Date: Dec 8, 2009

Item No. 2 File No. 09077

## SUNSHINE ORDINANCE TASK FORCE

#### **COMPLAINT COMMITTEE**

**AGENDA PACKET CONTENTS LIST\*** 

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Completed by:	Chris Rustom	Date:	Dec. 3, 2009	
		-		

\*This list reflects the explanatory documents provided

~ Late Agenda Items (documents received too late for distribution to the Task Force Members)

\*\* The document this form replaces exceeds 25 pages and will therefore not be copied for the packet. The original document is in the file kept by the Administrator, and may be viewed in its entirety by the Task Force, or any member of the public upon request at City Hall, Room 244.



## <complaints@sfgov.org> 11/18/2009 10:02 AM

To <sott@stgov.org>

CC

bcc

Subject Sunshine Complaint

To:sotf@sfgov.orgEmail:complaints@sfgov.orgDEPARTMENT:Public Health

CONTACTED: Maria X. Martinez

PUBLIC\_RECORDS\_VIOLATION:No

PUBLIC MEETING VIOLATION: Yes

MEETING\_DATE:

SECTIONS VIOLATED:

DESCRIPTION: See attached.

**HEARING:**Yes

PRE-HEARING: Yes

DATE:11/06/09

NAME:Melvin Banks

ADDRESS:

CITY:

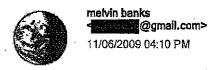
ZIP:

PHONE:

CONTACT\_EMAIL @gmail.com

ANONYMOUS:

CONFIDENTIALITY\_REQUESTED: Yes



- To SOTF <sotf@sfgov.org>
- cc "Byers, Jeff (CDPH-OOA-HCB)" < Jeff.Byers@cdph.ca.gov>, jbyers1@dhs.ca.gov, mitch.katz@sfdph.org, DMorgan@hrsa.gov, "Cook, Gary (HRSA)"

bcc

Subject Request public access to SFDPH Privacy Board Meetings

Dear Sunshine Ordinance,

In an email dated October 30, 2009, I asked Maria X Martinez, Deputy Director and Privacy Officer Community Programs, SF Department of Public Health explain why I would not be allowed to attend DPH Privacy Board meetings. In her response, she claimed, "The DPH Privacy Board is not a legislative body covered under the Brown Act (Govt. Code §54952(b)). Its role is to implement HIPAA and other federal, state and local laws/policies regarding client and patient confidentiality." [See dphprivacyboard] I disagree with her claim because the California Constitution as amended by Proposition 59 in 2004 provides for openness of government.

#### ARTICLE 1 DECLARATION OF RIGHTS, SECTION 3 provides:

- (a) The people have the right to instruct their representatives, petition government for redress of grievances, and assemble freely to consult for the common good.
- (b) (1) The people have the right of access to information concerning the conduct of the people's business, and, therefore, the meetings of public bodies and the writings of public officials and agencies shall be open to public scrutiny.
- (2) A statute, court rule, or other authority, including those in effect on the effective date of this subdivision, shall be broadly construed if it furthers the people's right of access, and narrowly construed if it limits the right of access. A statute, court rule, or other authority adopted after the effective date of this subdivision that limits the right of access shall be adopted with findings demonstrating the interest protected by the limitation and the need for protecting that interest.

Two decisions or actions by the SFDPH that were made without public knowledge and the opportunity for public comment gives rise to this complaint. First, it implemented the San Francisco Share Mandate Policy that created the SAN FRANCISCO'S LOCAL SHARE MANDATE FORM. [See attached] The second attachment, CDPH 8693, contains the form created by the California Department of Public Health, Office of AIDS. There is a major distinction between the two forms. The State Form, CDPH 8693 (8/07), has the Share/

Non-Share option. In contrast, the SFDPH Form, LSM 8693 (8/07), has only one option, Share. Second, SFDPH appears to have decided to withhold services from people suffering from HIV who do not give their consent to Share information in ARIES. In an email, dated October 28, 2009, she states, "after reading the Local Share Mandate policy, counties 'may require most clients to share their data as a condition for receiving services'." [See condition4receivingservices]

The scope of this complaint is not whether the SFDPH has the authority to create a client consent from that is different than the one issued by the California Department of Public Health, Office of AIDS or withhold services from people with HIV who choose not give their consent to share information in the ARIES system.

Rather, the issue is that SFDPH created and implemented policies, procedures, and forms without public comment or scrutiny. Since the consequences of these actions directly affect more than 20,000 consumers of HIV services, I request that the SOFT order that DPH Privacy Board meetings be noticed and open to the public for comment. I also requested on October 30, 2009 a copy of the San Francisco Share Mandate Policy in which she cited on October 29, 2009. As of the date of this complaint, I have not received a copy of the San Francisco Share Mandate Policy.

If you have any further questions, please feel free to contact me. Thank you.

Sincerely,

Raymond Banks

dphprivacyboard.rtf San Francisco's Local Share Mandate Form (English).pdf cdph8693.pdf conditions4receivingservice.rtf

hide details Nov 3 (3 days ago)

Mr. Banks,

The DPH Privacy Board is not a legislative body covered under the Brown Act

(Govt. Code §54952(b)). Its role is to implement HIPAA and other federal, state and local laws/policies regarding client and patient confidentiality.

Over the next few months, as I noted before, we will be addressing the form itself.

Regards, Maria

Maria X Martinez, Deputy Director and Privacy Officer - 415-255-3706 Community Programs, SF Department of Public Health 1380 Howard St., SF, CA 94103

DPH e-mails sent to and from personal email accounts or outside the DPH/UCSF servers are not secured data transmissions for Protected Health

Information (PHI), as defined by the Healthcare Portability and Accountability Act (HIPAA). It is the responsibility of all parties involved to take all reasonable actions to protect this message from non-authorized disclosure. This e-mail is intended for the recipient only. If you receive this e-mail in error, notify the sender and destroy the e-mail immediately. Disclosure of the PHI contained herein may subject discloser to civil or criminal penalties under state and federal privacy laws.



#### ARIES Client Consent Form for San Francisco

In addition to providing information, I will provide an original letter of diagnosis signed and dated by my doctor or have a blood test that shows that I am HIV positive. I understand that I will also need to answer questions about my income. By signing this form, I state that I live in San Francisco or intend to reside there.

I understand that certain services may be available to HIV-negative partners, family members, or other caregivers affected by HIV, and registration and service information for these clients will not be shared between agencies regardless of my own share status.

SHARE: By signing below, I understand my registration information will be shared with other agencies I receive services from that are part of ARIES. Only authorized personnel at an agency will have access to my information on a need-to-know basis. The information shared may include information about services received or my treatment at a particular agency. Mental health, legal and/or substance abuse services will only be shared as allowed by law. By stating that my information will be shared, I will usually not need to re-register (in ARIES) or provide a letter of diagnosis when I require services from an agency providing services funded by the Ryan White CARE Act or the California Department of Public Health (CDPH)/Office of AIDS.

I understand my name and information will not be shared outside the ARIES system unless I provide my specific, informed consent to such a disclosure.

I understand that the information I provide may be made available to my local health department, to fiscal agents who fund the services I receive, and to the CDPH/Office of AIDS for mandated care and treatment reporting requirements, and may be used for program monitoring, statistical analysis and research activities. This information includes, but is not limited to, gender, ethnicity, birth date, zip code, diagnosis status, and service data. No identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.

My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may exclude me from services at other ARIES agencies.

By signing this form I acknowledge that I have been offered a copy of the ARIES Client Consent Form for San Francisco and have talked about and understand my rights to confidentiality with respect to ARIES with the staff person indicated below. I understand that this form will be stored in my paper file.

