



A Standardized System of Client Intake, Monitoring, and Assessment

Prepared for

MULTNOMAH COUNTY HEALTH DEPARTMENT

HIV CARE SERVICES ADMINISTRATION

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1. INTRODUCTION

The goal of this study is to recommend a standardized system of intake and monitoring. The recommended system, at a minimum, will:

- Determine clients' eligibility to receive different RWCA funded services;
- Track clients' status;
- Provide data for evaluation of services.
- Have the capacity to share data between providers contingent on consumer permission.

The following section, **METHODOLOGY**, is the overall methodology of the report and includes a description of the sources of data that provided much of the in-depth information in this report. Protocols and detailed notes of the interviews are shown in Attachment A and Attachment B.

The third section of this report, **SERVICE DESCRIPTIONS AND ELIGIBILITY**, continues with a description of services and eligibility criteria in the Portland EMA, and compares it with the eligibility criteria in four other EMAs: Austin, Houston, Miami-Dade, and San Francisco. It also reviews the eligibility criteria for each of the EMAs as outlined by the Health Resources and Services Administration (HRSA). A brief description of each of the services along with an eligibility matrix comparing Austin, Houston, Miami, Portland, and San Francisco is shown in Attachment D.

The fourth section, **PROVIDER AND ADMINISTRATOR CONCERNS**, reports on the interviews conducted with council, provider, and administrative agents to identify the problems encountered in implementing standardized systems and how the problems were (or are being) solved. It presents highlights of their concerns and recommendations based on the experiences in their respective environments.

The fifth section, **SYSTEMS REVIEW**, provides a system synopsis, which details the system requirements, cost, and applications. It discusses:

- The criteria of an intake and assessment system;
- The problems encountered in implementing automated intake, tracking and assessment systems, standardized systems of intake, and monitoring clients;
- The data elements and service data captured throughout the various systems.

The sixth section, **RECOMMENDATIONS** provides a summary and recommendations based on reviewed systems. It includes a detailed description of each recommended option and basis for the recommendation. This section includes:

- A discussion of the specific advantages and disadvantages of the existing models;
- An evaluation of the various models in terms of their appropriateness/applicability to the Portland EMA;
- A recommendation of key options for models to be considered by the HIV Services Planning Council for the Portland EMA.



2. METHODOLOGY

Three basic methods of data collection were used to review eligibility standards and determine and assess a standardized system of intake and monitoring. These three methods were:

1. A review of existing models for standardized intake.
2. In-depth interviews with Council/administrative agents.
3. A workshop with providers, consumers and grantees.

Review of Existing Information

A combination of web research, referrals from EMA managers and providers, and documentation from HRSA was used as background resources for the selection of software reviewed.

This document presents a wide range of pricing and HIV database software sources available on the market, and reports on the evaluation of database applications from private vendors, government agencies, and not-for-profit organizations.

Eight data collection systems were reviewed as part of this study. While there are a wide range of data collection systems across the country for client reporting, there are a limited number of databases specifically targeted for the use with Ryan White care providers. Many EMAs currently use a combination of paper and electronic media for reporting purposes. This study has focused on the electronic systems that have been used or are being developed to specifically collect and evaluate services funded under the Ryan White Care Act and would, at a minimum, provide data for an AAR report.

In determining the software for review, a broad group of applications were included that allowed a comparison and evaluation of different approaches to data collection and reporting issues that exist at the EMA and provider levels. The review selection criteria included:

- 1) An existing track record of HIV, AIDS, and Ryan White data collection and reporting. With three exceptions, systems included in this evaluation have been used for Title I and/or Title II reporting in more than one EMA.
- 2) A requirement to collect, at a minimum, basic demographic, service and eligibility information. Most of these systems can be customized to meet other Portland requirements. At least four of the applications are comprehensive databases that collect data and generate reports for a wide range of HIV, case management, medical care, referrals, and billing functions.
- 3) A broad range of approaches to HIV data collection and management. For example, systems reviewed included “real time” data collection systems that enable a network of agencies to pool “live” data for referral and service follow-ups, as well as database systems that are housed at individual agencies and do not feature real-time inter-connectivity. Systems reviewed ranged from very basic systems whose main function is to generate Ryan White



reports to more complex systems that produce a wide variety of internal and external reports and billing materials.

In depth Interviews

Interviews were held with ten HIV/AIDS Council, provider, and administrative agents to identify:

- The problems encountered in implementing standardized systems and how the problems were (or are being) solved, as well as
- Any problems in determining and enforcing eligibility criteria.

These interviews were conducted in the second and third weeks of February and were held with the Ryan White Program Directors/Coordinators from Austin, Houston, Miami-Dade, Portland, and San Francisco EMAs. In addition, four interviews were held with service providers in the Portland EMA. One additional interview was conducted with a case management provider in Seattle, WA who has experience using one of the data systems assessed in this study.

Table 1 shows the individuals who were interviewed for this project.

Table 1 In-depth Interviews

EMA	Position	Name	System Used
Austin	Grants Manager	Bob Sendera	Compis
Houston	Title I – Grantee – Administrative Agent	Charles Henley	Compis
Miami	Title I – Grantee – Administrative Agent	Yocasta Juliao	ACMS –Casewatch
Portland	Title I – Grantee – Administrative Agent	Steve Bardi	RWCareware
Portland	Central City Concern – (PAHC) Program Manager	David Eisen	R-base
Portland	Partnership Project – Executive Director	Becky Harmon	Partnership Project Client Management System
Portland	Cascade AIDS Project – Deputy Director	Dan Bueling	Access
Portland	Multnomah County HIV Clinic – Executive Director	Donna Cassidy	HIV Information System Case Management Network Social Work Database (3 separate systems)
San Francisco	Database Administrator, Dept. of Public Health Division of Community Health and Safety:	Steve Solnit	Reggie
Seattle	Harbor Univ. Medical Center – Case Management Program	Pam Ryan	Provide



The interviews were semi-structured and were conducted over the telephone. The interview protocol is shown in Attachment A. Attachment B presents a summary of the interviews conducted with each of the individuals listed above.

In addition, initial one-on-one interviews with follow-up discussions and software demonstrations were held with the following vendors/developers.

Table 2 In-depth Interviews – Vendors and System Administrators

Vendor/System	Name
Abilitech	Mr. Sam Samat
AIDS Institute URS	Ms. Vida Behn
Casewatch	Ms. Andrae Corrigan
Central Patient Care Data Management System	Mr. Bob Ferguson Mr. Patrick Birch
Compis	Ms. Eileen Killoren
ECHO	Mr. Joseph Viger
Provide	Ms. Cheryl Hass-Vaughn
RWCareware	Dr. John Milberg

Workshop

A workshop with service providers, grantees and consumers was held on March 8, 2000. During this session, PCH presented the findings and recommendations of this project and solicited participant input. The goal of the workshop was to review the draft report and discuss standard eligibility criteria and different systems to determine appropriateness and applicability to their clients, organizations and EMA. Participants of the workshop are shown in Attachment C.



