Civil Rights (OCR) within 180 days from the date of the alleged discriminatory act. OCR may extend the 180-day period for a showing of “good cause.”

Upon receipt of the complaint, the OCR will review it. If the complaint raises covered issues, an investigation will be initiated. (If OCR determines that the complaint is not within their jurisdiction, OCR may forward it to an appropriate agency.) If discrimination is found, OCR will negotiate with the institution or agency to voluntarily correct the discrimination. If negotiations are unsuccessful, enforcement proceedings may be instituted to suspend federal funding. Finally, clients have the right to consult a private attorney and to seek relief through the filing of a private law suit.

Other agencies to assist with discrimination claims include:

- a. The Equal Employment Opportunity Commission (EEOC);
- b. The San Francisco Human Rights Commission;
- c. The California Department of Fair Employment & Housing (DFEH);
- d. ALRP; and
- e. The Bar Association of San Francisco, Volunteer Legal Services Program.

2. Right to Grieve

If a client believes that s/he been treated unfairly or that s/he is receiving inadequate services, the client has the right to file a grievance. A copy of the written grievance policy should be prominently posted at each program location and available for review by clients or other interested parties on request. If applicable to the service, each client should be informed of the policy at the time of intake and a signed copy of the policy should be maintained in the client’s file. The client should be given a copy. The policy should be available in languages other than English, dependent on the language needs of the program clients.

Clients have the right to have a grievance procedure that includes the following:

- a. the conditions for a client to express a grievance, including dissatisfaction with decisions concerning the client, dissatisfaction with services or information provided, and allegations of discrimination or mistreatment;
- b. information about the grievance procedure should be presented in a clear, fair and non-intimidating manner;
- c. the grievance process must include steps for an appeal and the steps should be numbered. The policy should provide assurance that a determination by the agency will be reached in a timely manner for each step in the process. A timeline should be stated

- for each step. (It is recommended that no more than 30 days be allowed for a determination to be reached at each step.);
- d. the agency address as well as phone number for obtaining names and phone numbers of those individuals in positions of determination relating to the grievance should be provided;
 - e. the client has the right to discuss the grievance with those who will be making the determination;
 - f. the client has the right to grieve without the threat of retaliation or denial of services;
 - g. the client has the right to have a representative of their choice at anytime during the grievance process to act as an advocate or observer;
 - h. the client has the right to file a grievance that will remain confidential to the extent possible while enabling the agency to investigate the grievance;
 - i. the client has the right to file a grievance without replacing any existing avenue of review or redress provided by law;
 - j. the client has the right to file a grievance in writing or orally. If a grievance is filed orally, the agency must summarize the grievance in writing and obtain the client's signature, if possible. When necessary, grievances may be filed in another format to accommodate a disability;
 - k. the client has the right to be provided copies of documents relevant to his or her grievance to the extent that the documents are not confidential and/or legally protected from disclosure. Client may be required to pay a reproduction charge but this charge should be waived if financial hardship can be demonstrated and if the quantity to be reproduced is reasonable; and
 - l. the client has the right to be advised of other avenues of complaint outside the agency.

For more information contact:

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