

Evaluating the CSAD Process: Challenges and Strategies

Luis Mejia, PhD

Abstract: This article describes the evaluation procedure that was applied to the Care System Assessment Demonstration (CSAD) Project. The article examines issues related to the methods and design of the evaluation activities, the way the local teams were set up and trained, how the project's tools were adapted to local realities, and how the project's monetary needs were addressed.

Key words: System assessment, evaluation, community participation, field work, protocols, minority populations.

The Care System Assessment Demonstration (CSAD) Project was designed to be completed in three stages: data collection, data analysis, and preparation of recommendations for the local planning bodies in charge of allocating CARE Act Title I funds.

The most important feature of the project was its conceptual framework, which specified seven dimensions or characteristics of systems of care and provided a basis for organizing and analyzing the data (see chapter 4 of this volume). The data were collected through the following three processes: 1) an adaptation of RARE (Rapid Assessment, Response, and Evaluation) techniques to examine the health-seeking behaviors of people living with HIV/AIDS (PLWH) and the barriers that interfere with their access to care; these provided an array of research tools that had already been tested for rapid assessment of unmet HIV prevention needs among specific populations (see chapter 3 of this volume); 2) interviews conducted according to the system assessment framework, eliciting descriptions of care system characteristics; and 3) a review of documents generated by local government agencies and HIV planning bodies containing information on how the system of care was organized, supervised, and evaluated.

The data collected from the various sources (specifically, RARE, system assessment interviews, and document reviews) were organized according to the seven dimensions of the system assessment model (see chapter 4). Analysis of the information thus organized identified the main system-related barriers to care entry and retention in each CARE Act Title I Eligible Metropolitan Area (EMA) in which the project was conducted.

In the final stage of the project, the findings were presented at community forums

LUIS MEJIA is an economist and consultant. His areas of interest are health care services, underserved populations and evaluation. He can be reached at mejialuis@netzero.com.

that were attended by PLWH, providers, planners, and others affected by the epidemic. Participants in the forums drew on the findings to formulate strategies to deal with the barriers identified in each EMA, prioritize the allocation of resources, and suggest enhancements to the local system of HIV-related primary care.

The CSAD Project also had a national evaluation component that was expected to document and assess (1) the extent to which the sites followed the original design of the project in both its organization and implementation; (2) how the project orientation, methodological recommendations, and technical assistance offered by the Federal and national teams were implemented by the site teams; and (3) the extent to which the site teams adapted the RARE and the system assessment tools to local conditions.

During the project, the National Evaluator participated in coordination meetings with the Principal Investigator, the Project Analyst, and the Federal team and in technical review visits to the project sites (several of them conducted alone, and others conducted in concert with the Principal Investigator and the Project Analyst); the National Evaluator also conducted an evaluation of the training offered to the sites' Field Teams. Additionally, the evaluator prepared detailed descriptions of the field work completed at each of the project sites and of the community meetings at which stakeholders were presented with findings from the project to generate recommendations for CARE Act Planning Councils and grantees. At the end of the project, the Evaluator submitted a detailed report on the challenges and risks faced by the project and the strategies that were implemented successfully by the national and local teams to carry it to completion.

At all stages of the evaluation process, the National Evaluator relied on the members of the teams involved in the project to provide the information needed for his work. The Federal team was supportive at all times, offering guidance for and relevant feedback concerning the evaluation documents prepared during the life of the project. The other two members of the national team, the Principal Investigator and the Project Analyst, freely shared the information available to them on all issues related to the project. Two of the three sites cooperated fully with the evaluation effort, submitting all the information requested of them, facilitating contacts with all the local stakeholders who had information relevant to the project, and contributing time and effort to the completion of the evaluation process. The remaining site provided assistance to the extent that its Coordinator could spare time from an extremely busy schedule.

Engaging the Community

As chapter 2 indicates, the criteria for the selection of project sites included (1) diversity in the regions of the country in which they were located, (2) diversity in the minority populations they planned to target, and (3) a commitment to support the project on the part of local health authorities, HIV care planning bodies, providers of HIV-related services, CARE Act grantees, and chief elected officials. Based on these criteria, three out of six EMA applicants from across the country were selected: Orange County in California, Palm Beach County in Florida, and Hennepin County in Minnesota. The Orange County applicants proposed to study the barriers to care encountered by African Americans and Latinos; the Palm Beach County applicants wanted to look into

barriers affecting African American women and migrant women of African descent from Haiti and the Caribbean islands; and the Hennepin County applicants intended to study sub-Saharan African immigrants and refugees.