3. SERVICE DESCRIPTIONS AND ELIGIBILITY

For a system to record and determine eligibility, there must be clear definitions of services and unambiguous criteria for eligibility. The service categories used in Portland and their corresponding units of care are shown in Table 3 below.

Table 3 Services & Unit of Measurement

SERVICES AND SUB-SERVICES	UNITS OF SERVICE
Buddy/Companion Services 1.1 Practical support services 1.2 Emotional support services	Hour Hour
Case Management 2.1 Face-to-face encounters 2.2 Other encounters	15 minutes 15 minutes
Client Advocacy 3.1 Advocacy services 3.2 Advocacy targeted to Latinos	Contacts Contacts
Complementary Health Care 4.1 Acupuncture treatments 4.2 Naturopathic treatment 4.3 Massage treatments 4.4 Herbs and nutritional supplement vouchers	Visit Visit Visit Voucher
Day Care 5.1 Day care program 5.2 Meals in group setting	Visits Meal
Dental Care 6.1 Clinic visits 6.2 Lab tests	Visit Test
Direct Emergency Financial Assistance 7.1 Assistance with utility payments 7.2 Assistance with medication, health aids and other emergency personal needs 7.3 Phone cards	Payment Payment Cards
Drug Reimbursement 8.1 AIDS Drug Assistance Program payment for prescription medications	Payment
Food Bank/Home Delivered Meals 9.1 Home delivered meals 9.2 One-to-one nutrition counseling 9.3 Nutritional supplements (for example, Ensure) 9.4 Food bank/pantry	Meal Visit One can or packet Food boxes
Health Insurance Continuation 10.1 Insurance premiums paid	Premiums paid
Housing Assistance 11.1 General 11.2 Information and referral – emergency housing 11.3 Intake assessment 11.4 Eviction prevention assistance 11.5 Weekly motel vouchers 11.6 Rental assistance payments 11.7 Deposit and application fee payment assistance 11.8 Transitional housing	Contacts Contacts Sessions Contacts Weekly voucher Payment Payment Units/resident days
Home Health Care 12.1 In-home medical services 12.2 In-home personal care and homemaker services	Hour Hour



SERVICES AND SUB-SERVICES	UNITS OF SERVICE
Legal Services 13.1 Legal consultation with lawyer 13.2 Legal referrals	Contact Contact
Mental Health Therapy 14.1 Intake assessments 14.2 Individual, couple and/or family therapy sessions 14.3 Group therapy sessions	Sessions Sessions Sessions/Contacts
Outpatient Medical Care 15.1 Clinic visits 15.2 Lab tests	Visit Test
Outreach for Services 16.1 Outreach with agencies, community organizations and providers 16.2 Outreach at community events 16.3 Outreach with at-risk populations (one-on-one) 16.5 Outreach with at-risk populations (group) 16.6 Outreach to persons with HIV (one-on-one) 16.7 Outreach to persons with HIV (group)	Contacts Event Contacts Groups Contacts Groups
Health Education and Risk Reduction 17.1 Outreach to at risk populations 17.2 Interventions to reduce risk/spread of HIV (one-on-one) 17.2 Interventions to reduce risk/spread of HIV (group) 17.3 HIV Counseling and Testing 17.4 Needle Exchange*	Contacts Contacts Groups Test Contacts
Residential Care 18.1 Long-term residential care services 18.2 Hospice (end stage) services 18.3 Occupational therapy 18.4 Physical therapy	Resident day Resident day Visit Visit
Targeted Services for Women & Children 19.1 Outreach and advocacy services 19.2 Child care	Contacts Hours
Substance Abuse Treatment 20.1 Outpatient treatment 20.2 Alcohol and drug free housing for clients in outpatient treatment	Hours Units/Resident Days
Transportation 21.1 Direct transport of client to appointment 21.2 Bus passes 21.3 Bus tickets 21.4 Gas vouchers	Round-trip transport Pass Ticket Voucher
Other Counseling 22.1 Peer Counseling 22.2 Support Groups 22.3 Nutrition Education	Session Session Session
General 23.1 Newsletters 23.2 Telephone information & referral	Newsletter Contacts

* Part of continuum of care but not funded under Ryan White Title I.



A brief description of each of the services along with an eligibility matrix comparing Austin, Houston, Miami, Portland and San Francisco is shown in Attachment D.

Across the five EMAs examined for this project, eligibility for services was based on the three factors set forth under the HRSA guidelines. The three factors were: 1) an HIV positive diagnosis; 2) income within specific federal poverty levels (FPL); and 3) geographic residency. There was variation in the degree of poverty required to qualify for specific services, with some services not basing eligibility on income while others allowing incomes of up to 500% of FPL. While there was also some variation in eligibility by the stage of HIV disease, most services were open to all HIV positive individuals, without specifying the stage of their infection. The exceptions included services that often required the client to have an AIDS diagnosis or have “disabling HIV.” These included emergency financial assistance, respite care, adult day care, home health care, hospice care and housing.

In four out of five of the EMAs, PLWH/A access most services only through a case manager. That is, a client has to be case managed within one of the organizations and in most cases an individual can have only one primary case manager. While this is also the case for Title II funded services in Oregon, it is not the case in the Portland EMA. In Portland clients are not required to have a case manager to access services.

In addition to discussing the eligibility criteria presented in Attachment D, each of the five EMAs were asked to discuss the acuity scales used in their determining client eligibility or creating client service plans. *None of the EMAs reported using acuity scales.* However, two case managers interviewed were familiar with acuity scales and felt they were too complex and often failed to adequately reflect the needs of the clients.

One of the data collection systems reviewed as part of this project, Abilitech, presents predefined fields to capture acuity measures which correspond to measures used by AIDS Action, an ASO in Philadelphia. AIDS Action’s Acuity Assessment Tool is shown in Attachment E.