Signature of Client or Parent/Guardian of Minor Child	Date	
For Local Health Car	re Agency Use Cinly	
Administered By	Agency Name	
Signature	$\overline{ ho_{ic}}$	
For Local Health Cai  Administered By  Signature  This client is a NON-SHARE client because (check all that apply): Unable	to give consent Related/Affected Client	FIV-Negative

LSM 8693 (8/07)



## **ARIES Client Share/Non-Share Consent Form**



I,, (print full name) wish to register with ARIES in order to receive services funded by the Ryan White CARE Act or the California Department of Public Health (CDPH), Office of AIDS. During registration, I will be asked to provide information about myself, including my name, race, gender, date of birth and other demographic data. Depending upon the agency or program I am registering with, I may also be asked questions about my CD4 cell count, viral load, use of HIV medications, my general physical and medical condition and other medical history questions.
In addition to providing information, I will provide an original letter of diagnosis signed and dated by my doctor or have a blood test that shows that I am HIV positive. I understand that I will also need to answer questions about my income. By signing this form, I state that I live in the California County I am seeking services from, or intend to reside there.
l understand that certain services may be available to HIV-negative partners, family members, or other caregivers affected by HIV, and registration and service information for these clients will not be shared between agencies regardless of my own share status.
SHARE: By checking the "share" box below, I choose to share my registration information with other agencies I receive services from that are part of ARIES. Only authorized personnel at an agency will have access to my information on a need-to-know basis. The information shared may include information about services received or my treatment at a particular agency. Mental health, legal and/or substance abuse services will only be shared as allowed by law. By stating that I am willing to share my information, I will usually not need to re-register (in ARIES) or provide a letter of diagnosis when I require services from an agency providing services funded by the Ryan White CARE Act or the CDPH/Office of AIDS.
NON-SHARE: By checking the "non-share" box below, I choose not to share my information with ARIES agencies that I go to for services. If I do not want my information shared between ARIES agencies, I will provide all ARIES registration and other information, including an original letter of diagnosis, to each agency that I go to for services.
I choose: Share Non-Share
I can change my decision about sharing/not sharing by informing the staff at any agency where I go for service and by signing a new ARIES Client Share/Non-Share Consent Form. I understand that changing from Non-Share to Share opens my ARIES record to other ARIES agencies I receive services from. No matter what I choose, my name and information will not be shared outside the ARIES system unless I provide my specific, informed consent to such a disclosure.
Regardless of my share/non-share status, I understand that the information I provide may be made available to my local health department, to fiscal agents who fund the services I receive, and to the CDPH/Office of AIDS for mandated care and treatment reporting requirements, and may be used for program monitoring, statistical analysis and research activities. This information includes, but is not limited to, gender, ethnicity, birth date, zip code, diagnosis status, and service data. No identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.
My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may exclude me from services at other ARIES agencies.
By signing this form I acknowledge that I have been offered a copy of the Share/Non-Share Consent Form and have talked about and understand the choices of sharing or not sharing with the staff person indicated below. I understand that this form will be stored in my paper file.
Signature of Client or Parent/Guardian of Minor Child  Date
For Local Health Care Agency Use Only
Administered By Agency Name

CDPH 8693 (8/07)

Signature

Maria X Martinez <Maria.X.Martinez@sfdph.org>
tomelvin banks <\_\_\_\_\_.com>
ccBill Blum <Bill.Blum@sfdph.org>,
Celinda Cantu <Celinda.Cantu@sfdph.org>
dateWed, Oct 28, 2009 at 9:28 AM
subjectARIES "consent" form

hide details Oct 28 (9 days ago)

Mr. Banks,

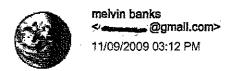
I wanted to let you know that I met with Bill Blum and Celinda Cantu yesterday about the form. After reading the Local Share Mandate policy, counties "may require most clients to share their data as a condition for receiving services." There are 3 conditions that would make-up this exception: (1) clients who demonstrate an inability to give consent as documented in the client record (e.g., decreased mental capacity), (2) are receiving services as a related/affected client; or (3) are receiving services as a HIV-negative client. In San Francisco, clients who request their information not be shared are also given an exception. As I mentioned in our phone conversation, HIPAA and state laws allow for HIV treatment providers to share health information with each other for treatment purposes without signed authorization (see attached for references), but the ARIES notice (entitled "ARIES Client Consent Form for

San Francisco") limits this sharing to certain agencies.

In any case, I maintain that the form itself is confusing and problematic and we are checking with the State to see if/how we can change it to be clearer.

Given vacations and extremely short staffing shortages at the state level, I don't forsee us resolving this issue anytime soon. I will be in touch as soon as I have findings.

Maria



To SOTF <sotf@sfgov.org>

cc "Byers, Jeff (CDPH-OOA-HCB)" <Jeff.Byers@cdph.ca.gov>, mitch.katz@sfdph.org, barbara.garcia@sfdph.org, Bill Blum <Bill.Blum@sfdph.org>, Maria X Martinez

bcc

Subject ADDITIONAL DOCUMENTS

HI SOFT,

PLEASE ATTACH THE DOCUMENTS TO MY COMPLAINT. THANK YOU





RAYMOND BANKS ARIESShareNonShareClientProvInfoDoc.pdf 066098036n.pdf



## AIDS Regional Information and Evaluation System (ARIES)



#### What Is ARIES?

The AIDS Regional Information and Evaluation System (ARIES) is an HIV/AIDS web-based computer system that is used by agencies who receive HIV/AIDS money from the State and Federal government (through the Ryan White CARE Act). Agencies who receive money from the CARE Act must keep track of the clients they see and the services they provide to those clients; ARIES helps agencies carry out this task. By entering information into ARIES, it will be easier for the agencies you see to plan and manage your care.

#### To Share Or Not To Share?

You will be able to choose whether or not you want the agencies you see for services to share your information with each other. When making your decision you need to consider the benefits of sharing your information vs. not sharing your information. Once you make your decision, you will need to sign the ARIES Share/Non-share Form.

### What Are The Benefits Of Share VS. Non-Share?

You have the choice to either share your data or not share your data between agencies. When you first go to an agency for services, they will ask you if you want to share your data.

### Choosing the Share Status

If you agree to share your information with other agencies, ARIES will help you get services more easily. While you will still have to go through the normal client intake process the first time you go to an agency for services, ARIES may cut down the amount of paperwork you need to fill out when you go to other agencies for services. This will also help agencies work together to provide you with the services you need. You will have to sign a form at each agency to let them know that you agree to share your information, but you won't need to complete most of the same forms more than once. By sharing, you won't have to give the same basic information like address, phone number, race, etc., over and over again to each agency. The system works best for you if you choose to share your information because the registration process will be easier when you go to more than one agency for services. Important: only the agencies you go to for

# services will be able to see your information. Agencies that you have never visited for services will never see your information.

#### Choosing the Non-Share Status

If you decide not to share your information with other agencies, you will still need to sign a form when you first come to an agency for services. You will need to provide all of your information each and every time you go to a new agency just like you do now. You will also have to give each and every agency your most recent information each time you go in for services.

You have the right to change your mind about sharing your information at any time. If you choose not to share your information at first, but later decide you do want to share your information, all you have to do is tell your provider. They will ask you to sign a new consent form. The appropriate agency staff can then go into ARIES and indicate that you have changed your mind and would like to share your information. If you change from share to non-share, the information collected from that date forward will not be shared.

It is important to note that regardless of your share or non-share choice, fiscal agents and public health departments may see your data to meet their funding and reporting requirements. Your confidentiality is always safe in these instances. No identifying information, such as your name and social security number, will be released, published or used against you without your consent, except as allowed by law or to ensure compliance with policy.