The project designers anticipated that a combination of efforts from local health department (grantee) employees, community advisory groups, and project site teams would see the project through. The local grantees were to provide institutional and political support; the community advisory groups were to create links between the target population(s) and the care system providers; and the site teams were to conduct the data collection and analysis, dissemination of findings, and presentation of recommendations to planning bodies and community forums.

The whole process of data collection, data analysis, and selection of strategies was open and transparent to all stakeholders (i.e., Planning Council members, providers, PLWH, grantees, elected officials, and others interested in HIV-related services) in order to avoid the controversies that often surround Planning Council decisions. This was the purpose of involving the local community throughout the project. The project needed community participation to provide input into the RARE and system assessment processes; to increase the likelihood of acceptance of project findings; to generate recommendations based on the findings; and to build support among service providers and other people with interests in the current system of care for eventual changes in the way services were delivered. Opposition from some political and service sectors was expected (see chapter 6), but it was hoped that the community's interest and activism would provide a counterbalance to those forces.

Each site had formal and informal advisory bodies which served as points of contact between the site's team leaders and the local community; they also facilitated contacts with people who had information on systems of care and knew the social and cultural environments in which the project's target populations lived. There were several ways of establishing informal advisory bodies. Most commonly, the sites' leaders invited groups of people to attend a series of meetings held at different times during the life of the project, at which the site teams presented the project's goals, methods, and findings. Participants in these meetings were encouraged to express their views, voice their concerns, and make suggestions regarding the project. The formal advisory body was a steering committee set up at each site with representation and participation of service providers, consumers, government employees representing local regulatory and supervisory agencies, and private activists and health experts interested in the delivery of services to PLWH.

The steering committee's main purpose was to give the project broad support, to advise the Site Coordinator regarding strategies to reach the target population and key informants for the care system assessment, and to make recommendations regarding the best ways to adapt the research tools to local conditions. The steering committees faced some difficulties in operating efficiently. Many of their members held full-time jobs that interfered with their regular attendance at meetings, which generally took place during work hours. Some people saw their membership in the committee as a mark of distinction that required no effort on their part. Others lacked the expertise or understanding of their roles needed to make a positive contribution to the project. In addition, there was a high turnover in membership at two of the sites. As a result,

some meetings had high attendance and some, low attendance, although at all three sites there was a core group of people who attended regularly.

The three sites were expected to organize and coordinate community meetings to present the findings of the CSAD study and involve the community in the design of action plans for each EMA that, based on these findings, would increase the utilization of primary medical care by their target populations. The sites' leadership teams were also expected to assist the community of PLWH and the people affected by the epidemic, as well as the planning bodies, in monitoring, documenting, and assessing the results of what was done with the information collected for the project.

The sites' leaders were actively engaged in seeking opportunities to present the project at community events and through community-based media outlets. These presentations, along with the public meetings held with stakeholders at each site to introduce the project and present its findings, created interest in the project and broadened awareness of its recommendations. This was consistent with the goal that the project be conducted in a transparent manner, to help create a sense of local ownership and a commitment to carrying out the recommendations that the project generated.

Setting Up the Site Teams

Following the procedure described in chapter 6 for the appointment of site team leaders, a person was selected for the Site Coordinator position by consensus of the steering committee at two of the sites; at the third site, the Title I administrator exerted strong influence in the selection and, in the early stages of the project, attempted to perform a supervisory function in relation to the project's staff; however, this was not part of the project's design. At two of the sites, the Site Coordinator joined the steering committee and participated in the selection of the Site Assistant and Field Team Coordinator; at the third site, the committee made these decisions. In the one place at which the Site Assistant was appointed by the steering committee without input from the Site Coordinator, the person selected turned out not to be an optimal professional match for the project.

In general, the site teams were well-qualified. The three Site Coordinators had good research backgrounds; the two Field Team Coordinators who stayed throughout the project had some administrative skills and good research experience; one of them provided valuable liaisons with the target populations. One of the Site Assistants was an excellent researcher and data analyst. Although the Site Coordinators had good professional qualifications, not all of them had the managerial or teamwork skills that were required for this project. In two of the sites, real friction occurred between the Site Coordinator and the Field Team Coordinator: they disagreed over the extent of each one's supervisory functions in relation to the field workers. At one of these sites, a working relationship between Site Coordinator and Field Team Coordinator was eventually established with help and encouragement from the Principal Investigator and the Federal project officer. At the other, there was a continuous crisis at the leadership level that hampered the project; several people occupied and left the Site Assistant and Field Team Coordinator positions; and for most of the data collection period, the Site Coordinator preferred to run the Field Team without assistance.