4. PROVIDER AND ADMINISTRATOR CONCERNS

Based on interviews with providers and administrators of Ryan White Emergency Funds, several items were highlighted that would increase the chances of success for the development and implementation of an intake and tracking system. They included:

- Provider and staff input into the design, implementation, and utilization of any system results in the recognition of the needs of the provider, and encourages provider and staff support of the system.
- While encouraging provider input, EMA administrators must keep the data collection system focused, relevant and easy to use for its providers.
- The system must protect client confidentiality.
- The system should provide feedback about clients to agencies on a timely basis, and it should be capable of generating reports that meet both the internal data needs and the external reporting requirements for providers.
- Scaled systems have to be created that match the system requirements with the size, computer sophistication, and resources of agencies.
- Newly created or adopted systems must be compatible with existing systems.
- Technical assistance and training is a key component of any successful software implementation, and must be carefully planned and organized.
- For a centralized system to be implemented, providers must see an advantage to sharing information/clients with other agencies.
- A plan detailing who and how to update the system must be created.
- Quality control issues, i.e., how data problems are handled and who is responsible for overseeing quality assurance, must be dealt with thoughtfully.
- Cost benefit analysis of the size and maintenance of the system are significant considerations.

Provider and Front-line Staff Input into Need Assessment and Design

Providers interviewed strongly felt that they should have input into determining the need and the design, implementation and management of any intake, tracking, and monitoring system. Past experience reveals that the systems with a higher degree of provider buy-in, ranging from administrators to front-line personnel, have a greater chance of being successfully implemented and adopted.

One of the EMAs told of the evolution of their system development. It started from addressing individual provider needs where the approach was to adopt current tracking systems at different agencies to meet HRSA data requirements. Consultants modified existing systems and incorporated HRSA data elements into them. In a couple of cases it was necessary to develop new databases for agencies. The end result of that effort was a high maintenance system where every agency had its own custom database, but each database included at least HRSA required elements.

Given the high cost of maintaining multiple agency databases and inability to share and aggregate data, this particular EMA funded the development of a centralized database. The advantages would be lower maintenance cost and ease of data sharing; however, when a



centralized system was developed, it did not respond to provider and consumer concerns. In retrospect, administrators and providers agree that providers had little input into assessing the need and design of the central database. One reason for its slow adoption and poor utilization was that providers had no buy-in, and providers had little incentive to change to a new system. Currently, developers are "back to the blackboard" trying to configure a system that meets provider and consumer needs.

In another EMA, the decision making and implementation process took approximately six months. In this case, the EMA had already reached consensus about a basic need to unduplicate clients and to develop uniform intake forms for use by their four case management agencies. The question was, "which system to implement?" Unfortunately, front line staff who would be responsible for data entry were not included in the decision making process. The database that ultimately was selected was interactive and fairly complex, requiring considerable training. In addition, it was adopted from another EMA with a different model of case management. Consequently, case managers sometimes did not agree with the "system's" treatment recommendations. Also, even after an extensive decision making process between the administrative agencies and the providers, the front-line staff were ready to walk out. The system is currently being reassessed in that EMA, and it is likely that a more basic system will be implemented that is less proscriptive and interactive.

From the administrators' viewpoint, a standardized database system has to have nearly universal compliance to be useful. As one administrator said, "One thing to keep in mind for planning and evaluation is that it's hard to study data when you don't have all the providers on board. It hurt us that only 22 of 65 providers were on board." In the beginning, this administrator noted, "It's important to strategize about who to bring on first. It probably takes a few years to bring everybody on, and we went after large providers, and also picked providers who could give us a good cross section so when we did look at data we wouldn't leave out entire communities."

Database systems must be kept focused, easy-to-navigate and relevant

While it is necessary for EMA administrators to solicit feedback and to build support among providers, they must maintain a delicate balancing act. If they add too many data elements to a software system in their attempt to satisfy all provider requests, they run the risk of creating a cumbersome database that is difficult to use. Administrators must stay focused on the goals of their information system.

Client confidentiality

Safeguards protecting client confidentiality are a critical part of any system. Providers and administrators noted that one of the biggest barriers in developing a shared data system, both internally among departments and among agencies, is the feeling that client confidentiality would be compromised. Providers reported that building the trust of clients was an essential part of their service. If clients perceived that a data collection system violated that trust, then the result would be an inability of the agency to serve their clients. Clients are rightfully suspicious, many providers noted. Across the EMAs reviewed, numerous instances were reported where client confidentiality had been breached and clients had suffered discrimination in their



community, work, and services. (Notably, most instances were not the result of breach in computer security, but rather the distribution of names or lists once they were printed.) Some providers believe that administrative agents "tend to run roughshod over confidentiality concerns." Some providers say that sometimes the administrative mentality of "a client gets public funding so they don't have any rights" undermines their ability to serve clients.

Providers and administrators also believe that clients should be given a choice between the strictest confidentiality and the convenience of allowing some data to be shared across agencies, thus reducing duplicated eligibility documentation and the time necessary to conduct intakes and to obtain medical histories. A couple of the administrators noted that historically about ten percent of clients choose not to share private information, and that advocates concerned about confidentiality are a vocal but small minority.

A unique identifier for each client is part of every system. Most agencies use the HRSA standard, but some providers are concerned that unique identifiers provide inadequate protection. For example, one provider said, if you know the name, DOB and gender, you can find out with some certainty if the client is in the database. Hence, there is a need to encrypt the unique identifiers and keep the codes in a separate and protected database.

In systems under development, administrative agents said they took several measures to assure the system was very secure. They incorporated the certificate of confidentiality from HRSA, which protects data during a predetermined time period and guarantees to providers and clients that the data would not be subpoenaed. Administrative agents said that the perception that the system developers were seriously looking at issues of confidentiality helped give the administration more legitimacy.

Although concerns about confidentiality are multi-tiered, they can be addressed by technology and staff training. At a minimum, each provider should have a user name and password in order to log-on to the system. However, an agency-wide log-on is inadequate. Users also have to have individual passwords, with different levels of access to data, based on "need to know." Providers and administrators expressed a strong preference for systems that allowed multiple levels of user access. For further protection, some of the people interviewed suggested that there be an auditing function built into the system where it is possible to track who viewed what in the system. In one system under development, the system will be able to produce auditing reports of which users were looking at which clients.

System administrators noted, however, that many breaches in security are due to staff leaving computers on with access to client information, leaving names or lists of PLWH/A on their desks or in open files, and other procedural lapses.

One goal of an intake and tracking system is the reduction of red tape through the sharing of client information. Yet several administrators, providers, and system developers say that clients must be given the choice of what, if any, of their data would be seen by other agencies. While each provider can access its own information, access by other agencies would be limited to data that is "needed." Exactly what key data elements are needed by different agencies would be determined based on essential information to provide a specific service. Deciding on what data



elements are to be shared requires negotiations, letters of agreement, and collaboration between providers.