### What Does Sharing My Information Mean? How Does It Work?

If you choose to share your data, you must sign a form that says you are allowing that agency to share your information with other agencies you go to for services. Only agencies you see for services can view your information. When you go to an agency for the first time, they will ask you if you have already received services from an agency that uses ARIES. If you have already been to an agency that uses ARIES and you are a share client, your information will come up on the computer after you give the agency some important information. In ARIES, this information is called the *client keys*. These keys are important because there are certain letters and numbers from each of the keys that make up a unique client ID for you. This client ID is how ARIES tracks you in the system. The client keys consist of the following:

- 1) First Name,
- 2) Middle Initial,
- 3) Last Name,
- 4) Date of Birth,

- 5) Gender, and
- 6) Mother's Maiden Name.

Once the computer finds your record, you won't have to give your information all over again when you go to a new agency for services that also uses ARIES. You must remember your client keys the exact same way each time you go into an agency. For example, if you go to one agency for services and you tell them your name is Bob but later go into a different agency for services and tell them your name is Robert, ARIES will not be able to find you in the system. You must use the same "keys" at all agencies where you receive services. If your keys are not the same, ARIES will create more than one record for you in the system, thus making it harder for agencies to correctly identify and serve you.

### Why Does ARIES Use Mother's Maiden Name?

ARIES uses mother's maiden name simply because it's specific to you and easy for you to remember. It's in no way related to your banking and/or financial records. In addition, ARIES only stores the first and third letter of your mother's maiden name—not the entire name—as a way to uniquely identify you in the system. If your mother's maiden name is <u>Jones</u>, for example, only the letter J and the letter N would be stored in ARIES as part of your *client keys*.

Client keys are important because they make you unique in ARIES. Providers use these six pieces of information to look you up in the system. This ensures that each agency looks up YOUR data in ARIES and doesn't get you mixed up with other clients. The federal government branch called the Health Resources and Services Administration (HRSA) first came up with the idea of a unique client identifier. HRSA used: first name, last name, date of birth and gender. This client identifier, however, did not prove to be as unique as they had hoped particularly in large states like California, Texas, and New York who have a large number of people living in one state. To make sure the client identifiers or keys are unique to you, it was necessary to add on other pieces of information; thus, mother's maiden name and middle initial were added.

Furthermore, only certain employees at the provider agency are allowed to see your client keys in ARIES. If one of these employees pulls up your client keys, ARIES will not show them the mother's maiden name. ARIES always hides MMN.

## Is My Information Safe?

Your information is <u>very</u> safe in ARIES. In fact, your information is more secure in ARIES than your on-line banking information! The California State Office of AIDS (OA) must approve each staff person before he or she is allowed to go into ARIES.

Each staff person is given a "digital certificate" before they can go into the system. The digital certificate is linked to their own name and password. The digital certificate also checks to make sure that provider staff are using State approved computers. This means that staff who use ARIES cannot get into ARIES from any computer they want to. For example, they cannot go to a public library to get into ARIES. OA does not approve computers that are used in public places. This is not true of Internet banking systems: banks allow you to access your information from any computer as long as you know the user name and password. But for ARIES, only specific approved computers and approved staff will be allowed to use ARIES.

Once staff have been approved to use ARIES, they are given permission to view very specific information - only the specific information they need to know about you. Information such as mental health, substance use, legal issues are available to a very limited and approved group. This information is never shared between agencies in ARIES, even if you have agreed to share your information.

ARIES also uses encryption when storing your information. This means that the information that identifies you in ARIES (for example, your six client keys mentioned earlier as well as your address, telephone number, etc.) are jumbled or scrambled in the system. Only certain approved users have the keys to unscramble the data. Encryption is also used to scramble information as it travels across the Internet. If hackers try to get your information as it travels across the Internet lines, they would not be able to read any information since it is scrambled.

ARIES also uses firewalls to protect your information. A firewall is a piece of computer software used to prevent hackers from getting into or seeing system information. ARIES uses three firewalls to ensure your data is stored safely.

## Who Can I Call If I Have More Questions?

You may contact you local provider agency if you have more questions or concerns about collecting and storing your information in ARIES.

You can also read more about ARIES by visiting the California State Office of AIDS' website at: <a href="http://www.dhs.ca.gov/aids/Programs/ARIES/default.htm">http://www.dhs.ca.gov/aids/Programs/ARIES/default.htm</a> or <a href="http://projectaries.org">http://projectaries.org</a>

PROJECT NARRATIVE

98036

980376

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 <u>Voices of Experience</u>, 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 <u>HIV Health Services Comprehensive Five Year Plan: A Client-Centered System of Care</u>. 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 finds, 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).

eri.

- 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 analysis 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.
- e 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 12/h/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.



#### Eileen Shields/DPH/SFGOV

11/24/2009 01:54 PM

To SOTF/SOTF/SFGOV@SFGOV

cc Maria X Martinez/DPH/SFGOV@SFGOV

bcc

Subject Re: Sunshine Complaint Received: #09077\_Raymond Banks v Public Health

History:

This message has been forwarded.

#### Dear Sunshine Task Force:

According to the complaint #09077 from Raymond Banks, the complainant is asking that the SOTF require the San Francisco Department of Public Health to treat the DPH Privacy Board meetings as subject to the Brown Act, thereby requiring the Department of Public Health to post and open the DPH Privacy Board meetings to the public.

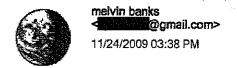
It is the position of the Department of Public Health that the DPH Privacy Board is not a legislative body covered under the Brown Act. Its role, as we have explained to Mr. Banks, is to implement HIPAA and other federal, state and local laws regarding client and patient confidentiality.

Because we deal with thousands of patients, as Mr. Banks has correctly noted, our responsibilities include protecting the rights of those patients, by implementing the laws and codes stipulated by the myriad agencies that have jurisdiction over this Department. The DPH Privacy Board is comprised solely of DPH staff whose purpose is to grapple with complicated and fundamentally difficult HIPAA and other federal and state requirements. At these meetings, we frequently discuss patients, patient care, and patient services. To treat these staff meetings as subject to the Brown Act would have far reaching implications on all staff meetings that take place in the normal course of daily business throughout the city.

We would therefore respectfully ask that the SOTF Complaint Committee find that this complaint has no basis in merit, is not an issue of improper adherence to the Brown Act and that it be dismissed at the committee level.

At this time, we do not anticipate sending a representative to the Complaint Committee hearing. If you have any further questions, please contact me.





To SOTF <sotf@sfgov.org>

cc Bill Blum <Bill.Blum@sfdph.org>, barbara.garcia@sfdph.org, Celinda Cantu <Celinda.Cantu@sfdph.org>, "Cook, Gary (HRSA)" <gcook@hrsa.gov>, DMorgan@hrsa.gov, "Byers,

bcc

Subject | wish to amend complaint #09077 with more detail.

Dear Sunshine Ordinance Task Force,

On November 6,2009. I submitted complaint #09077. I wish to amend complaint #09077 with more detail.

In an email dated October 30, 2009, I asked Maria X Martinez, Deputy Director and Privacy Officer Community Programs, SF Department of Public Health to explain why I would not be allowed to attend DPH Privacy Board meetings. In her response, she claimed, "The DPH Privacy Board is not a legislative body covered under the Brown Act (Govt. Code §54952(b)). Its role is to implement HIPAA and other federal, state and local laws/policies regarding client and patient confidentiality." [See dphprivacyboard] I disagree with her claim because the California Constitution as amended by Proposition 59 in 2004 provides for openness of government.

