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PROJECT NARRATIVE

PROJECT PURPOSE - Defining the need: The impact of the HIV/AIDS pandemic on American society cannot be overestimated. As an epicenter of the disease, San Francisco has experienced a total of 21,538 AIDS cases, accounting for a staggering one fourth of all AIDS cases in California and 5% of cases nationwide. During the same period, 1,454 and 1,242 cases have been reported respectively in San Mateo and Marin Counties. With approximately 1 in 25 of all San Franciscans infected with HIV, there are few people in the City who have not experienced the loss and suffering associated with this illness.

In 1990, the federal Department of Health and Human Services designated San Francisco, Marin and San Mateo Counties as an Eligible Metropolitan Area (EMA) for Ryan White CARE funds with the San Francisco Department of Public Health (DPH) AIDS Office (AO) designated as the administrator. These funds are specifically limited to low income persons living with HIV and residing in the EMA. It is estimated that currently somewhere between 14,000 to 17,000 persons receive CARE funded services in the EMA. With these funds assisting 68 service providers (non-profit and government) to offer a comprehensive array of eighteen different types of health and social services to a wide diversity of affected and infected communities, this "San Francisco Model" has set precedents for HIV care throughout the world.

Today, HIV Health Services in the Bay Area are at a critical juncture. Through medical advances and early intervention, HIV disease is changing from an acute to a chronic illness, requiring a more sophisticated approach to long-term care. It is also increasingly a disease of disenfranchised, hard-to-reach populations who cannot easily access available services. Because of epidemiological and economic forecasts, the constellation of services cannot continue to expand. Avoiding costly duplication of services and distributing available resources more equitably is of utmost concern to HIV-affected communities and health care planners as well.

In 1994, the San Francisco HIV Health Services Planning Council (the community policy body for the EMA) commissioned a study of client experiences with HIV services in San Francisco. The results, published in a report entitled Voices of Experience, were based on in-depth interviews with 193 clients in 22 focus groups. Although clients indicated that they liked the diversity of providers and services, they were extremely frustrated with the lack of coordination in the current system of care. Clients were especially critical of the burdensome intake process which required, for every service they wished to access, an original signed letter of diagnosis from their medical provider, proof of residency, proof of income, and answering a long list of questions required by the AO and the Federal agency responsible for the CARE dollars (Health Resources and Services Administration-HRSA). Additionally, clients had difficulty accessing clear and current information about services. Subsequently, clients were not always able to access those health and social services necessary to help them maintain health and independence for as long as possible.

In 1995, based on the information in the Voices of Experience, other needs assessments, and quantitative/qualitative data on the epidemic, a comprehensive strategic planning process involving DPH, the Planning Council, community and client groups resulted in the HIV Health Services Comprehensive Five Year Plan: A Client-Centered System of Care. It has as it's overarching purpose "to create a Client-Centered System of Care that is comprehensive in scope and integrated in function". To accomplish this goal, the Planning Council specifically identified

and voted to approve two objectives for System-wide Development for the San Francisco EMA: (1) Establish a coordinated, standardized client registration system, with decentralized access, relevant to each county, so that clients will never have to duplicate the intake process. Once a client is registered at one service provider site, the range of services will become available; (2) Develop a unified information and referral (I & R) system with decentralized access so that providers and clients can obtain the most current AIDS-related information.

Coinciding with these local directives, in 1995 HRSA began requiring that all service providers receiving CARE funding report aggregate client and service data. In addition, HRSA funded the San Francisco EMA (and a small number of other EMAs) for three years to begin collecting client level data. The encrypted client level data would then be sent to HRSA to assist the federal government in planning and would be available on the local level to assist agencies and the San Francisco EMA to improve local planning.