Ability of the system to provide accurate feedback and utility of reports

Those interviewed agreed that any system has to provide needed feedback on data to assist them in internal management, demonstrate the accuracy of the data, and to show them that their efforts to track clients are actually being used. A recurring theme during the interviews reported by administrators as well as providers was that providers were constantly putting an extensive effort into reporting, yet, they felt like they were simply dumping data into a black hole. Further, some comments indicated that because there have been few quality checks, providers have learned that they can submit inaccurate data and that it's not detected because, in their opinion, nobody is really looking at the data. One EMA noted that feedback loops served to motivate agencies to use the system. The system administrator noted, "When providers see data on an agency or EMA, they tend to report more accurately."

Several provider and administrative agents interviewed expressed a desire to use data for their own management and planning purposes. Many of those interviewed said that the easier the system was to extract data for their use, the more likely the system was to be adopted. Administrators and providers often required more information than HRSA mandated. They wanted to know, for example, which department saw clients, and they needed additional demographic information, including sexual orientation.

Providers and administrators were aware that a good system would provide an opportunity to do local evaluation. But, it also required a substantial effort to define a good set of evaluation questions which was often outside the expertise or resources of line agencies. One EMA reported that they spent six months bringing data specialists, epidemiologists and managers to define sets of questions and the related data elements necessary to answer them. Providers as well as administrators were concerned with the ability to measure co-morbidities such as TB and drug use, and to investigate the types and frequency of behavior that put clients at risk for disease progression. Once the data elements were defined, front line staff input was elicited to develop wording of questions on forms that they felt comfortable with and that would provide accurate client responses.

Scaled systems have to match agencies' resources

Another barrier reported in the implementation of an automated intake, tracking, and assessment system is the amount of time and resources required for data entry, processing, and analysis. One administrative agency noted that the centralized system being implemented was incredibly beneficial to some agencies, but to other agencies it was burdensome in the sense that it increased workload.

Some administrative agents give their providers the necessary equipment. But often agency staff possess little expertise on how to configure or maintain hardware and software. According to those providers and administrative agents interviewed, many agencies lack the resources for maintaining the system, and require extensive technical assistance or training, which is expensive



for an EMA. And even the agencies that are capable of maintaining systems are often reluctant to support data entry personnel or to reallocate program time to data entry or support functions. One administrative agent noted that because his EMA did not provide funding for data entry costs, some agencies were very uncooperative. He recognized that there is a necessity to provide understaffed agencies the necessary resources for data entry in order to increase compliance with the system. "The reality", he added, "is that if you don't do it for them or support them, it doesn't happen."

At some agencies, front line service staff are reluctant to take time from client contact to enter data, and often there are no data entry staff available. As a result, the front-line staff assume an extra burden, client services are reduced, or an additional cost is added to support more data entry clerks at a time when the ceiling for administrative caps is dropping.

Even for some larger agencies, one administrator noted, "It makes a major difference whether an agency can use the system as a primary data entry system or whether they will do double and triple data entry." For example, hospitals are likely to have a pre-existing intake system linked to billing. Consequently, any Ryan White intake and tracking system is likely to be additional work for them.

Compatibility with Existing Systems

New systems are not created nor implemented in a vacuum. Providers and administrators had many stories of unsuccessful attempts to migrate all data into new systems. Three obstacles were highlighted:

1. Different databases have different structures; and even when the same factors are captured, they may be categorized differently making the exporting of data difficult. In one EMA, a different extraction tool had to be developed for every agency. In that instance, the developers handled the extracted data, validated it and processed it for HRSA.
2. Some database systems do not have good export functions; and consequently, the data is difficult to export. Moreover, in some customized systems, there is no documentation and support is nonexistent.
3. In many instances, the quality of existing data is poor and requires substantial "cleaning" as part of the data transfer process.

When the data is relatively clean and exportable, automated data transfer is desirable. However, for smaller agencies or those with poor data quality, re-entering data may be necessary. For some agencies that use a spreadsheet and/or paper based system, back-entry of data can be a large and time-consuming task.

When data migration and exportability are not integrated into the implementation of a new system, agencies may find themselves continuing the old system while adopting the new system. The resulting logjam is the opposite of the original plan for greater internal efficiency. For some who relied on old systems for data, it means doing double data entry, with the new system providing little added value.



Mandatory Use Combined with Technical Assistance

Administrative agents that were interviewed emphasized that if universal use throughout the system and/or shared client data are the goals, provider participation in any data entry system has to be mandatory. Some providers may see the benefits to clients or to their own ability to intake and track clients. However, without some type of enforcement, most providers will not come on board. One administrator said, "Basically if it's not tied to funding it's not going to happen. Some agencies are great at follow-through, but if the word around the community is that they don't have to do it, they won't do it." From the providers' perspective, there is little incentive to do the hard work necessitated by the implementation and maintenance of a database system. From their perspective, there is little history of successful systems that provide them with good internal data, and sharing data across agencies is a goal that has rarely been achieved.

While provider participation may need to be mandatory, there also has to be some type of reward linked to the production of accurate data. The outcome of reduced red tape and better care is too distant for most providers. More intermediate rewards might be a support plan that provides technical assistance on:

- Configuring computers and installing software.
- Integrating the new system with prior systems and transferring existing data to the new system.
- Establishing protocols for data entry.
- Analyzing workflow to reduce redundancy and improve efficiency.
- Training in data entry and report generation.

For smaller agencies without personnel and/or equipment, allowing a paper system that can be entered at a central site or having a basic system with only limited mandatory fields may encourage agencies to start using the system. As the staff's technological skills increase, as the hiring requirements for the computer literacy of data entry staff are raised, and as line staff sees some advantage to the intake and reporting system, they may gradually accept a more complex system.

Trust and Reliance on Other Agencies

Although sometimes shrouded in the conversation on confidentiality, another issue that is raised by providers and administrators is having trust in other providers. An important element of any referral system is the assurance that the person referred will be treated well and receives high quality service.

Those assurances are not always present. Along with building a proficient technical system, part of any referral system is the interaction between agencies to develop a service model where there are options for clients and confidence in the services being delivered across agencies.

Agencies also express suspicion that other agencies will "steal" clients. As most agencies depend upon client counts or delivery of units of service as part of their contract, if sharing data has the effect of losing clients, then agencies are unlikely to participate in the system.



Quality Control

There are several elements that were raised in relation to quality control including:

- accuracy of data collected;
- accuracy of data input;
- consistency checks across agencies;
- timely data entry; and
- purging of out-of-date data.