#### ARTICLE 1 DECLARATION OF RIGHTS, SECTION 3 provides:

- (a) The people have the right to instruct their representatives, petition government for redress of grievances, and assemble freely to consult for the common good.
- (b) (1) The people have the right of access to information concerning the conduct of the people's business, and, therefore, the meetings of public bodies and the writings of public officials and agencies shall be open to public scrutiny.
- (2) A statute, court rule, or other authority, including those in effect on the effective date of this subdivision, shall be broadly construed if it furthers the people's right of access, and narrowly construed if it limits the right of access. A statute, court rule, or other authority adopted after the effective date of this subdivision that limits the right of access shall be adopted with findings demonstrating the interest protected by the limitation and the need for protecting that interest.

Two decisions or actions made by the SFDPH give rise to this complaint. First, it implemented the San Francisco Share Mandate Policy, which in turn created SAN FRANCISCO'S LOCAL SHARE MANDATE FORM. [See attached] The second attachment, CDPH 8693, contains the

form created by the California Department of Public Health, Office of AIDS. There is a major distinction between the two forms. The State Form, CDPH 8693 (8/07), has the Share/ Non-Share option. In contrast, the SFDPH Form, LSM 8693 (8/07), has only one option, Share.

Second, SFDPH appears to have decided to withhold services from people suffering from HIV who do not give their consent to Share information in the ARIES reporting system. In an email, dated October 28, 2009, Ms. Martinez states, "after reading the Local Share Mandate policy, counties 'may require most clients to share their data as a condition for receiving services'." [See condition 4receivingservices] However, the ARIES Share/Non-Share Client Provider Information Document does not contain the requirement that clients must share their information as a condition for receiving services. [See ARIESShareNonShareClientProvInfoDoc]

The scope of this complaint is not whether the SFDPH has the authority to create a client consent form that is different from the one issued by the California Department of Public Health, Office of AIDS or withhold services such as medicine, housing, and food, from people who suffer from HIV who do not choose to give their consent to share information in the ARIES reporting system. Rather, the issue is that SFDPH created and implemented policies, procedures, and forms without the opportunity for public scrutiny because the DPH Privacy Boards meetings were not noticed which eliminated the opportunity for public comment. San Francisco has prided itself with the development of the HIV community-driven and consumer- centered model that allows all stakeholders to participate and provide input on policies and decisions.

For instance, when SFDPH developed the Reggie date collection and reporting system, there was according to the <u>Reggie Narrative</u>, "<u>COMMUNITY INVOLVEMENT</u>: <u>As detailed in this application, the San Francisco EMA is a community-driven/community 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 a wide array of perspectives, values and stakeholders in the San Francisco EMA HIV/AIDS community." [See reggienarrative, p. 4,8]</u>

The narrative also informs us that "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, [AIDS Office], 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." The development of the "Reggie Policy Advisory Committee" shows that, in the past, SFDPH has allowed the public the opportunity for comment about its policies.

Unfortunately, SFDPH appears to be retreating from that model and policy. The minutes from the HIV/AIDS Provider Network or HAPN also suggest that the SFDPH is unconcerned about providing the opportunity for all stakeholders to be heard. For example, on September 11, 2009, a HAPN member "pointed out that Celinda Cantu of the AIDS Office has scheduled a meeting of providers to address issues regarding the shift from Reggie to ARIES reporting systems. The meeting is set for Tuesday, September 22, 2009, Conference Room 330A at 25 Van Ness, 10 to 11:30 AM." In other words, a segment of the public, providers of HIV services, were given the opportunity to comment publicly about their concerns. [See HAPN 9-11-09]

However, another segment of the AIDS Community, consumers of services and activists, have not been given the opportunity to express their concerns. During the HAPN meeting on October 2, 2009, its members "pointed out the [problem] of requiring that every client sign the 'ARIES Share Form,' [because] many clients protest this requirement." [See HAPN-Minutes of October 2] This statement is very important because it acknowledges the fact that consumers are concerned about privacy and confidentiality issues and do not want to sign the SAN FRANCISCO LOCAL SHARE MANDATE FORM. More importantly, these consumer concerns are not being heard by the SFDPH.

Furthermore, clients' concerns about privacy and confidentiality appear to be justified. During a recent meeting of the Mental Health Board, there was a directive issued stating, "There was a recent and serious breach of confidentiality by individuals both within DPH and our contractors/affiliates. Please review the following privacy reminders regarding protected health information about our clients and patients. If your program works with contractors, affiliates or partners with Memorandum of Understandings (MOUs), please take time to remind them of the importance of adhering to DPH privacy policies, especially when talking to reporters." The directive also warns that if employees of DPH and their contractors "are contacted by the media or the Public Information Officer regarding a client, do NOT refer them to the program where the client is/was engaged (essentially "outing" the individual as a client of behavioral health services). Media referrals may be made to programs for their general expertise, but not to respond to media questions about identifiable clients. [See mentalhealthboard]

Although the scope of this complaint is not necessarily the issue of privacy and confidentiality of consumers Ryan White CARE Services, the issue still remains that the members of the public, consumers of Ryan White CARE Services, must be allowed the opportunity to comment publicly to relate their concerns about confidentiality and privacy at DPH Privacy Board meetings. In an

email dated October 29, 2009, Ms. Martinez admits, "that the form itself is confusing and problematic and we are checking with the State to see if/how we can change it to be clearer." [See conditions4receivingservices]

I request that these future conversations and discussions, in whatever format, be noticed so that there can be public comment by CARE consumers. Since the consequences of these discussions and actions directly affect more than 20,000 consumers of HIV services, I request that the SOFT order that DPH Privacy Board meetings or meetings concerning ARIES be noticed and open to the public for comment. In other words, I want consumers of Ryan White CARE services, members of the public, to have the opportunity to express their views on issues that directly affect them.

I also requested on October 30, 2009 a copy of the San Francisco Share Mandate Policy in which Maria cited on October 29, 2009. On November 19, 2009, I submitted an Immediate Disclosure Request." I respectfully requested a copy of the "the San Francisco Share Mandate Policy" and the notes taken by SFDPH employees about the concerns and challenges providers were experiencing during the transition from REGGIE to ARIES at the meeting on Tuesday, September 22, 2009, Conference Room 330A at 25 Van Ness, 10 to 11:30 AM. As of the date of this complaint, neither request was honored. I have not received a copy of the San Francisco Share Mandate Policy or the notes taken by SFDPH employees about the concerns and challenges providers expressed at the September 22, 2009 meeting.

If you have any further questions, please feel free to contact me via email. Thank you.

Sincerely,

dphprivacyboard.rtf San Francisco's Local Share Mandate Form (English).pdf cdph8693.pdf

ARIESShareNonShareClientProvInfoDoc.pdf reggie narrative.pdf Hapn 9-11-09.doc HAPN-Minutes of October 2.doc

mentahea&hboard. conditions4receivingservice.rtf

hide details Nov 3 (3 days ago)

Mr. Banks,

The DPH Privacy Board is not a legislative body covered under the Brown Act

(Govt. Code §54952(b)). Its role is to implement HIPAA and other federal, state and local laws/policies regarding client and patient confidentiality.

Over the next few months, as I noted before, we will be addressing the form itself.

Regards, Maria

Maria X Martinez, Deputy Director and Privacy Officer - 415-255-3706 Community Programs, SF Department of Public Health 1380 Howard St., SF, CA 94103

DPH e-mails sent to and from personal email accounts or outside the DPH/UCSF servers are not secured data transmissions for Protected Health

Information (PHI), as defined by the Healthcare Portability and Accountability Act (HIPAA). It is the responsibility of all parties involved to take all reasonable actions to protect this message from non-authorized disclosure. This e-mail is intended for the recipient only. If you receive this e-mail in error, notify the sender and destroy the e-mail immediately. Disclosure of the PHI contained herein may subject discloser to civil or criminal penalties under state and federal privacy laws.