A Credible Solution: In 1995, responding to the local client based directives and the national emphasis on accurate data for planning - **"Reggie"** was launched and is currently completing the beta phase of development.
WHAT IS REGGIE? Reggie is a computerized client registration and I & R system networked among CARE-funded service providers in the San Francisco EMA. The system is named after Reggie Williams, a leader in the fight against AIDS in the Bay Area. In 9/30/2000, when Reggie is fully implemented:

- Clients will be able to register once at any CARE funded agency and be registered at all.
- All agency local and federal reporting requirements will be drawn from Reggie.
- It will be possible to track services provided to individual clients in order to improve care coordination.
- Agencies will have access to up-to-date local and national information about services and treatment as well as e-mail connections to all CARE funded agencies.

REGGIE ALPHA: Using Ryan White CARE funds, in 2/95, the AO hired independent technical consultants, to help design and test the concept and feasibility of centralized client registration and information/referral with decentralized access. The AO, working with CARE funded community agencies developed a registration dataset that included all the data fields required by HRSA and some additional data elements helpful to agencies and the AO for planning purposes. Building on the expertise of CARE funded agency staff, Planning Council members, and persons living with HIV, Reggie Alpha was planned and developed as a client server system operating on a wide area network. The database software was donated by Sybase and the front end was designed in Microsoft Access. Alpha agencies were given ISDN lines that provided the connectivity for the application. Confidentiality was a critical factor in designing Reggie Alpha. Several methods were utilized to insure the confidentiality and security of client information. The methods included: server security, network security, software security (certified user permissions and predefined transactions), client level security (consent to share and personal identification number [PIN]), and agency level security. The I & R component in Alpha consisted of a Reggie Website that linked to the San Francisco Library/ AIDS Foundation's AIDS services database for Northern California and several national links

Five CARE funded agencies enthusiastically volunteered to participate in the Alpha. The agencies represented a wide diversity of services, clients and size. During the months of 2/96 and 3/96,

over 100 clients were registered into Reggie Alpha. Because the AIDS Office was testing the feasibility and acceptance of Reggie as a system, the Alpha sites were asked to maintain their own database in addition to registering people in Reggie.

In 4/96 Arthur Andersen LLP was hired by the AIDS Office to conduct a technical evaluation of Reggie Alpha and an independent consultant (Alan Pardini) was hired to evaluate Reggie Alpha from the perspective of the clients and the agency staff. The evaluations showed that Reggie was well received by both clients and agency staff. The programmatic evaluation found that Reggie met agency and client expectations. The technical evaluation also reported that the technology was well selected and appropriate.

REGGIE BETA: Responding to the success of Reggie Alpha, the planning for Reggie Beta began in the summer of 1996. In 1/97, after a competitive process, Cambridge Technology Partners (CTP), an international development firm was hired at a rate well below what they normally charge to develop Reggie Beta (appendix A). Working with a team of highly talented and energetic staff at CTP, the development and implementation of Reggie Beta has been an exciting and intensive experience. Since 1/97 through 3/98 the following has occurred:

Technical Approach:

- Eight **Beta agencies** were selected: San Francisco General Hospital, AIDS Outpatient Service (the largest HIV outpatient service provider in San Francisco, and one of the largest in the nation), the San Francisco AIDS Foundation, Shanti, and UCSF AIDS Health Project (the three largest AIDS case management and multi-service providers in the Bay Area), and four of the original Reggie Alpha agencies. Together these sites serve 70% of all clients.
- As part of **planning**, the AO Reggie Team and CTP developed a list of functionality that is included in Beta and additional functionality that may be added in the future when funds and timing are appropriate (**appendix B**). Staff from the Beta sites and clients from the Alpha participated in user design sessions with the Cambridge and AO Team's to discuss and design the screens that correspond to the different functionality in Reggie.
- Two major **functional modules** were added to Reggie. This additional functionality is built on the basic registration data fields and protected and enhanced by the security and other functionality built into the application: (1) A housing waiting list for four major categories of housing available to eligible persons living with HIV. This database, utilized by CARE funded housing providers, has existed separately in the AIDS Office for the past few years and is now incorporated into Reggie. (2) Three of the Beta sites called "the Collaboration" (AIDS Foundation, AIDS Health Project, and Shanti) hired CTP and developed a care coordination module which was incorporated into the application. In the future, this care coordination database will be available to other HIV/AIDS case management programs.
- After much research and careful assessment, it was decided that the Reggie **software architecture** would remain a traditional client/server approach. The server-side components are: (1) CTP-developed software written in Java 1.1; (2) Sun Microsystems Java Virtual Machine: a DOS-based program that runs the Java code; (3) Visigenics Visibroker: middle-ware software that enables communication with the Java client software; (4) FastForward Java Database Connection (JDBC): allows the Java server to access the SQL database; (5) Microsoft SQL Server 6.5: database server. The client-side components are: (1) CTP developed software written in Java 1.1; (2) Sun Microsystems Java Virtual Machine: a DOS-based program that runs the Java code; (3) Visigenics Visibroker: middle-ware that enables