Providers and administrators recognize that the data coming out of an information system will only be as good as the data going into it. The quality of the data is dependent on the software, its training and support, and the commitment of the agencies to maintain and verify quality of data. There is a history in most EMAs of poor data collection and inaccurate reporting that goes without detection or censure. In fact, since larger numbers of clients and "head counts" are typically rewarded, there are incentives to inflate client counts and services.

A program director in one EMA described his agency's data validation process as follows, "Data entry is only garbage in garbage out. We have one case manager for 350 clients – she fills out a standard form and the data entry person processes those forms."

In another EMA, the Grants and Contracts Financial Officer portrays a laissez faire validation procedure. He said quality assurance is limited. "The data manager, runs QHX to look for fields that are abnormally high with unknowns, and we do the unduplicating. We don't attempt to second guess the validation of clients' eligibility or types of service they are getting. If it's entered, it's assumed to be valid. The data manager looks for the obvious things with the problems of the systems or the data – and making sure that the data adds up. There is no requirement put on the provider regarding data validation." Another EMA said, "We pretty much lived with what they put in because we didn't trust this database a lot."

The process of correcting and updating information can be extremely time consuming. In one EMA, a system developer described how the EMA started running into problems with quality of data. They found that the EMA level errors needed to be corrected at the provider site and resubmitted. They, however, found that the turnaround was unmanageable. It was too long to be effective. The systems developer said, "One of the first things we learned was that validation should be done on site, at an agency site, making them responsible for validation of data. They had felt once they were done with data they were done with it, and all quality assurance problems were our problems."

As a result, in this particular EMA, a validation tool was developed which was installed at each agency. It required them to process the data through the tool before they could submit it. What that meant was they could do repeated extractions and validations with a turnaround of hours instead of weeks. Also, what that meant was that they really owned the validation work because they couldn't submit the data until it passed validation.



Cost Benefit Analysis

When epidemiologists and bureaucrats develop systems there is a tendency to ask for a broad range of data. Providers, however, said it is better to "keep it lean." They noted that it is expensive to collect data and when you ask too many questions the quality of everything drops. They noted that, "Asking fifty questions is so burdensome for providers, and it's hard to collect as well...sometimes it's better to ask 20 questions than 50 questions."

In the end, the system has to add to the quality of care of clients. In one EMA, they did a needs assessment as to what the barriers were for clients getting served. Two things came out as top barriers:

- Red tape - repeated registration and eligibility processes.
- For more independent and discerning clients, the repeated questions are considered invasive.



5. SYSTEMS REVIEW

Systems Synopsis

PCH reviewed eight systems that provide client intake, monitoring, and assessment of services. They range from basic data-entry systems to those that are more interactive and require greater participation from the staff providing services. Table 4 assesses each system regarding key output, users, and system requirements. It is divided into two sections, each assessing four systems. Table 5 assesses features of each system. Table 6 assesses different reporting features of each system. Following the tables there is a discussion of each system.

Table 4 Comparison of Eight Intake, Assessment, and Monitoring Systems

	ABILITECH (HIVCMS)	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT CARE DATA MANAGEMENT SYSTEM
Description	Foxpro for Windows	Foxpro database software (Windows 95/98/NT)	Visual Basic and Cache Script platform; Windows NT platform.	SQL server/Windows NT
Ad Hoc Reports	✓	✓	✓	
Billing module		✓	✓	
Case management	✓	✓	✓	✓
Client demographics	✓	✓	✓	✓
HIV/AIDS Info	✓	✓	✓	✓
Pharmaceuticals		✓	✓	✓
Pre-Formatted Reports	✓	✓	✓	✓
Ryan White Reports	✓	✓	✓	✓
Scheduling module			✓	
Service tracking	✓	✓	✓	✓
User Defined Fields	✓	✓	✓	
Locations where software is currently used	About 100 sites in New Jersey, Maryland and Pennsylvania.	Used for Title I and II reporting by more than 150 providers in New York State.	Title I for Miami/Dade and Los Angeles EMAs. Orange County Cal. EMA, Gainesville Florida.	Houston EMA
RAM requirements	32 MB recommended	32 MB recommended	Workstation 32 MB; NT server, 128 MB	512 MB for server ;64 MB recommended for workstations.
Processor speed	100 MHz	100 MHz	Workstation: 433 MHz; Server, 600 MHz	400 MHz server; 350 MHz workstations.



	ABILITECH (HIVCMS)	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT CARE DATA MANAGEMENT SYSTEM
Hard disk space	10 MB	10 MB	9 GB server	9 GB server hard drive; 5 GB hard drives on workstations.
Licensing fee	\$2000 initial fee plus \$200 per site.	Must be negotiated with AIDS Institute, Albany, NY	License ranges from \$2500 to \$4500 per user. Cache license is \$750 per user.	Negotiate with Houston.
Training and technical assistance	\$55 per hour on an as-need basis.	Must be negotiated with AIDS Institute, Albany, NY	Support is priced at 15 percent of software cost. Training and project planning services and SQL database engine range from \$15,000 to \$25,000.	Negotiate with Houston.
Contact	Sam Samat 1-888-270-6060 ssamat@abilitech.org	Vida A. Behn NYSDOH AIDS Institute 518-402-6825 VAB01@health.state.ny.us	Andrae Corrigan, 818-505-6911, acorrigan@acmsinc.com http://www.acmsinc.com	Charles Henley 1-713-439-6034 chenley@hd.co.harris.tex.us
Review Status	Demo	In-house	Demo, documentation	Demo, documentation



	COMPIS	ECHO	PROVIDE (GROUPWARE TECHNOLOGIES, INC.)	RW CAREWARE
Description	DOS application can be run in a Windows environment.	SQL server/Windows NT	Lotus Notes/Lotus Domino Server/Windows platform	Microsoft Access 97 (Windows 95/98/NT)
Ad Hoc Reports	✓	✓	✓	
Billing module		✓		
Case management	✓	✓	✓	
Client demographics	✓	✓	✓	✓
HIV/AIDS Info	✓	✓	✓	✓
Pharmaceuticals	✓	✓	✓	
Pre-Formatted Reports	✓	✓	✓	
Ryan White Reports	✓	Created via crystal reports	✓	✓
Scheduling module	✓	✓	✓	
Service tracking	✓	✓	✓	✓
User Defined Fields	✓	✓	✓	✓
Locations where software is currently used	Title I reporting in San Bernardino County and Fort Worth/Arlington EMA. Title II reporting in Arkansas, Hawaii, Mississippi and Texas.	Echo has customers in all 50 states.	Title I for Detroit, Kansas City, MO; Seattle; Title II for South Carolina.	Newly introduced, beta tested with 10 grantees around the country from Puerto Rico to Hawaii.
RAM requirements	8 MB	32 MB recommended for workstations (all hardware specs may vary based on the style of implementation chosen/performance desired)	16 MB recommended for workstations.	16 MB
Processor Speed	50 MHz	266 MHz	100 MHz minimum for workstations; higher recommended.	233 MHz
Hard disk space	40 MB for workstations;	9 GB server hard drive	40 MB for workstations; 2 MB recommended for server.	50 MB
Licensing fee	\$150 for basic system that generates all Ryan White reports. \$799 for add-on modules.	License for eight concurrent users, \$24,000.	\$900 per Provide license; Lotus desktop license is \$90 per user; Lotus server license is \$2000.	Free to Ryan White providers.



