

Los Angeles County
Commission on Health Services
HIV/AIDS
TREATMENT ADVOCACY/EDUCATION
STANDARDS OF CARE

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County of Los Angeles Commission on HIV Health Services

**Standards of Care Committee
HIV/AIDS Treatment Advocacy/Education
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HIV/AIDS Treatment Advocacy/Education

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I. Executive Summary

The standards found in this document are intended to be used in providing treatment education and advocacy to individuals living with HIV/AIDS. Recognizing that the role of treatment advocacy and or treatment education may vary with the needs of individual clients and with the ever-changing treatment options. These standards can provide the basic description of acceptable service as practiced among HIV/AIDS treatment advocates. The foundation of these standards is the basic right of individuals living with HIV/AIDS to determine their own treatment.

II. Treatment Advocates/Educators

I. Definition

Treatment Advocates/Educators provide services that inform and empower people living with HIV disease to make conscious and well informed decisions regarding their medical care. These standards provide a framework for the evaluation and application for the provision of services. Standards also define the Treatment Advocates/Educators accountability to the public and the client outcomes.

Treatment Advocates/Educators provide accurate evidence based and current information about HIV disease and its related infections and information on approved, experimental and complementary therapies used in the treatment. Treatment Advocates/Educators may also participate in community advisory boards (CAB), research advocacy for clinical trials, and patient advocacy.

Treatment Advocates/Educators will advocate for culturally, linguistically and gender appropriate services, provide empowerment through information, and assist clients in adherence issues. Treatment Advocates/Educators may also provide cross training to staff and collaborate with healthcare professionals (physicians, dietitians, social workers, vocational rehabilitation counselors, etc.) and others (significant others, care givers, etc.) to address the client's need for proper treatment information, and understanding of medications and lab reports.

Often the roles and responsibilities of Treatment Advocates/Educators will overlap. The term TAE will be used in place of Treatment Advocate/Educator unless otherwise noted.

II. Skills

- Knowledge of HIV disease including pathogenesis, transmission, scope of disease, evidence based treatment modalities, alternative and experimental treatment modalities and relevant social issues

- Ability to interact with AIDS Service Organizations (ASO's), Community-Based Organizations (CBO's) and other healthcare providers
- Understanding and knowledge of the Department of Health and Human Services (DHHS) Guidelines for the Use of Antiretroviral Agents in HIV-infected Adults and Adolescents
- Ability to comprehend general and technical medical information and to communicate such information that is understandable to the community in which services are provided
- Ability to perform client intake, assessment and follow-up activities as referenced in Section III
- Assessment and provision of appropriate referrals
- Ability to establish positive and effective working relationships with clients and healthcare providers

III. Responsibilities

A. Client Registration and Intake

The process, by which an individual is registered, evaluated for services and accepted as an HIV/AIDS TAE client. Collection of Intake information will include demographics, ethnicity, finances, support system needs, healthcare provider information, HIV status, CD4 count, viral load measurements, and medication history. (see appendix for sample form)

Note: Obtain release of information for Medical Providers

B. TAE Treatment Plan (TAETP)

1. The development of an ongoing written individualized TAE treatment plan (TAETP). The TAETP is always developed with the client and in collaboration with the client's primary healthcare provider when possible. The TAETP will identify the goals and actions required to meet the client's needs including a suggested timeline and outcome. (see appendix for sample form)

2. Updates and revisions of the TAETP will be completed with the client. TAETP's will be updated and revised according to the client's individual needs.

C. Advocacy/Education

1. Advocacy: An Advocate provides current and specific information to empower individuals to make conscience, well-informed decisions regarding their medical care. Advocacy is intervening on behalf of a client who needs assistance in accessing various services
2. Education: Provide current and specific information on treatment modalities (approved, experimental, and complementary/alternative), including information on clinical trials, side effects management and adherence techniques. Provide written materials in the form of current treatment strategies, drug interactions, drug profiles and HIV/AIDS treatment fact sheets
3. Linkage: Linkage includes contacting a referral source for a client to ensure that a connection is made with that service.
4. Referrals: Contact with a client which involves providing them with the name and phone numbers of at least three providers of a particular service to allow clients a choice.