communication with the Java server software. The Reggie architecture is very scaleable and the application is designed to support open sharing of data (appendix C).

- In some cases, Reggie is replacing an agency's current data collection system and in other cases Reggie is working along side other data systems within the agency. Using an Access Database, an agency's client data in Reggie can be downloaded and linked to other client data that may be collected by the agency. Another feature of the application allows client service data to be linked to an agency's contract and funding sources.
- The network is designed to provide the optimal security of the data and performance of the application. The Reggie servers, running Windows NT 4.0, are physically located at the AO in a locked room and are protected by several software-based security mechanisms (firewalls). Agencies access these servers via ISDN lines (appendix D).
- In order to insure an agency's ability to maintain and report client and service data from the beginning of the calendar year, it was agreed that, as each agency was brought on, client and service data would be converted from their previous data base back to the first of the calendar year and added to the Reggie database.
- For reporting, we selected Crystal Info from Seagate Software (makers of Crystal Reports). All reports are accessed using a client-side desktop tool, developed by Seagate. All reports will be stored and processed on a server at the AO. Seagate generously donated the software and all user licenses for Crystal Info.
- Microsoft generously donated software to Reggie for the Beta and full implementation (appendix E). Please note that originally we planned to use Windows 95, however Windows NT is a more stable platform for the Reggie application and it provides more security. Microsoft agreed to replace their donation of Windows 95 with Windows NT.
- The Reggie Website was revised to be more user friendly and useful to agencies and clients. An I & R Advisory Committee made up of clients and agencies has met regularly to review and improve this Reggie component (appendix F). In addition, the Support Center for Nonprofit Management (a sole source contract agency that provides the AO with consulting staff) received a grant from the National Library of Medicine to develop and provided training on the Internet and Reggie Website to staff from CARE funded agencies.

Security and Confidentiality:

- Because the security of client information is a top priority in Reggie, additional security methods were added during the design of Reggie Beta (appendix G). In April, 1998 as a further check on the security measures built into, Reggie hired Dataway Designs, a network security firm to conduct a security audit on the Reggie System.

Applicant Qualifications (appendix H):

- The AO Reggie Team expanded from the Alpha to include: two full-time Systems Administrators who were cross trained and worked with the Cambridge Team to develop Reggie. The Project Director was assigned 100% to Reggie and a Data and Reports Manager was assigned 80% to Reggie.
- A team of five part-time site analysts (technical and program consultants) were funded by a three year grant from HRSA to work directly with all the agencies to bring them into Reggie.

Community Involvement:

- A Reggie Policy Advisory Committee made up of clients, agencies, AIDS Office staff, and CARE Council members has been meeting since 12/96 to discuss and advise the AO on policies that affect Reggie. The result has been the development of Reggie policies that will continue to grow and be refined with time and experience.

- A Users Group, made up of agency users, technical and program staff, was organized in 1/98 and meets monthly to provide feed-back and suggests improvements on the system.
- Alan Pardini was hired to provide a through client and agency evaluation of Reggie Beta. This pre/post Beta evaluation is in process and will be completed by 9/98.