	COMPIS	ECHO	PROVIDE (GROUPWARE TECHNOLOGIES, INC.)	RW CAREWARE
Training and technical assistance	Support costs \$1 per minute and is available from 9 a.m. to 5 p.m.	Support is priced at 15 percent of software cost. Training and project planning services and SQL database engine range from \$15,000 to \$25,000.	Support is priced at \$125 an hour, including installation time, user training, agency customization and data conversion. Training costs \$1000 per day.	Free phone support from 1 p.m. to 4 p.m. EST. E-mail assistance also is available.
Contact	Eileen Killoren Data Design & Development 661-255-1833 ek@datadesign.net http://www.DataDesign.net	Joseph Viger 800-635-8209 joseph@echoman.com	Cheryl Hass-Vaughn 1-414-454-0161 Cheryl@Grouptech.com	John Milberg Office of Science and Epidemiology HIV/AIDS Bureau Health Resources and Services Admin. 301-443-8729 Jmilberg@hrsa.gov
Review Status	In-house	Demo, documentation	Demo	In-house



System Features

Table 5 System Features

	ABILITECH (HIVCMS)	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM	COMPIS	ECHO	PROVIDE (GROUP-WARE TECHNO- LOGIES, INC)	RW CARE WARE
Duplication checks	Yes	Yes	Yes	Yes	Yes	User queries software.	Yes	Yes, has separate unduplication utility.
Levels of access (security measures)	Password links to two security levels.	Multi-tiered security precautions	Multi-tiered security precautions.	Multi-tiered security precautions.	Multi-tiered security precautions.	Password links to several security levels; individual fields can be secured.	Multi-tiered security precautions	Password links to two security levels.
Shared/ centralized system	Can run on network.	Can run on network.	Client/server	Can run on network	Can run on network.	Client/ Server	Client/ server. System requires one or more servers. Workstations can access system via client/server, ie no local workstation based data, or can work offline with local system and periodically synchronize with server over analog dialup or network connection using most protocols.	Can run on network.



	ABILITECH (HIVCMS)	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM	COMPIS	ECHO	PROVIDE (GROUP-WARE TECHNO- LOGIES, INC)	RW CARE WARE
All required RW reporting fields	Yes	Yes	Yes	Yes	Yes	Must be customized. Configuration tools are provided to the customer.	Yes	Yes
Medicaid Billing	Add-on module	NYS COBRA CM, Adult Day Health Care, Primary Care are part of base software	Add-on module	No	Generates billing data, but billing must be done by another application.	Add-on module.	Generates billing data, but billing must be done by another application.	No
Grant tracking	Yes	Yes		No	Yes	Yes	Yes	No
Referral library	Yes	Yes	Yes	No	Yes	Yes	Yes	No
Scheduling	Add-on module	Yes	Add-on module	No	Yes, base software	Yes	Yes	No
Medications	Yes		Yes	Yes	Yes	Yes	Yes	
E-mail/ com- munication	No	No	Yes	No	Yes	Yes	Yes	No
Case notes			Yes			Yes	Yes	
Coordinate/ track services	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Evaluate client Outcomes	Tracks historical services and follow-ups. Daily log history.	Yes	Yes		Yes	Yes	Yes	No



	ABILITECH (HIVCMS)	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM	COMPIS	ECHO	PROVIDE (GROUP-WARE TECHNO- LOGIES, INC)	RW CARE WARE
Assess provider performance	Daily log tracks provider time and interactions.	Yes	Yes	No	Yes	Yes	Yes	No
Assess cost of care	Yes	Yes	Yes	Drugs	Yes	Yes	Yes	No
Determine units of services received	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Assess health service utilization	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Report on network of care	Add-on consortium module that can export all data from other agencies.	Yes	Yes	Yes	Yes	Yes	Yes	No
Monitor multiple patient services	Yes (agency and consortium)	Yes	Yes	Yes	Yes	Yes	Yes	Yes



Reports

Table 6 System Reporting Capabilities

	ABILITECH ¹	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM ²	COMPIS	ECHO ³	PROVIDE	RW CARE WARE
CD4 Batch Report			✓		✓	C	Currently tracks T-cell panels including CD4, CD8, Helper Ratios, and allow reporting and graphing of the values.	
AIDS Drug Assistance Program (ADAP) Report			✓			C	✓	
AIDS Pharmaceutical Assistance Annual Administrative Report (APA)			✓			C	✓	✓
Health Insurance (HIP) Annual Administrative Report			✓			C	Each community tracks the data elements differently.	✓
AAR Reports		✓	✓		✓	C	✓	✓
AIDS Surveillance Report		✓	✓			C	Supports data elements for confidential testing sites. Could support anonymous testing data elements with assignment of creative name identifiers.	



	ABILITECH ¹	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM ²	COMPIS	ECHO ³	PROVIDE	RW CARE WARE
Appointment Cards			✓		✓	✓	✓	
Client Profile		✓	✓		✓	✓	✓	
Clients Without Services		✓	✓			✓	✓	
Contract/Staff Distribution Report by Contract		✓	✓		✓	✓	✓	
Encounters and Services Listing		✓	✓		✓	✓	✓	
Group Activities Report		✓	✓			✓	✓	
Outcome Indicators Report		✓	✓			✓	✓	
Overdue Auto Alert Reports			✓		✓	✓	✓	
Pharmacy Formulary			✓		✓		✓	
Prescription Labels							Prescriptions are currently generated. Labels could be done.	
Primary Physician Questionnaire			✓			✓	Coming in Release 5.2.	
Pre-Test Counseling Report		✓				C	Currently found in Clinical System as required by Title III Early Intervention Services.	
Progress Notes Report		✓	✓		✓	✓	✓	
Referrals		✓	✓		✓	✓	✓	
Referral Form			✓		✓	✓	✓	
Referral Library List		✓	✓		✓	✓	✓	



	ABILITECH ¹	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM ²	COMPIS	ECHO ³	PROVIDE	RW CARE WARE
Scheduled Activities		✓	✓		✓	✓	✓	
Security Log			✓		✓	✓	The system tracks on log ons and all data updates. Third party software can be added to track all reads.	
Security Rights		✓	✓			✓	✓	
Service Deliveries		✓	✓		✓	✓	✓	✓
Service Delivery Cost Analysis Reports			✓		✓	✓	✓	
Staff Summaries		✓	✓			✓	✓	
Staff Report/Listing		✓	✓		✓	✓	✓	
Staff/Contract Distribution Report by Worker			✓		✓	✓	✓	
Statistical Analysis of Active Client Count			✓		✓	✓	✓	
Statistical Analysis of Demographic Data			✓		✓	✓	With Release 5.3 system will have an automated data synchronization tool to build and maintain a relational database for OLAP.	