D. Training

TAE's must stay current on all treatment modalities:

1. Attend medical updates, conferences, symposia, treatment/community forums, and specialized training programs.
2. Independent studies; i.e. researching medical journals, treatment newsletters, internet web sites, national newspapers, magazines and other publications. (see appendix for resource listing).

E. Client Contact and Follow-up

1. Development and implementation of the TAETP: Create and implement an TAETP specific to client's needs including frequency of contact and anticipated duration of services.
2. Follow-up and Update of the TAETAP: Maintain personal contact as needed with individual client and update the TAETP based on client specific needs and changes: i.e., new medication regimen (including alternative), side effects, OI's.

F. Required Activities

1. Case Conference: Selected clients are discussed with designated personnel and/or medical providers from the agency providing medical

care to obtain input and determine benefits of treatment education and advocacy based on client's needs. All cases should be reviewed and/or discussed at least annually and more frequently, if needed.

2. Meetings/Supervision: TAE must have regular contact with their supervisor at least monthly to discuss services provided. In addition, TAE must participated in regular structured supervision as defined by their agency or agency contract at least once a month.

3. Treatment Advocates/Educators Medical Advisory Boards: Develop working relationship among TAE's and medical providers to improve the quality of treatment counseling provided to individuals living with HIV/AIDS regarding the care and management of HIV disease.

4. Case conferences and supervision meetings should be documented.

H. Optional Activities

1. Community Forums: TAE may provide treatment and community forums regarding HIV treatment options: i.e., current drug options, opportunistic infection information, alternative/complementary therapies, etc.

2. Staff Training: TAE may provide intra/inter agency staff with information pertaining to HIV/AIDS drugs and other treatment options.

3. The TAE is urged to locate and participate in existing TAE Advisory Boards.

Treatment Advocates/Educators Standards

Category	Standard	Comments
TAE Qualification	TAE's will have a Bachelor's Degree in a biological or related field, or hold a high school diploma (or a GED equivalent) and possess at least three years experience in a related field of HIV/AIDS health services.	
Supervisor Qualification	Supervisor should be at least an M.D., RN, RNP, or PA.	
TAE Level of Care	TAE's shall ensure that client's are involved in all phases of treatment advocacy/education to the greatest extent possible. The TAE's shall make every effort to foster and respect maximum client self-determination. The TAE is responsible for helping clients make informed decisions about treatment options.	
TAE Confidentiality	<p>TAE's shall ensure the client's right to privacy and ensure appropriate confidentiality when information about the client is released to others.</p> <p>All information about a client and the client's family that is obtained by the TAE's in carrying out the TAE tasks shall be held in the strictest of confidence. Information may be released to other professionals and agencies only with the written permission of the client or his/her guardian. This release shall detail what information is to be disclosed, to whom, and for what purpose.</p>	
TAE Client Services	<p>TAE's shall be client centered, providing and/or coordinating the delivery of direct service to clients and their families. TAE's services shall consist of the following components in the provision of direct service to clients and their families:</p> <p>Assessment of client's treatment, education, and advocacy needs background</p> <ul style="list-style-type: none"> • Development of an individualized TAETP • Implementation of the individualized TAETP • Coordination and monitoring of service delivery • advocacy on behalf of clients, including creating, 	