#### ARIES Client Consent Form for San Francisco

In addition to providing information, I will provide an original letter of diagnosis signed and dated by my doctor or have a blood test that shows that I am HIV positive. I understand that I will also need to answer questions about my income. By signing this form, I state that I live in San Francisco or intend to reside there.

I understand that certain services may be available to HIV-negative partners, family members, or other caregivers affected by HIV, and registration and service information for these clients will not be shared between agencies regardless of my own share status.

SHARE: By signing below, I understand my registration information will be shared with other agencies I receive services from that are part of ARIES. Only authorized personnel at an agency will have access to my information on a need-to-know basis. The information shared may include information about services received or my treatment at a particular agency. Mental health, legal and/or substance abuse services will only be shared as allowed by law. By stating that my information will be shared, I will usually not need to re-register (in ARIES) or provide a letter of diagnosis when I require services from an agency providing services funded by the Ryan White CARE Act or the California Department of Public Health (CDPH)/Office of AIDS.

I understand my name and information will not be shared outside the ARIES system unless I provide my specific, informed consent to such a disclosure.

I understand that the information I provide may be made available to my local health department, to fiscal agents who fund the services I receive, and to the CDPH/Office of AIDS for mandated care and treatment reporting requirements, and may be used for program monitoring, statistical analysis and research activities. This information includes, but is not limited to, gender, ethnicity, birth date, zip code, diagnosis status, and service data. No identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.

My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may exclude me from services at other ARIES agencies.

By signing this form I acknowledge that I have been offered a copy of the ARIES Client Consent Form for San Francisco and have talked about and understand my rights to confidentiality with respect to ARIES with the staff person indicated below. I understand that this form will be stored in my paper file.

Signature of Client or Parent/Guardian of Minor Child	Date
For Local Health C	rate Agency Use Only
Administered By	Prency Vane
Signature	Date: United the Community of the Commun
This client is a NON-SHARE client because (check all that apply) . Unab	are Agency Use Only  Agency Name  Date:  Date: Hity Negative

LSM 8693 (8/07)



## **ARIES Client Share/Non-Share Consent Form**



the Ryan White CARE Act or the California Department of Public Health (CDPH), Office of AIDS. During registration, I will be asked to provide information about myself, including my name, race, gender, date of birth and other demographic data. Depending upon the agency or program I am registering with, I may also be asked questions about my CD4 cell count, viral load, use of HIV medications, my general physical and medical condition and other medical history questions.
In addition to providing information, I will provide an original letter of diagnosis signed and dated by my doctor or have a blood test that shows that I am HIV positive. I understand that I will also need to answer questions about my income. By signing this form, I state that I live in the California County I am seeking services from, or intend to reside there.
I understand that certain services may be available to HIV-negative partners, family members, or other caregivers affected by HIV, and registration and service information for these clients will not be shared between agencies regardless of my own share status.
SHARE: By checking the "share" box below, I choose to share my registration information with other agencies I receive services from that are part of ARIES. Only authorized personnel at an agency will have access to my information on a need-to-know basis. The information shared may include information about services received or my treatment at a particular agency. Mental health, legal and/or substance abuse services will only be shared as allowed by law. By stating that I am willing to share my information, I will usually not need to re-register (in ARIES) or provide a letter of diagnosis when I require services from an agency providing services funded by the Ryan White CARE Act or the CDPH/Office of AIDS.
NON-SHARE: By checking the "non-share" box below, I choose not to share my information with ARIES agencies that I go to for services. If I do not want my information shared between ARIES agencies, I will provide all ARIES registration and other information, including an original letter of diagnosis, to each agency that I go to for services.
l choose: Share Non-Share
I can change my decision about sharing/not sharing by informing the staff at any agency where I go for service and by signing a new ARIES Client Share/Non-Share Consent Form. I understand that changing from Non-Share to Share opens my ARIES record to other ARIES agencies I receive services from. No matter what I choose, my name and information will not be shared outside the ARIES system unless I provide my specific, informed consent to such a disclosure.
Regardless of my share/non-share status, I understand that the information I provide may be made available to my local health department, to fiscal agents who fund the services I receive, and to the CDPH/Office of AIDS for mandated care and treatment reporting requirements, and may be used for program monitoring, statistical analysis and research activities. This information includes, but is not limited to, gender, ethnicity, birth date, zip code, diagnosis status, and service data. No
identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.
identifying information, such as name and social security number, will be released, published, or used against me without my
identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.  My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may
identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.  My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may exclude me from services at other ARIES agencies.  By signing this form I acknowledge that I have been offered a copy of the Share/Non-Share Consent Form and have talked about and understand the choices of sharing or not sharing with the staff person indicated below. I understand that this form
identifying information, such as name and social security number, will be released, published, or used against me without my consent, except as allowed by law/or to ensure compliance with policy.  My registration in ARIES does not guarantee services from any other agency. Wait lists or other eligibility requirements may exclude me from services at other ARIES agencies.  By signing this form I acknowledge that I have been offered a copy of the Share/Non-Share Consent Form and have talked about and understand the choices of sharing or not sharing with the staff person indicated below. I understand that this form will be stored in my paper file.
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CDPH 8693 (8/07)

Signature



## AIDS Regional Information and Evaluation System (ARIES)



#### What Is ARIES?

The AIDS Regional Information and Evaluation System (ARIES) is an HIV/AIDS web-based computer system that is used by agencies who receive HIV/AIDS money from the State and Federal government (through the Ryan White CARE Act). Agencies who receive money from the CARE Act must keep track of the clients they see and the services they provide to those clients; ARIES helps agencies carry out this task. By entering information into ARIES, it will be easier for the agencies you see to plan and manage your care.

#### To Share Or Not To Share?

You will be able to choose whether or not you want the agencies you see for services to share your information with each other. When making your decision you need to consider the benefits of sharing your information vs. not sharing your information. Once you make your decision, you will need to sign the ARIES Share/Non-share Form.

## What Are The Benefits Of Share VS. Non-Share?

You have the choice to either share your data or not share your data between agencies. When you first go to an agency for services, they will ask you if you want to share your data.

## Choosing the Share Status

If you agree to share your information with other agencies, ARIES will help you get services more easily. While you will still have to go through the normal client intake process the first time you go to an agency for services, ARIES may cut down the amount of paperwork you need to fill out when you go to other agencies for services. This will also help agencies work together to provide you with the services you need. You will have to sign a form at each agency to let them know that you agree to share your information, but you won't need to complete most of the same forms more than once. By sharing, you won't have to give the same basic information like address, phone number, race, etc., over and over again to each agency. The system works best for you if you choose to share your information because the registration process will be easier when you go to more than one agency for services. Important: only the agencies you go to for

# services will be able to see your information. Agencies that you have never visited for services will never see your information.

#### Choosing the Non-Share Status

If you decide not to share your information with other agencies, you will still need to sign a form when you first come to an agency for services. You will need to provide all of your information each and every time you go to a new agency just like you do now. You will also have to give each and every agency your most recent information each time you go in for services.

You have the right to change your mind about sharing your information at any time. If you choose not to share your information at first, but later decide you do want to share your information, all you have to do is tell your provider. They will ask you to sign a new consent form. The appropriate agency staff can then go into ARIES and indicate that you have changed your mind and would like to share your information. If you change from share to non-share, the information collected from that date forward will not be shared.