	ABILITECH¹	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM²	COMPIS	ECHO³	PROVIDE	RW CARE WARE
Statistical Analysis of Distribution by CDC AIDS Year			✓		✓	✓	With Release 5.3 system will have an automated data synchronization tool to build and maintain a relational database for OLAP.	
Statistical Analysis of Distribution by Discharge Date			✓		✓	✓	With Release 5.3 system will have an automated data synchronization tool to build and maintain a relational database for OLAP.	
Statistical Analysis of Distribution by Drug Enrollment Date			✓		✓	✓	✓	
Statistical Analysis of Distribution by HIV Test Year		✓	✓		✓	✓	With Release 5.3 system will have an automated data synchronization tool to build and maintain a relational database for OLAP.	
Statistical Analysis of Distribution by Registration			✓		✓	✓	✓	
Statistical Analysis of Medical Data			✓		✓	✓	✓	



	ABILITECH ¹	AIDS INSTITUTE URS	CASEWATCH	CENTRAL PATIENT DATA MANAGEMENT SYSTEM ²	COMPIS	ECHO ³	PROVIDE	RW CARE WARE
Syringe Exchange Reports		✓				C	✓	
User Definable Reports		✓	✓		✓	✓	✓	✓
Weekly Billable Units		✓	✓		✓	✓	✓	
Zipcode Analysis		✓	✓		✓	✓	✓	
Notes		Creates extracts that can be imported into reports software				✓	Creates extracts that can be imported into reports software	

1. No information provided

2. CPCDMS will do requested reports listed in the All Titles Annual Program Data Report (Draft) 10/99. It will also do the reports based on the old URS system.

3. NOTE: Echo's open architecture design allows the use of a variety of 3rd party reporting tools including Crystal Reports, SPSS, etc. Some of the reports listed are reports we are not intimately familiar with, but it is likely that a tool like Crystal Reports can create the reports to be attached into the application by the user. Additionally, we will contract to customize our product to meet specific reporting requirements that involve changes to our product on a cost/estimate basis. While Echo would like to get a better understanding of these reports to insure that we can produce them, using this method, there are few reporting requirements Echo can not accommodate. In the table above, this is indicated with a "C" in the column.



Lean, basic systems

For the purpose of this report, “lean” systems are defined as systems whose main function is to generate Ryan White reports. Two systems evaluated fell into this category: 1) the RWCAREware software, which is distributed for free to EMAs by HRSA; and 2) the Central Patient Care Data Management System, a new database commissioned by the Houston EMA.

The advantage of a small database is that one data entry person can key in the minimal amount of demographic and service information necessary to generate a Ryan White report. The disadvantage of such a system is that it won’t create reports for other funding sources. It won’t house progress notes or a referral archive, and it won’t generate raw billing data. Therefore, it would be necessary to operate at least one other database system requiring duplicate data entry at most agencies.

RWCAREware

HRSA’s replacement for Toolbox is programmed in Microsoft’s Access 97 database software and can be run on Windows 95/98/NT platforms. Two standalone databases are available by CD or can be downloaded by grantees for free from the HRSA web site (www.hrsa.gov). The first “standard” database can be run under an off-the-shelf Access 97 application. Many agencies will choose this option. A second “runtime” (or self-launching, standalone) version of the database would be the preferable choice for agencies that use the Microsoft Office 2000 because this would avoid some of the software conflicts between the Access 97 database and Office 2000.

HRSA also offers an unduplication utility that will enable its grantees to pool and unduplicate client data from multiple agencies. The utility uses the URN – HRSA’s standard unduplication algorithm – which is compiled by using data elements from the first and last name, the birthdate and gender of the client. The URN is the algorithm used by most of the HIV software packages reviewed here.

The bottom line goal of the CAREware database is to collect the data to generate AAR, AIDS Pharmaceutical Assistance (APA), and Health Insurance Program (HIP) reports. Its demographic fields ask for limited client information that is mapped to specific reporting requirements. Its services module collects all Ryan White eligible services in encounter or batch mode. A limited number of user defined fields are available to agencies; but clearly, RWCAREware is not intended to be an all-purpose HIV and case management database.

There is password access to the system and two security levels only, for users and system administrators.

A major advantage of this software is that it is logically laid out, with clear documentation and a graphic user interface that will facilitate use by data entry personnel already familiar with Office applications. There is limited, but free technical support offered every afternoon by phone and email support as well. According to HRSA officials, the software has been beta-tested in several cities from Puerto Rico to Hawaii, but it is still new and has some bugs. These are likely to be largely resolved in the follow-up service release.



Central Patient Care Data Management System

This database, programmed in SQL by Macro Enterprises, Inc., runs on a Windows NT network. It recently was commissioned by the Houston EMA. Implementation in Houston has started but it is not fully operationalized. Like RWCAREware, the system has a baseline goal of generating federal CARE reports; and it also meets the administrative needs of the Houston Ryan White Care Title I Administrative Agent. While its data collection capacity currently is limited to the demographics and service information contained needed by HRSA and the Grant Administrator, its programmers have expressed an eagerness to expand their database to suit the specifications of other HIV and AIDS providers. It can be configured as a distributed system or a real-time central database.

PCH saw a demonstration version of the software. Its screens have a crisp Visual Basic interface, and again, will offer a quick study to staff familiar with Microsoft Windows applications. Mandatory and optional fields are noted. A recommendation to the programmers would be to include tools that allow for easier navigation from screen to screen within the software.

The largest advantage to this system is that it is professionally designed and supported and the designers are eager to enhance its functionality to meet the needs of other EMAs. The largest concern with this software is that it has not yet been “battle-tested” in an agency environment.

The system is owned by the Houston EMA. Negotiations for the base price of the software should be conducted with Houston, and the price is expected to be quite low. Additional expense should be planned for customization.