All Beta agencies will be brought into Reggie by 9/98.

SPECIFIC PROBLEMS TO BE ADDRESSED BY THIS PROPOSAL: Between 10/98 and 9/2000, the AO will add, incrementally, the additional 60 CARE funded agencies to Reggie. It is only when all the CARE funded agencies are registering clients in Reggie that the system will truly benefit the clients and agencies. During full implementation period (10/98-9/2000), in addition to bringing on each new agency, the Reggie system must be maintained and upgraded as needed to support the 8,000 to 10,000 clients and eight agencies of the Reggie Beta phase and the additional 7,000 clients and 60 additional agencies brought on during full implementation. While the AO has been successful in leveraging CARE funding during the Alpha phase, and City General Funds, HRSA and CARE funding during the Beta phase, CARE funding has been reduced drastically and only General Funds and HRSA funds are available beginning 10/98 to support and bring Reggie into full implementation by 9/2000. However, once fully implemented at all 68 CARE funded agencies, the General Fund dollars to support Reggie will be adequate.

There are four activities which are critical for putting into place the structures necessary for the long term success of the system and for which we are seeking funding: (1) establishing quality assurance measures, feed back mechanisms and training to implement quality data collection by each of the CARE funded agencies brought into the Reggie system; (2) developing a quick and efficient triage system to respond to programmatic and technical questions, problems and issues raised by CARE funded agencies and clients; (3) designing and conducting an effective education and training program for the end users at each agency about the Reggie system/software and a general overview of Reggie for the target community; (4) insuring sound network connectivity, data conversion, and installation of hardware and software with each agency that is brought into Reggie. The DPH/AO is applying for funding from the Telecommunications and Information Infrastructure Assistance Program to support the staffing **(an epidemiologist, a services manager, an education manager, one additional systems administrator)** for the above activities. The activities provided by these staff are short term (24 months from 10/1/98 through 9/30/2000)to help us get through the critical stage of bringing on the 60 new agencies and will be completed or absorbed into the activities of the AO/Reggie Team during the last six months of this period.

OBJECTIVES/METHODS/EVALUATION FOR THE FULL IMPLEMENTATION OF REGGIE (10/1/98-9/30/2000): **(See appendix I for Full Implementation Timelines)**

1. By 9/30/2000, approximately 15,000 -18,000 unduplicated clients will be registered in Reggie with 80% reporting satisfaction with and confidence in the system. Additionally, all 68 CARE funded agencies will be using Reggie to register clients receiving CARE eligible services and 70% will be satisfied with the system.

- The Reggie System Administrators will ensure the technical network connectivity and smooth technical transition of each new agency brought into Reggie (including but not limited to ordering and installing hardware, software and router, arranging for an ISDN line, coordinating data conversion, installing the desk top application). In addition, they will

maintain all other aspects of the system including monitoring security, running system administration reports, coordinating merge processes, arranging for download of an agency's local data, providing system repairs, fixing bugs, programming and installing new cuts of the application, maintaining the Reggie Webpage, managing the internal e-mail system and maintaining and updating technical documentation.. Three System Administrators will be needed during the two year when all the agencies are brought into Reggie. Once all agencies are using Reggie, only two System Administrators will be needed to maintain the system.

- The Data and Reports Manager will prepare canned reports needed by the agencies and work with agencies to prepare adhoc reports. The manager will also develop and prepare reports required by the AO and HRSA.
- The site analysts will be responsible for working directly with the CARE funded agencies brought into Reggie during full implementation. Their role will include: assessing the hardware, software, staffing skills, reports needed, current methods and process of data collection, and developing and implementing a plan to bring the agency into Reggie. The site analyst serves as the liaison between the agency staff and the AO Reggie Team to carry out the plan. These positions will no longer exist once all the agencies are folded into Reggie.
- A limited amount of CARE Funding has been set aside to purchase equipment, and install ISDN lines needed for the 60 new agencies brought on during full implementation.
- A yearly security audit will be conducted by Dataway Designs to ensure continued security.
- Evaluation: (1)The Reggie Users Group (clients and agencies) will continue to meet on a regular basis to discuss issues and problems. This group will provide feed back to the Reggie Team and will work together to reach solutions. (2) During the last 6 months of full implementation (4-9/2000) an evaluation consultant, Alan Pardini, will be hired to evaluate this objective. Utilizing focus groups, interviews, paper questionnaires, documentation, and site visits, the results of the evaluation will be presented to the Reggie Policy Advisory Committee and Reggie Users Group to review and make recommendations (appendix J). (3) Service logs of problems and resolutions will provide on going feed back to the Team.