In retrospect, it seems that some of this friction could have been avoided if lines of authority, responsibility for management of the project, and a policy for grievance resolution had been set in place from the beginning of the project. Additionally, the steering committees and the CARE Act grantees who selected the Site Coordinator and other members of the leadership teams would have benefited from technical assistance from the Federal team and the Principal Investigator for this task. It may have been beneficial had the Site Coordinators been given the opportunity to select the other members of the site leadership teams that they directed.

The project's original plan called for Field Team members who could conduct community-based research. But community involvement in research activities poses challenges that were soon apparent at two of the sites, where the Field Team members, lacking the skills necessary to put into writing their field observations and the information they were collecting from the respondents, were giving very complete and detailed oral presentations at debriefing sessions that took place weekly. Coping with this challenge, the Site Coordinators decided to tape-record the field workers' meetings in order to collect as much data as possible. Even if the field workers had had the skills necessary to write good field reports, however, time constraints might have precluded them from doing so in a timely and complete manner, since they were budgeted only for part-time work and were expected to keep other jobs if they had them.

At the third site, there was a different problem, as field workers joined the project, withdrew from it, and rejoined at different times. This may have been a result of the improvisation that occurred during recruitment, but it also had to do with culture, gender, and team members' competition for positions of influence within the community. High turnover of staff at the site also affected relations with the community and the target population, as some of the people who left had leadership roles in the community and were listened to when they criticized the project or its managers. For this and other reasons, this site was the least successful in recruiting PLWH to participate in the RARE portion of the project.

Supervision of the fieldwork at one of the sites was close and efficient. It was less effective at a second site because, owing to a lack of experience, the Field Team Coordinator failed to monitor the submission of deliverable work by the members of the Field Team early in the project. With regard to the third site, there were quite specific circumstances for the local team—i.e., high Field Team turnover, only two of the initially trained field workers remaining active throughout the field work, several personnel changes in the Field Team Coordinator position, the Coordinator's being somewhat removed from the daily activities of the team, and the Site Coordinator's assumption of oversight responsibilities, especially when there was no Field Team Coordinator. The team thus lacked effective supervision most of the time. Hence the supervision of the field work may have been inconsistent and lines of authority may have been unclear to the team, particularly regarding the person who was ultimately responsible for supervision.

The fieldwork was expected to last 45 to 60 days and Field Team turnover was not expected to interfere with the project's timeline. In anticipation of any unpredictable situation, however, provisions were made to replace Field Team members who dropped out of the project with people who had been trained as alternates. Difficulties in finding

the target populations at the three sites extended the fieldwork by several months at Hennepin County and by several weeks at the other two sites. Alternates filled in for principals who died, fell too sick to work (the field teams included PLWH at different stages of illness), or departed for other reasons. Only at one site did several new field workers have to be trained by the Site Coordinator. No provisions were made to handle turnover among the sites' leaders.

Training the Site Teams

The field teams were trained during four-day workshops conducted at each site by a trainer specializing in community-based research (see chapter 6). The following features of the training were reviewed favorably by members of the leadership teams: (1) the format followed by the trainers—the combination of theory and practice, the selection of topics, and the level of detail covered in their presentations; (2) the role-playing with participation of all the trainees and the actual observations the team conducted outside the training facilities, under the trainer's guidance, to provide hands-on experience; (3) the repetition of main themes, which served to reinforce them for trainees.

On the other hand, the leadership teams made the following recommendations to improve the training: (1) extend the training to a whole week so that trainees have more time to assimilate the material offered to them; (2) have the Site Coordinator participate actively in the training so that he/she can master all the fieldwork techniques taught to the team and assert a leadership role within the team; (3) spend more time doing practical exercises; (4) place more emphasis on the practicalities of focus group facilitation; (5) anticipate the needs of Field Team members who lack full command of English but are needed in the project when the target population is multilingual and multicultural; and (6) reduce the number of field work strategies presented in the training to those most likely to be used in the project, given its time and budgetary constraints.

The members of the field teams were allowed to keep their copies of the fieldwork manual that had been used for their training so that they could use it as field guide and in refresher trainings conducted by the Site Coordinator and the Field Team Coordinator. The Principal Investigator listed in her reports several recommendations she heard from the sites to improve the manual. The following were among the most important ones: (1) since the field workers were expected to use tape-recorders and computers, the project should provide them with a short introduction on how to use these tools; (2) the language of the fieldwork manual was too advanced for the educational levels of most members of the Field Team, especially when they were members of the target populations; (3) the ethics of social research and issues of confidentiality and privacy should be discussed in more detail with the trainees; and (4) the fieldwork manual should have a companion trainer's manual.