It is important to note that regardless of your share or non-share choice, fiscal agents and public health departments may see your data to meet their funding and reporting requirements. Your confidentiality is always safe in these instances. No identifying information, such as your name and social security number, will be released, published or used against you without your consent, except as allowed by law or to ensure compliance with policy.

## What Does Sharing My Information Mean? How Does It Work?

If you choose to share your data, you must sign a form that says you are allowing that agency to share your information with other agencies you go to for services. Only agencies you see for services can view your information. When you go to an agency for the first time, they will ask you if you have already received services from an agency that uses ARIES. If you have already been to an agency that uses ARIES and you are a share client, your information will come up on the computer after you give the agency some important information. In ARIES, this information is called the *client keys*. These keys are important because there are certain letters and numbers from each of the keys that make up a unique client ID for you. This client ID is how ARIES tracks you in the system. The client keys consist of the following:

- 1) First Name,
- 2) Middle Initial,
- 3) Last Name,
- 4) Date of Birth,

- 5) Gender, and
- 6) Mother's Maiden Name.

Once the computer finds your record, you won't have to give your information all over again when you go to a new agency for services that also uses ARIES. You must remember your client keys the exact same way each time you go into an agency. For example, if you go to one agency for services and you tell them your name is Bob but later go into a different agency for services and tell them your name is Robert, ARIES will not be able to find you in the system. You must use the same "keys" at all agencies where you receive services. If your keys are not the same, ARIES will create more than one record for you in the system, thus making it harder for agencies to correctly identify and serve you.

### Why Does ARIES Use Mother's Maiden Name?

ARIES uses mother's maiden name simply because it's specific to you and easy for you to remember. It's in no way related to your banking and/or financial records. In addition, ARIES only stores the first and third letter of your mother's maiden name—not the entire name—as a way to uniquely identify you in the system. If your mother's maiden name is Jones, for example, only the letter J and the letter N would be stored in ARIES as part of your *client keys*.

Client keys are important because they make you unique in ARIES. Providers use these six pieces of information to look you up in the system. This ensures that each agency looks up YOUR data in ARIES and doesn't get you mixed up with other clients. The federal government branch called the Health Resources and Services Administration (HRSA) first came up with the idea of a unique client identifier. HRSA used: first name, last name, date of birth and gender. This client identifier, however, did not prove to be as unique as they had hoped particularly in large states like California, Texas, and New York who have a large number of people living in one state. To make sure the client identifiers or keys are unique to you, it was necessary to add on other pieces of information; thus, mother's maiden name and middle initial were added.

Furthermore, only certain employees at the provider agency are allowed to see your client keys in ARIES. If one of these employees pulls up your client keys, ARIES will not show them the mother's maiden name. ARIES always hides MMN.

## Is My Information Safe?

Your information is <u>very</u> safe in ARIES. In fact, your information is more secure in ARIES than your on-line banking information! The California State Office of AIDS (OA) must approve each staff person before he or she is allowed to go into ARIES.

Each staff person is given a "digital certificate" before they can go into the system. The digital certificate is linked to their own name and password. The digital certificate also checks to make sure that provider staff are using State approved computers. This means that staff who use ARIES cannot get into ARIES from any computer they want to. For example, they cannot go to a public library to get into ARIES. OA does not approve computers that are used in public places. This is not true of Internet banking systems: banks allow you to access your information from any computer as long as you know the user name and password. But for ARIES, only specific approved computers and approved staff will be allowed to use ARIES.

Once staff have been approved to use ARIES, they are given permission to view very specific information - only the specific information they need to know about you. Information such as mental health, substance use, legal issues are available to a very limited and approved group. This information is never shared between agencies in ARIES, even if you have agreed to share your information.

ARIES also uses encryption when storing your information. This means that the information that identifies you in ARIES (for example, your six client keys mentioned earlier as well as your address, telephone number, etc.) are jumbled or scrambled in the system. Only certain approved users have the keys to unscramble the data. Encryption is also used to scramble information as it travels across the Internet. If hackers try to get your information as it travels across the Internet lines, they would not be able to read any information since it is scrambled.

ARIES also uses firewalls to protect your information. A firewall is a piece of computer software used to prevent hackers from getting into or seeing system information. ARIES uses three firewalls to ensure your data is stored safely.

## Who Can I Call If I Have More Questions?

You may contact you local provider agency if you have more questions or concerns about collecting and storing your information in ARIES.

You can also read more about ARIES by visiting the California State Office of AIDS' website at: <a href="http://www.dhs.ca.gov/aids/Programs/ARIES/default.htm">http://www.dhs.ca.gov/aids/Programs/ARIES/default.htm</a> or <a href="http://projectaries.org">http://projectaries.org</a>

PROJECT NARRATIVE

98036

980376

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 sires 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).

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- 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 63 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 needlest 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 12/h/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.

# Hapn 9/11/09

# Minutes of September 11, 2009 Meeting

I. <u>Introductions, Minutes Approval</u>: Mike Smith,
President, called the meeting to order and introductions were made and the August minutes were approved.

Federal, State and City Overview: Mike Smith noted that he would be departing for Washington later in the day for the CAEAR Coalition meeting and to meet with legislators regarding the Ryan White CARE Act, which is set to expire on Sept. 30 unless Congress acts on a new version which is now being drafted.

Courtney Mulhern-Pearson (SFAF) took the floor to talk about state and local political actions, noting that the Steinberg lawsuit against the governor over his 'personal cuts' powers has not received much attention but is still moving forward. Courtney added that it appears that the city will hold off on further cuts until October 15 and that there is a possibility that the Board of Supervisors will restore some of those cuts with reserve funds.  $\square$ 

"Laura Thomas said that the council had heard that the <u>DPH</u> cuts may come by October 31 and those cuts would not be retroactive, but that there is no firm word yet from the Board of Supervisors. Laura also explained that the Planning Council has decided that the City would cover State Cuts to HIV Services to make them whole by mid-Octoberif local HIV Services is flat funded, the plan is to use CARE money to backfill general fund contracts to make them whole."

Courtney noted that she is gathering important information on the effects of the state cuts on clients and services, culled from news stories. She asked

that providers relay stories and data to her and keep them on file, so that we can use them in advocacy efforts. Courtney and Michael Strain to send separate message to HAPN members on this topic. Courtney added that Ernest Hopkins has reported that he expects the Appropriations Committee to act on the CARE Act shortly and that the re-drafting of the language regarding needle exchange sites is moving forward – SFAF staff are working with Nancy Pelosi's office on this, since the 1000 feet restriction, as written, is too restrictive for many urban EMAs. The re-draft language allows greater local control on the location of the sites. She also noted that there have been two meetings with Sen. Feinstein's staff and if this goes through, it represents a 'big win' for San Francisco.

III. <u>HIV Services Planning Council</u>: Laura Thomas expanded on her earlier comments about the Council. She noted that the Council held its annual Prioritization/Allocation Summit in August and that although there were no changes to the priority order of service categories, two categories were added: Early Intervention Services and Therapeutic Monitoring, two categories that have been de-funded by the state.

Funding Scenarios: Laura stated that stop-loss funding is here now – the \$4M of new unallocated dollars for next year, which was authorized via Speaker Pelosi's office, came through and was used by the County (as we expected). After that, \$1.5M was used to pick up programs that were defunded by the State. The plan is to put those state programs into the system and then to cut across the board as needed for

FY 2010 that begins on March 1. Laura also said that if there is increased funding, the priority is to make everything whole, including the \$300,000 cut to the Denti-Cal program. Laura pointed out that this all ties into the CARE Act, since we may be looking at flat-funding next year. She pointed out that hearings are set on Capitol Hill next Wednesday regarding the funding mechanism – at GAO and HRSA.

