

**ORANGE COUNTY CALIFORNIA
CARE SYSTEM ASSESSMENT DEMONSTRATION PROJECT REPORT
SEPTEMBER 2005**

I. Executive Summary

Introduction: Through a HRSA competitive request for proposals, Orange County was chosen as one of three sites for the Care System Assessment Demonstration (CSAD) Project. The purpose of the project was to demonstrate research methods that would make it possible for EMAs to find out why sub populations of HIV infected individuals who know they are not infected do not seek healthcare. The information from the field was used with data gained from written documents and from individuals within the health care delivery system to provide a triangulation of information. Researchers, client advocates, the Ryan White CARE Act grantee, and providers will use the results to develop a plan to increase the percentages of HIV positive African Americans and Latinos in Orange County who are in care. The projected outcome of the study is a plan that will be successful when implemented.

The first assumption is that some health seeking behaviors are determined by individual desires. Another assumption is that other influences are determined by the health care system. In this study we looked at underlying cultural assumptions as well as research domains developed by the creators of the project: Client Health Seeking Behavior, System Comprehensiveness, Capacity, Integration, Acceptability, Accessibility and Technical competence (of the clients, community, service providers).

The Orange County HIV Planning Council chose African American and Latino populations as the study groups.

Process: The principal investigator developed an orientation in Washington, DC that was attended by the Leadership Teams from each site. Then, principal investigator guided the leadership teams in preparing for the field team training. Site coordinators worked with the principal investigator to develop the timeline and deliverables for each member of the leadership team at each site.

The Orange County HIV Planning Council convened an Advisory Committee to the Project to recruit the leadership team. Team members met each other and had the project explained to them at the orientation meeting in Washington. Two days after Washington the leadership team met with some members of the Advisory Committee to divide up responsibilities and to establish level of support provided by the grantee. The grantee provided space, telephone system, computers and printers, access to photocopying and conference room space. The leadership team recruited the field team.

The field team was comprised of individuals from the Latino and African American communities who have access to infected individuals who are not in care. They were comfortable working in situations with the homeless and other marginalized individuals. The team either reflects the demographic groups represented in community or they have a relationship with individuals within an unrepresented category.

The leadership team and one Steering Committee member provided the site organization for the training session for the Field Team.

Outcomes: Why are some Latinos and African Americans who know they are HIV positive not in care?

When asked directly why they are not in care, the majority of responses in the RARE research indicate that the decision not to seek care is a personal one. The responses can be grouped in the following themes:

1. Fear of medication
2. Fear of community response
3. Decision to keep present life style (usually alcohol or other drugs)
4. Denial (seeing oneself as continuing to be healthy)
5. Mental illness and/or depression
6. Immigration Issues
7. Cost
8. Doctors have not recommended medications

People who are in care give answers that are substantively different from providers. People Living with HIV (PLWH) give answers that are personal and not necessarily critical of the healthcare system. Shame, drugs, fear of community stigma, feelings of isolation, language barriers and denial are responses from both PLWH and service providers.

Only Latinos mentioned language barriers, legal status and fear of losing employment. Both African Americans and Latinos mentioned feelings of isolation. African Americans, meaning that there are so few African Americans in Orange County; Latinos meaning that many are here without family support.

Service providers' statements were more general about the culture of the society. They mentioned that people traditionally stay away from doctors, that there is a high level of prejudice against African Americans in Orange County, that providers do not do outreach and that people mistrust government systems.

People who are in care, cultural experts, and providers give the following reasons:

1. Drugs
2. Fear of community stigma
3. Depression
4. Being married (for Latinas)
5. Shame
6. Denial
7. Lack of culturally trained providers; fear of cultural bias among providers; the level of prejudice against African Americans in OC; cultural bias
8. Legal status
9. Fear of losing employment
10. Feelings of isolation
11. Language barriers
12. Traditionally stay away from doctors

13. People mistrust government systems
14. Providers do not do the outreach

What are the issues with the system?

COMPREHENSIVENESS

The system needs the following to be more comprehensive: culturally competent staff, mental health services, needle exchange, client availability for prophylaxis, support groups for women, support groups for heterosexual men, dental services, more access to providers in North Orange County, after hours services, specialty care at the HIV Clinic, more housing and insurance continuity.

CAPACITY

The system's capacity in these areas is strained: housing, transportation and medications

INTEGRATION

The system looks well integrated because it is small. In reality, it cannot function well outside of the Ryan White network.

ACCESSIBILITY

The biggest issue, which no one specifically mentioned in the interviews, but which was addressed in the community forum is accessibility to health care before the diagnosis—access to testing, especially for individuals not living in the central core of the County.

ACCEPTABILITY

1. Few providers see enough African Americans to make a statement. One physician had several Africans, but no African Americans in his practice.
2. Several service providers remarked about the need for more visible Latinos and African Americans in decision-making positions.
3. Disclosure laws initiate conflict between partners of infected people and the clinic.

One positive statement made by the service providers at the time of the community meeting is that Latinos are well represented in the clinic.

TECHNICAL COMPETENCY

We were able to collect a great deal of information about how individuals think about HIV and about how they perceive their communities. The focus of this project, however, is to identify problems within the healthcare system that might keep people from accessing care. Part of what we want to see is whether care system professionals can correctly identify the beliefs we find within the community and work to correct misconceptions and bolster correct ideas. Also, we want to know whether the communities from which the clients come present barriers that need to be addressed or whether the communities where providers live might also provide attitudes that can become barriers to healthcare provision and access.

CLIENT HEALTH SEEKING BEHAVIOR

When we asked people what they did to access care after they were diagnosed, the differences between the people in care and those not in care became apparent. Most of the individuals who were in care, went into care immediately after they found out that they were infected. It is impressive that for almost half of the respondents who were not in care, the first reaction was one of shock, of disbelief. Twenty-two percent of the Latinos went into depression and 15% of the African Americans did. African Americans were definitely more likely to get retested.

Community Recommendations:

Three objectives were chosen at the community meeting. The objectives were expanded with strategies that include the responsible person or agency for getting them implemented. The three objectives are:

Objective I: To increase community education

Objective II: To increase culturally competent staff

Objective III: To develop a client centered approach

Conclusions:

The issues addressed in the conclusion include personal issues, community issues and system issues.

Personal: drugs, mental illness, legal status, Latino and African American women in general do not know that they are in high-risk groups.

Community: US culture is in denial,

System: the Orange County Health care system provides wonderful health care to any infected individual who is also poor. People with money and resources get mediocre care at best, remove the infectious disease/HIV sign from the clinic, training staff not to disclose in public, cultural competence, Lack of continuity across healthcare funding sources, transportation, and childcare.

Further: epidemiological data contain no separate statistics for Africans and African Americans, medication availability, no accessibility illiterate or functionally illiterate persons, revive Noches de Feria, HCA should develop a "HIV Get Tested Day"