	<p>obtaining, or coordinating needed client resources</p> <ul style="list-style-type: none"> • referral to clinical trials and medical services • escort client to medical service provider as needed • reassessment of the client's treatment status • termination of treatment advocacy/education services on as needed basis 	
Service Evaluation	<p>TAE's shall participate in evaluative and quality assurance activities designed to monitor specific outcomes that ensure the appropriateness and effectiveness of both the service delivery system in which TAE operates, as well as the TAE service provision to assure full professional accountability.</p> <p>The quality, effectiveness, and appropriateness of TAE services shall be reviewed and evaluated no less than once every month to ensure established standards are maintained.</p>	
Interactive Skills	<p>The TAE shall strive to work with outside professionals, such as healthcare providers, practitioners of complementary therapies, pharmaceutical representatives, mental health professionals, self-help, and case managers.</p> <p>TAEs shall foster working relationships with other care providers on behalf of individual's specific client needs. TAEs must recognize the expertise that each individual care provider holds, and always strive to present these options to empower the client, encouraging the client to work with these professionals when appropriate.</p>	
Personal and Agency Training	<p>Training: Agencies shall provide/coordinate an orientation and general TAE training to all new TAE before they are assigned clients, such as Treatment Advocacy training. TAEs shall participate in ongoing education/training sessions on a monthly basis regarding HIV/AIDS treatment-related matters to ensure they are providing up-to-date and appropriate service to clients. In-service training's may include, but are not limited to:</p> <ul style="list-style-type: none"> • HIV/AIDS and medical updates, • adherence issues, • mental health issues, • alternative/complementary therapies, • nutrition • conflict resolution • communication skills 	

Treatment Advocates/Educators Ethics

Ethical principles govern right and wrong practices and moral conduct. These principles may include, but are not limited to:

Propriety	<ul style="list-style-type: none"> The TAE shall maintain high standards (define) of personal conduct in the capacity or identity as a TAE. 	
Competence and Professional Development	<ul style="list-style-type: none"> The TAE shall strive to become and remain proficient in the performance of his/her professional function. 	
Integrity	<ul style="list-style-type: none"> The TAE shall act in accordance with the standards (define) of professional integrity. 	
Primacy of Clients' Interests	<ul style="list-style-type: none"> The TAE's primary responsibility is to client's rights and prerogatives as well as their general health and well being. The TAE shall make every effort to foster maximum self-determination on the part of clients. 	
Confidentiality and Privacy	<ul style="list-style-type: none"> The TAE shall respect the privacy of clients and hold in confidence all information obtained in the course of professional service 	
Respect, Fairness, Courtesy	<ul style="list-style-type: none"> The TAE should treat clients and colleagues with respect, courtesy, fairness and good faith. 	
Community Service	<ul style="list-style-type: none"> The TAE should assist in making Treatment Advocacy/Education services available to the general public. 	
Employment Commitments	<ul style="list-style-type: none"> The TAE should adhere to commitments made to the employing organization 	
Maintain Integrity	<ul style="list-style-type: none"> The TAE shall uphold and advance the values, ethics, knowledge, and mission of Treatment Advocacy/Education services. 	
Knowledge Development	<ul style="list-style-type: none"> The TAE shall take responsibility in continuing his/her education/training as needed to provide Treatment Advocacy/Education services. 	

Treatment Advocates/Educators Terms and Definitions

Advocacy - Intervening on behalf of a client when warranted to ensure access to resources and services.

Assessment - Evaluating a client's treatment situation to determine his/her resources and needs.

Case Conference - A review of the service provision to a client among the individuals providing assistance to that client to ensure quality of care.

Client - Any individual who has been affected by HIV disease and seeks service.

Client Contacts - Any contact with a client via telephone, face-to-face, reports from others, etc.

Compliance – Consistent and appropriate administration of a medication as outlined in a course of treatment.

Consultation - A collaboration with other professionals to determine the optimum method of providing treatment to clients.

Coordination of Services – Intra- and inter- agency efforts aimed at coordinating activities to ensure the quality of care.

Documentation – The notation of any client activities in written or computer-based form.

Intake – The process of obtaining client demographic information and providing information regarding Treatment Advocacy/Education services.

Outcome – An evaluation of the affect which Treatment Advocate/Education had in assisting the client in meeting their needs.

Quality Assurance – Activities and measures that ensure that clients receive competitive, appropriate, culturally sensitive, professional services.

Referral – Assisting a client with a connection to a potential resource or service.

Supervision: - Oversight of activities and performance of TAE's to assure performance that meets the standards of care.

Treatment Advocate Educator Treatment Plan (TAETP) – A plan designed by the Treatment Advocate/Educator and the client which identify the client's needs and the method(s) which those needs will be addressed.