2. By 9/30/2000, there will be a written and implemented quality assurance protocol for Reggie. Furthermore, the data collected and reported by Reggie will meet the standards set in the protocol and set by HRSA for client level data.

- A Reggie epidemiologist will be hired and be responsible for setting up quality assurance (QA) measures, feed back mechanisms and training to implement quality data collection by each of the CARE funded agencies brought into the Reggie system. The epidemiologist will develop and staff a Quality Improvement (QI) Committee to review QA/QI reports and studies and make recommendation. The Committee will report through the Reggie Policy Advisory Committee to the AO Reggie Team. During the last six months, the duties of this position will be assessed and, if appropriate, transitioned to DPH.
- Evaluation: The quality assurance protocols/standards and tools to measures are documented, training has been given and quality of data is assessed and meets required standards. The QI Committee will provide regular feed-back to the Policy Advisory Committee and the AO Reggie Team. HRSA will prepare a yearly QA report on the encrypted client level data in Reggie submitted to them from the San Francisco EMA.

3. By 9/30/2000, there will be a system in place to respond to questions, problems and issues raised by agency staff and clients and 75% of persons using the system will indicate satisfaction.

- A Services Manager will be hired and responsible for planning, establishing and managing a system to respond to programmatic, policy and technical questions, problems and issues

raised by agencies and clients. This manager will work with the System Administrators and will report directly to the Data and Reports Manager. During the last six months, the duties of this position will be assessed and responsibilities divided up among the AO Reggie Team.

- Evaluation: By 12/31/1999, the Services Manager, using focus groups, paper surveys, and interviews will formally assess client and agency staff satisfaction with the timely resolution of problems, issues and questions. A Service Log of all calls and drop-ins will be maintained including statement of problem and resolution. Standards will be set for response time and resolution and measured against the log on a monthly basis. In addition, feedback from the Users Group will help identify problems and issues, and suggest solutions to improve service.

4. By 9/30/2000 a new and revised Reggie dataset will be defined and published, agency staff trained and the new dataset will replace the old dataset on the database software in Reggie.

- The Reggie Database/Reports Manager will hold an annual dataset conference inviting clients, agencies and AO staff to review and recommend changes in the Reggie data elements. The manager will prepare and publish the Reggie Dataset Guide, and train agencies on the new dataset. System Administrators will program the application and release a new cut.
- Evaluation: Participant evaluations will be done at the end of the dataset conferences. The dataset guide will be published 6/2000. Training on the new dataset will take place and be evaluated in 8/2000. The application will be modified to reflect the new dataset. The new dataset will be in effect in 10/2000.

5. By 9/30/2000 the staff who work with the Reggie system at each of the CARE funded agencies will have the knowledge and skills to use the Reggie system effectively. Clients and potential clients will have information and access to information about Reggie in order to make informed decisions about their participation.

- A Reggie Education Manager will be hired and will be responsible for coordinating the design, materials development, implementation and evaluation of all user training needed to bring agencies into Reggie. This includes but is not limited to training each agency on Reggie policies, general overview, quality assurance, the Reggie software, and Windows NT.
- The Manager will be responsible for designing, scheduling, conducting, and evaluating community forums/information sessions about Reggie for clients and potential clients.
- The Education Manager will be responsible for the development of training materials and tracking and storing all Reggie forms and documents.
- Evaluation: The manager will design evaluation tools to measure the immediate and long term effectiveness of all the training's and training materials. A Reggie Binder will be developed that will contain all the forms and documents that are part of the Reggie system along with a system for maintaining and updating the material and the Binder.