IV. Ryan White CARE Act: Mike Smith returned to this topic - he noted that congressional staff working on the new bill have used the Consensus Document (put forward by the CAEAR Coalition and others) as the basis for a first draft with a general agreement by HRSA, although HRSA prefers a 4-year bill, versus the 3-year, to avoid the election cycle. Mike added that HRSA agrees that EMAs need more time to convert their reporting from names-based to codes and there should be a hiatus to give folks time to catch up. Hold Harmless Clause: Although we had hoped that last year would be used as the base, it looks like this year's number will be used and this means the formula will be down by 5%. There is also a proposal being discussed to eliminate the EMA/TGA (urban vs. non-urban) distinction, Mike commented that this would be healthy in the longterm, but not helpful in the short term to San Francisco. Mike also noted that since the current round of meetings in Washington start on Monday, there is likely to be not enough time (or attention, given the focus on the national health care debate) to get the new CARE bill written and acted on before the Sept. 30 deadline. He added that the process also means that the bill will be 'nibbled on' from both sides. Meeting with Scott Bouley: Mike reported that members of the HAPN Executive Committee met recently with Mr. Bouley, of Speaker Pelosi's office, and that Scott is pessimistic about action on the Ryan White bill in the Senate by the 9/30 deadline.

## V. Announcements:

- 1.) Bill Hirsh announced that some federal stimulus funding for housing subsidies with some legal assistance has come through. The grant totals about \$2M over a 3-year period. Bill pointed out that ALRP is included, as well as AIDS Housing Alliance and Catholic Charities. George Simmons (CCCYO) noted that the Catholic Charities part is geared towards families and is patterned on the Season of Sharing model (applicants submit applications, which are reviewed by a panel). Bill pointed out that the contracts start on October 1.
- 2.) Bill Hirsh also announced that recent state cuts and changes to the IHSS (In Home Supportive Services) program will have a great impact on HIV+ clients and other disabled adults and seniors. The cuts will impact 8,000 individuals in San Francisco where 2,000 people will be cut from the program and 6,000 will have their services reduced. He pointed out that clients who receive those services will be receiving a 'notice of action' letter and those folks should follow the appeals process via Medi-Cal, County and State (services will continue during the appeal). Planning for Elders is scheduling trainings for providers. Bill Hirsh and Michael Strain will send out a document outlining this process with information on the trainings.
- 3.) ALRP has an opening for a staff attorney position. Contact Bill Hirsh at: 701-1200x308 or bill@alrp.org.
- 4.) Ernie Somers at St. Mary's Clinic pointed out that Celinda Cantu of the AIDS Office has scheduled a meeting of providers to address issues regarding the shift from Reggie to

ARIES reporting systems. The meeting is set for Tuesday, September 22, 2009, Conference Room 330A at 25 Van Ness, 10 to 11:30 AM.

- 5.) St. Mary's Clinic has an opening for an HIV Specialist. This clinic is seeking an M.D. or Mid-level clinicial (NP). Please contact: Ernie Somers at 415.750.5690
- 6.) Catholic Charities CYO has funds available to assist HIV+ clients with medical expenses through the Angels of Health fund. Contact George Simmons at 972-1344 or <a href="mailto:gsimmons@cccyo.org">gsimmons@cccyo.org</a>.

The meeting was adjourned at 10:15 a.m.

Attendance: Mike Smith, Pres. (AEF & BCEF); Bill Hirsh, Sec. (ALRP); George Simmons (Catholic Charities CYO); James Elerick (Larkin St. Youth Svcs.); Maritza Penagos (Mission Neighborhood Health Center); Ernie Somers (St. Mary's HIV Clinic); Courtney Mulhern-Pearson (SF AIDS Foundation); John Nyquist (Walden House); Laura Thomas, Michael Strain. Guests: None.

## 2009 Meeting Dates

9:00-10:30 a.m., 730 Polk Street, 4th Floor conference room.

[Generally, the first Friday of each month.]  $\Box$ 

Friday, January 9, 2009 (2<sup>rd</sup> Friday)

Friday, February 6, 2009

Friday, March 6, 2009

Friday, April 3, 2009

Friday, May 1, 2009

Friday, June 5, 2009

Friday, July 10, 2009 (2<sup>nd</sup> Friday)

Friday, August 7, 2009

Friday, September 11, 2009 (2nd Friday)

Friday, October 2, 2009

Friday, November 6, 2009

Friday, December 4, 2009

## Minutes of October 2, 2009 Meeting

State Budget News: Rumors & Innuendos: Courtney Mulhern-Pearson stated that the Mayor's office had recommended that the city backfill most of the State's cuts to HIV Services in San Francisco, by Oct. 31 (follow-up to Laura Thomas Council action above). Courtney reminded members that the Board of Supervisors must act on the Mayor's proposal, so this news is not definite at this point. Courtney also said that the Matier & Ross column in the Chronicle has opined that the city budget may not be as bad as expected. She also pointed that the EIP (early intervention project) funding is also expected to be backfilled by the city. Courtney informed the group that APLA has filed an amicus brief regarding the Governor's recent cuts post-budget and that other lawsuits (5) have also been filed in that matter; and in other state news, Courtney noted that the ADAP funding may still be in jeopardy due to the fact that at its current level, it will hit a crisis point sooner because of the way the cuts have been taken. Courtney again appealed to providers for stories from clients on the effects of the cuts (see

announcements).

- III. HIV Services Planning Council: Laura Thomas announced that the annual joint meeting of the HIV Services Council and the HIV Prevention Council is set for Thursday, October 8, at the Bahai Center on Valencia Street. Randy Allgaier, former Co-Chair of the HSPC, noted that the HIV Service Planning Council has joined with the LongTerm Care Coordinating Council to study how to address the issue of Aging and HIV. The group will meet on the 3rd Wednesday of each month from 3-5 at 25 Van Ness. Contact Randy at <a href="mailto:rallgaier@shanti.org">rallgaier@shanti.org</a> for more information. Randy noted that over 40% of the HIV population in the city are over 40 and have health issues relating to both HIV and aging. The group is looking at how to better serve that population. 

  \[ \]
- IV. ARIES Meeting: [Someone] reported on the recent ARIES meeting, and relayed the expectation that by November everyone will be active on the system. He also said that there was conflicting information about the trainings. Philip Ng of API Wellness reported that the data conversion process (from REGGIE) is difficult, resulting in too many empty fields - not all of the data gets transferred. Mike Smith pointed out that this represents one more 'unfunded mandate' for contractors - since this heavy data burden takes up additional staff time, forcing contractors to invest time & energy into making the system work. He noted that this is a real issue that should be reported to Bill Blum at DPH. Others pointed out the issue of requiring that every client sign the 'ARIES Share Form,' noting that many clients protest this requirement. Mike Smith suggested that we invite Bill Blum to a HAPN meeting to talk about these issues. Maritza Penagos noted that staff at MNHC had to stop mid-process to 'fix' problems with data entry and collection. She also pointed out that a major problem in the system is the accurate reporting of UDC (unduplicated clients) numbers, pointing out that the 'workaround' is a hand count and that accurate monthly reporting is required for invoicing.
- V. White House Office on National AIDS Policy Meeting: Randy Allgaier announced that the Office on National AIDS Policy (ONAP) will be hosting a Town Hall meeting on Friday, October 16, from 6:00 to 8:00 P.M. Randy said that Jeff Crowley of ONAP has been developing the town halls throughout the nation and the goal of the meeting on 10/16 is to hear from direct service providers and clients from the San Francisco Bay Area, including San Jose, Santa Clara, Marin and Sonoma County (there will be another meeting for the East Bay Counties). He said that the meeting's moderators will be Laura Thomas and Perry Rhodes III. Randy pointed out that as soon as a location has been determined, he will send out a message to all providers (M. Strain to assist) with some attachments to help folks prepare for the meeting. The documents that will be sent are an ONAP Call to Action (which outlines the meeting and application process) and a document from the HIV Justice Alliance on how to prepare clients and others to testify (public testimony is limited to one minute). [Note that the announcement has gone out the meeting will be held at the Mission Bay