The three Site Coordinators participated, with different degrees of involvement, in the initial training of the sites' Field Teams for the RARE fieldwork, but none of them, and none of the Site Assistants, was given sufficient training or guidance in the interpretation and application of the system assessment model. Their lack of familiarity with the dimensions of the model made it necessary for the Federal team, the Principal

Investigator, and the Project Analyst to provide intensive and extensive technical assistance to help them frame the research questions, organize the data, and plan the data analysis within the model's framework.

Adapting Tools to Local Realities

Although the site teams had at their disposal a variety of instruments to collect data for both the RARE and the system assessment parts of the project, document reviews, interviews, and focus groups were the main tools used to gather the informants' opinions. Based on the system assessment model, the Federal team and the Principal Investigator developed a template for survey questionnaires and question guides for the focus groups that the site teams were expected to adapt for different groups of respondents and to the language, conceptual universes, and cultures of the target populations.

Each site team followed its own procedure to adapt the questionnaires and question guides, but the best practices involved the following steps: first, the local leadership team prepared a draft of the questionnaires for feedback from the steering committee and local community experts; next, the Field Team tested them in mock interviews with outsiders and among themselves, taking notes about their experiences; after that, the Field Team was debriefed by the leadership team, which then reviewed the draft and adjusted it as recommended by the Field Team's observations.

The Field Teams' revisions of questionnaires and question guides can be grouped around the following areas: 1) *Language*: The target populations were poor and uneducated, and they found it difficult to understand long questions or questions written in formal language. In order to be accessible, the questions had to be short and, preferably, phrased in colloquial English. 2) *Concepts*: There were words or ideas that were not part of the conceptual universe of a substantial number of people in the target populations; to them, some notions had to be explained with examples. On occasion, a notion could be so alien to a respondent that the question would elicit no usable response. 3) *Internal consistency*: Questions could be repetitious or redundant, and the interviewers would notice that they were getting the same types of responses for questions that were intended to differ. Questions could also be inappropriate for the context, as reported by a field worker in Palm Beach County, where questions intended for people in care were for a time asked of people out of care.

The process of adapting the questionnaires to local conditions generated a set of field instruments that helped to capture specific features of the EMAs' care systems and barriers to care. Final versions of the instruments could have been completed sooner if provisions for their pre-testing had been anticipated in the design of the project.

Reaching Out to Target Populations

The target populations at the three sites, made up of PLWH who were out of care, were (almost by definition) difficult to reach. As the site reports document, a variety of circumstances conspired to keep many of these people away from the care system. It takes a lot of probing, insider contacts, incentives, messages, and letters for people associated with the government to find people who don't want to be found, even if the

purpose is benign. Each site went about finding respondents according to the cultural and residential features of the minorities targeted in the project.

The best practices included the following elements as keys for the success of the team's effort to find people not in care: 1) hiring Field Team members who have firsthand knowledge of the disease, the target populations, and the places where they congregate, so Field Team members could reach out to friends, acquaintances, and passersby who either fitted the description of potential respondents or could lead to those who did; 2) getting the word out that volunteer respondents were being sought, relying for this purpose on the people who had already been interviewed, service providers, activists, Field Team members, and local media; 3) distributing flyers in the waiting areas of clinics and health centers likely to attract customers from the target population, such as STD/HIV testing facilities and clinics and residential treatment facilities for HIV-positive addicts; 4) making formal and informal contacts with service providers and their staffs (i.e., counselors, case managers, nurses, and outreach workers) who might have members of the target population on their rolls; and 5) having the project staff attend community events to make presentations about the project and hand out information.

The three Field Teams all encountered difficulties in accessing respondents. Some of the difficulties were more or less common to all sites, such as an initial reluctance on the part of service providers to help Field Team members contact potential respondents, community leaders who were not as helpful as the project designers had hoped, and a fear of stigma that kept respondents away from the Field Teams. Stigma was apparent in various circumstances throughout the project. For example, PLWH did not want others such as family and fellow church members to know about their diagnosis. Where the target population included immigrants who were unable to distinguish between social researchers and government inspectors, people were afraid of being turned over to the Immigration and Naturalization Service (INS) for deportation. A lack of English fluency kept others unaware of the project, or they saw no reason to participate. Potential respondents were usually met by the Field Workers at places that were convenient to them, but it was noted that in small, culturally homogeneous communities respondents tended to avoid health care facilities since it was well known that neighbors kept close tabs on who went in and out of their doors.