SIGNIFICANCE/INNOVATION: Reggie is a trail blazing effort that is applying proven technology to address the needs of low-income individuals living with HIV/AIDS in San Francisco. No other major EMA in the United States serving people with HIV/AIDS has embarked on an effort of this magnitude that will coordinate and share client and service information among a large number of service providers while ensuring that client confidentiality is maintained at the highest level. Since its inception in January 1995, many EMAs around the United States have requested information about Reggie. Over the last six months however, the number of requests has increased, including a site visit by a team from the San Diego EMA and visits with the largest AIDS service provider in Hawaii. Besides AIDS service providers, requests for information have come from housing providers, adult day health providers, victims services,

and software developers. HRSA has asked the AO to speak about the Reggie development at national conferences. The development of Reggie Alpha was presented in a poster session at the 11th International AIDS Conference and the 10th,11th National HIV Update Conference. An abstract about Reggie Beta has been submitted to the June, 1998 12th International AIDS Conference. A government technical project that involves networking with non-profit agencies to improve access to care for an extremely vulnerable population is applicable to many areas. Not only can a system like Reggie be replicated in other EMAs, but Reggie, both the technical and the programmatic aspects, could be a model for any group of agencies serving similar clients (elderly, children, etc.) who need to work together to coordinate and share client and service data.

COMMUNITY INVOLVEMENT: As detailed in this application, the San Francisco EMA is a community-driven/community-centered model of care. The Reggie process has involved extensive client, agency, provider and activist input from its inception. Reggie arose from client-identified need, was defined in a community-based strategic planning process and has been supervised, created, and now implemented with input from the wide array of perspectives, values and stakeholders in the San Francisco EMA HIV/AIDS community **(appendix K)**.

REDUCING DISPARITIES: During the Beta development, the site analysts surveyed the CARE funded service providers to assess their technical ability and determine how they currently register clients, compile and submit data to the AIDS Office. Agency abilities range from collecting data and information on paper only, to having wide area networks and technical staff **(appendix L)**. As a centralized system with a customizable local data receptacle, Reggie levels the playing field for agencies without trying to create, develop and maintain complex information systems at each site. Local data capabilities and improved technical infrastructures will also allow many smaller agencies to more effectively plan, and to compete for private grant funds for the first time. CARE funded agencies will have training and equal access to e-mail and the most current information about AIDS/HIV through the Reggie Website. CARE funded agencies will, through Reggie, be linked to each other through the shared client and service information, and the shared group of clients that they previously served in isolation. Ultimately, and most importantly, Reggie will provide a welcomed relief to the repetitive and exhausting process clients currently need to endure. Reggie will eliminate a large barrier to care for the sickest and neediest in this population.

EVALUATION, DOCUMENTATION AND DISSEMINATION: Please see the above Objectives/Methods/ Evaluation section. The evaluation plan and documentation activities are spelled out for each objective. The Reggie Team has maintained detailed documentation of Reggie from its inception ranging from the minutes of meetings to a formal publication of the project called Connection to Care. Disseminating information about Reggie will take place in many forms: (1) a presentation at the 13th World AIDS Conference , 7/2000; (2) a presentation at the 12th/13th National AIDS Update Meeting 3/99, 3/2000; (3) presentations to HRSA (on site and in Washington); (4) a local press conference launching Reggie full implementation 10/98; (5) a paper about the project will be submitted to the following publications: American Journal of Public Health, New England Journal of Medicine, and "medical informatics" publications. The Reggie Team and the Department of Public Health are very excited about Reggie and we are committed to sharing what we know and what we've learned with any interested individual or agency. It is our greatest hope that in addition to serving the needs of our clients, the Reggie architecture, application, and the community process which has been key to our success will be able to benefit others.