### Conference Center at UCSF].

- VI. Member Spotlight Project Open Hand: Anne Marie Heineman, Client Services Director, Project Open Hand, gave an overview of the HIV Services program of the agency. She talked about eligibility requirements, scope of services and other details of their meal delivery and grocery center. She pointed out that most HIV+ clients are eligible by providing a form filled out by the client's doctor. The program allows the client to receive groceries once a week at the grocery center and up to 7 meals per week, either by delivery or at the grocery center (this is the equivalent of 1/3 of the nutrition value per week). Anne Marie noted that of Project Open Hand's 3200 clients, 2400 are HIV+; she added that the grocery center services about 450 clients per day and that 600 clients are served via the Ryan White CARE Act. Anne Marie outlined details of the meal delivery program and grocery center. She also pointed out that Project Open Hand has a half-time nutrition counselor who can meet with clients on request to assess their nutrition needs. Discussion: Anne Marie answered questions about other programs at POH, including the homebound non-HIV program, under which severely homebound clients can receive meals for 3-6 months. She also noted that the volunteer program (POH holds trainings for volunteers) at Project Open Hand has about 1,000 volunteers, who work in the kitchen, grocery center and deliver meals. She pointed out that that revised intake form is medical-based, not income-based. Bill Hirsh asked about the appeals process for clients who may be denied services due to behavior or other issues. Anne Marie noted that clients may designate a surrogate to pick up groceries and that POH works with clients to ensure that working things out on an individual basis can provide services. HAPN members thanked Anne Marie and she departed.
- VII. Ryan White CARE Act: Mike Smith reported that the re-drafted Act is moving through both houses of Congress and that, as expected, the act changes daily. Mike pointed out that many communities across the country signed on to the consensus document and much work has been done so that only one bill is going through both houses and that a continuing resolution extended the deadline for the act from Sept. 30 to Oct. 31. Mike also noted that Senators Enzi and Coburn have made an issue of not amending the act to cure the error in the most-recent version of the act, thus requiring Speaker Pelosi to continue to seek the stop loss funds for San Francisco and 7 other EMAs on an annual basis. The House version of the bill includes the 'stop loss' provision, but in the Senate version, the stop loss is carved out. The Bill is now on a 4-year timetable, to avoid the presidential election year, with a provision to provide a hiatus to allow states that are still using code-based reporting to switch to names-based. Mike also said that in both versions of the bill, there are changes to the formulas for TGAs (rural counties). He noted that in general, California would do better with names-based reporting, though some counties can't do surveillance as well as San Francisco. At this point, it appears that the bill will go into a conference committee between the House and the Senate and our best hope is for a compromise bill (versus no bill at all). Mike added that it is almost certain that Speaker Pelosi will have to fight for

the stop loss on an annual basis. Mike  $\square$ 

pointed out that we can expect a real effort in the next several weeks to get the bill passed.  $\Box$ 

VIII. CAEAR Coalition: Mike said that the January meeting of the CAEAR Coalition will focus on the intersection of the Ryan White CARE Act and Healthcare Reform that will be phasing in over 2012-13; and he noted the fact that most of our (low-income HIV+) clients could have some form of health insurance at that point. Therefore, community-based care may have different income streams, with less reliance on Medicaid and ADAP. In the short term, we are entering the last phase of the CARE Act looking as it does now. Discussion: Randy Aligaier pointed out that ADAP can now be used to cover the 'doughnut hole' in the Medicare Part D coverage. Courtney added that the issue of moving towards Medi-Cal funding poses challenges to community-based providers, since most of them are not prepared for the huge increase in paperwork involved in Medi-Cal billing. Maritza Pengaos pointed out that the issues of undocumented clients have not been addressed openly, although most community clinics still serve that client base.

### IX. Announcements:

- Bill Hirsh reminded HAPN members that some federal stimulus funding for housing subsidies with some legal assistance has come through, via AIDS Housing Alliance, Tenderloin Housing Clinic (non-HIV), Larkin Street Youth Services (clients under 25) and Catholic Charities (mostly housing for families). Case Managers should contact the appropriate agencies for more information.
- 2.) Courtney Mulhern-Pearson said that she is still gathering important information on the effects of the state cuts on clients and services, culled from news stories. She asked that providers relay stories and data to her and keep them on file, so that we can use them in advocacy efforts.
- 3.) Stephanie Godt said that Catholic Charities CYO has funds available to assist HIV+ clients with medical expenses through the Angels of Health fund. The contact person for the St. Joseph's Health Fund is Gloria Canas-Simon. Her number is 972-1337.

The meeting was adjourned at 10:15 a.m.

Attendance: Mike Smith, Pres. (AEF & BCEF); Bill Hirsh, Sec. (ALRP); Philip Ng (API Wellness Center); Jimmy Loyce (Black Coalition on AIDS); Stephanie Godt, Kevin Cune (Catholic Charities CYO); Lara Tannenbaum (Larkin St. Youth Svcs.); Maritza Penagos

(Mission Neighborhood Health Center); Nancy Heilner (New Leaf); Jim Illig, Anne Marie Heineman (Project Open Hand); Courtney Mulhern-Pearson (SF AIDS Foundation); Jules Dizon (SF Suicide Prevention/Nightline); Ross Kalmin, John Nyquist (Walden House); David Powell (Westside Community Services); Laura Thomas, Michael Strain. Guests: Randy Allgaier, HIV Services Planning Council.

## 2009 Meeting Dates

9:00-10:30 a.m., 730 Polk Street, 4th Floor conference room.

[Generally, the first Friday of each month.]

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Friday, August 7, 2009

Friday, September 11, 2009 (2nd Friday)

Friday, October 2, 2009

Friday, November 6, 2009

Wednesday, December 9, 2009 Holiday Party

Maria X Martinez <Maria.X.Martinez@sfdph.org>
tomelvin banks <@gmail.com>
ccBill Blum <Bill.Blum@sfdph.org>,
Celinda Cantu <Celinda.Cantu@sfdph.org>
dateWed, Oct 28, 2009 at 9:28 AM
subjectARIES "consent" form

hide details Oct 28 (9 days ago)

Mr. Banks,

I wanted to let you know that I met with Bill Blum and Celinda Cantu yesterday about the form. After reading the Local Share Mandate policy, counties "may require most clients to share their data as a condition for receiving services." There are 3 conditions that would make-up this exception: (1) clients who demonstrate an inability to give consent as documented in the client record (e.g., decreased mental capacity), (2) are receiving services as a related/affected client; or (3) are receiving services as a HIV-negative client. In San Francisco, clients who request their information not be shared are also given an exception. As I mentioned in our phone conversation, HIPAA and state laws allow for HIV treatment providers to share health information with each other for treatment purposes without signed authorization (see attached for references), but the ARIES notice (entitled "ARIES Client Consent Form for

San Francisco") limits this sharing to certain agencies.

In any case, I maintain that the form itself is confusing and problematic and we are checking with the State to see if/how we can change it to be clearer.

Given vacations and extremely short staffing shortages at the state level, I don't forsee us resolving this issue anytime soon. I will be in touch as soon as I have findings.

Maria