The research team found sub-Saharan African immigrants at the Hennepin County site extraordinarily elusive. As noted above, some people in the community created obstacles for the project. In addition, service providers withheld their cooperation at first. Nationality or clan affiliations interfered with contacts when some participants refused to be interviewed by team members from other countries or ethnicities. Fears of confidentiality breaches (i.e., some respondents knew of cases in which a person's HIV status was disclosed to the public by a leader or member of the African community and were afraid of suffering the same fate) and stigma (i.e., PLWH feared that they would be disowned by family and community if their HIV status became known) made people reluctant to come forward. Thus, the potential respondents were few in a relatively large community and did not want to be exposed. The issue of incentives was also mentioned as an obstacle, as the rewards offered were sometimes considered too low. Although the Principal Investigator and a member of the Federal team provided

technical assistance on how best to energize the field work, little more was accomplished. It seemed that attempts to reach this particular group of respondents would have benefited from stronger and more energetic interaction with the community by project leaders from the inception of the field work; it also needed more resources and time for Field Team members to get involved in community activities to prove their trustworthiness, as well as a better understanding of cultural codes regulating informal lines of moral authority and influence within the community. Detailed descriptions of the cultural characteristics of the populations affected by the project can be found in chapters 8, 9, and 11.

Budgeting for the Project

The Federal team expected that the fieldwork could be conducted at the same fast pace as in the original RARE prevention projects, but this proved unrealistic. This project's target populations were among the most difficult PLWH to reach; hence, more time and effort were required to recruit respondents than were in the project's budget. The Field Team Supervisor and the field workers were expected to work only part-time, and this further contributed to slower than expected fieldwork.

Funding was insufficient for the labor, technical service, and supply needs of the project. The insufficiency of funds was compounded by the disengagement of the non-governmental fiscal agency (a privately held corporation created to manage government funds as a fiscal agent or intermediary and to provide technical assistance to the Federal government in the design, development, and implementation of short-term projects, was contracted to manage the funds appropriated for the project by the Department of Health and Human Services) that was responsible for managing funds allocated for the payment of project staff and providing technical assistance on accounting issues to the site teams. The agency was often slow in turning work around and difficult in its dealings with project staff; it did not react in a timely manner to the situations developing at the sites nor in responding to the sites' queries and questions, and it lacked initiative in helping the sites develop procedures for the processing of bills, invoices, and payment requests. All of this had a negative effect on the site teams' performance.

Additional expenditures were anticipated, and the local health authorities (Title I grantees) were expected to cover them. These included office space and equipment, telephone and fax lines, computers and access to the Internet, photocopying, and conference room space. The site teams were provided with these facilities by the local grantees. Some unexpected expenditures occurred, such as for the transcription of taped interviews and other field materials collected on recording devices, and for translator and interpreter fees when respondents were not capable of communicating in English. Also, because of tight deadlines imposed on the site teams to submit their final reports, there was a need for additional staff hours to help the Site Coordinators organize and manage the data collected. These unexpected expenses were covered with supplementary funds provided by the Federal government.

Conclusions

The Federal officers who initiated and oversaw this project had several questions in mind regarding their agency's plans and policies to reduce disparities in access to HIV primary care, bring into care PLWH who were not in care, and retain in care those who were. These questions were:

- Are the RARE methods and the system assessment model fruitful for understanding barriers to care and how to overcome them?
- What level of support is necessary for sites to implement them effectively?
- Did it make a difference in reducing barriers to care for PLWH in the targeted population groups to have the project findings and the recommendations that the community made on the basis of those findings?

The project up to this point has not provided definitive responses to all of these questions, but it does provide important insights into identifying strategies, policies, and practices in the delivery of care that will make life better for the majority of low-income, underserved minorities living with HIV who are not yet in care. The participating EMAs tested a set of tools that helped them to understand why people out of care remained out of care and what could be done to bring them into care. The tools permitted a comprehensive study of the scope of services available in an area, the features of the care system that made it easy for consumers to enter and stay in care, the characteristics of current consumers of these services, the care-seeking behaviors of current and potential consumers, and the health beliefs of underserved populations. Funding and time constraints made it impossible to follow up to evaluate the use of the project's data and the implementation of its findings and recommendations by the local planning bodies and the CARE Act grantees (ideally, this would have been an integral part of the evaluation of the project). However, some information on these issues is provided in the next chapter of this supplement.

As chapter 5 indicates, a more systematic inclusion of cultural and poverty-related issues to help contextualize the system assessment framework might expand our understanding of emotional and economic barriers to care. Problems of despair, disenfranchisement, and weakened or nonexistent networks of social support that are linked to chronic poverty may have an influence on the health-seeking behavior of PLWH not in care, an influence that is worth understanding in a more systematic way.

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