Multifunctional databases

New York AIDS Institute (AI) Uniform Reporting System (URS)

A Foxpro application that can operate on Windows 95/98/NT platforms, the AI URS is a comprehensive database that performs a wide range of reporting, data management, agency management and billing functions. It currently is in use at more than 150 sites throughout New York State, and is the result of a rare collaboration between Title I and II administrators at the state and city levels. Thus the system reflects at least five years of provider and governmental input. Most agencies house the URS on their own networks or on a standalone computer, although it also can be run on a WAN. For Wide Area Networks, the system managers recommend CITRIX or the metaframe/terminal server technology that is now included in Windows2000.

The system has a three-page centralized intake form with required, optional and user-defined fields and many specialized screens that collect client data on HIV, HIV/AIDS risk, pregnancy, TB, substance use, diagnoses, laboratory test, insurance, and financial histories. It has a very comprehensive medications module which uses a full list of all FDA-approved drugs, and can print prescriptions. Users can also add clinical trial drugs to a short list for their own use. It also has an extensive case management care system, with an intake form, an encounter screen, a referral library with an accompanying referral tracking mechanism, and a form that captures collateral information.



Its services module captures encounter or event data for nine areas, including case management; primary care; supportive services; adult day health care; education, training and outreach; counseling, testing and partner notification (which is still under development); syringe exchange, mental health and substance use. A group activities form tracks all types of group functions including support groups, congregate meals and transportation. A fast track data entry form allows for batch data entry.

The URS also generates case management, adult day health care and primary care billing geared towards New York State regulations and it now also includes a HCFA 1500 output, which is a standard used by Medicare and several private insurers for claims. It has a grant-tracking mechanism that can map an employee's time to a grant. It produces the AAR, AIDS Surveillance and several pre-formatted reports that can be used for administrative purposes. It also creates a data extract of commonly used fields that enables providers to export data into reports software.

The URS has a security system that links a user password to a specific security level. The database comes with several pre-configured security levels, but allows a system administrator to customize security schemes. Thus, a system administrator can limit or expand the activities of his or her users to include read, write or delete rights on a screen-by-screen basis.

The largest advantage of the system is that it has been tested and is operational in several provider settings. Considerable community and programmer efforts have been expended to make the system meet the needs of the Ryan White Care Act providers. The largest disadvantages are that it is not intuitive to use, has not been developed to work as a centralized database, and has a mixed rating from users.

The software is owned by the AIDS Institute (part of the New York State Department of Health), which has indicated that it will distribute it for free to other governmental agencies. However, the cost of customization, training and technical assistance would have to be assumed by Portland EMA.

The system would have to be customized for Portland's use, with some of elements pared down and others expanded

HIVCMS (Abilitech)

HIVCMS is a Foxpro database for HIV and AIDS reporting and case management that runs on a Windows 95/98/NT platform. It is distributed by Abilitech, a Philadelphia-based not-for-profit organization that trains and employs disabled workers. The system currently is used at about 100 sites in Pennsylvania, Maryland and New Jersey, and is one of HRSA's prototypes for client level data collection in the Middletown, NJ EMA.

HIVCMS, compared to the URS, is a relatively small database that focuses on case management services and follow-up and the generation of AAR and other pre-formatted reports for client information, case management administration and insurance and grant management.



The system includes an on-line resource library that enables users to search for medical and service provider by name, zip code, medical specialty and service type. The database also will inform users whether an activity is billable to a client's insurance program.

A major attraction of the system is the reasonable price for software rights and technical assistance. The cost of the initial license is \$2,000; subsequent licenses are priced at \$200 per site. Technical assistance is priced at \$55 per hour, the lowest rate of any of the packages reviewed here, with the exception of the free technical assistance that comes with the HRSA RW CAREware software.

COMPIS

The oldest of the systems under evaluation here, COMPIS is a DOS-based application that can run on Windows systems. It currently is used for Title I and II reporting in at least six regions. COMPIS executives say they will make the transition to an application based on a graphic user interface sometime in the future.

COMPIS is the forefather of most current HIV and AIDS database systems. Its many screens and modules are obviously the product of a labor intensive effort, and it reflects the work of a programmer who is thoughtful and experienced in the HIV field. Its DOS-based environment, however, might represent a step backward for agency employees who are used to Windows menus.

COMPIS offers a reasonably priced software package, which costs \$150 for a system that is capable of generating all Ryan White Title I through IV reports. The basic application will collect client information, including demographics, HIV status, risk and AIDS illness data, and client issues or problems. It also enables a system administrator to create "auto alerts," or reminder memos that are triggered when a consistently repetitive care management event is due.

The basic software package also includes a grant management module, which assigns grant codes to funding sources; a referral module; a pharmacy module; and a service delivery module, where service delivery categories can be added, edited or deleted, and encounter time, cost of service delivery and grant and HRSA codes can be tracked.

Separate modules for scheduling, comprehensive lab test, a fairly extensive selection of forms and labels, case management care plan and pharmaceutical dispensation are available for \$799.

A concern about the system is that it limits users to an agency customized picklist of 10 "troubleshooting" issues per client. The first eight issues must be the same for every client.

COMPIS, again, has a thoughtful security system that utilizes user passwords and a denial of access to users after three incorrect logons. Passwords are linked to different levels of security, read-only rights are available, and some personnel fields are available only to the administrator. However, the database files produced by COMPIS are not protected by the system and can be accessed through any program that can read DBF files.



Multi-user interactive database systems

Interactive systems are “real time” databases. In other words, a staff member enters information during a client’s visit that is sent directly into a centralized pool of data shared by a network of agencies. The systems reviewed under this category also provide more cues, prompts, and interactive tools for the providers. They tend to suggest treatment protocols, remind the provider when visits are scheduled, and incorporate algorithms to determine eligibility.¹

Advocates for real time databases argue that they benefit clients because basic eligibility documentation only has to be entered once during intake. Thus, clients don’t have to prove their eligibility status repeatedly. Developers of these systems also believe that prompts to providers can improve client care. There are other advantages of interactive systems:

- Clients can be immediately referred to agencies on the network for follow-up services;
- Agencies can quickly ascertain whether a client is receiving services elsewhere.

Critics of real time and interactive databases argue that live data entry intrudes upon the “quality time” which staff members have with clients. The argument also has been presented that staff members who are good at providing client care may not be computer literate, and data entry can be a distracting burden to them. Some providers also find that the reminders and suggested protocols are inappropriate for their particular clients and find these features burdensome.

With so many data entry satellites feeding into a centralized pool, security is a concern for interactive databases. The two interactive systems reviewed here incorporate some of the most strenuous security features PCH saw in any database PCH considered. These security measures will be further discussed in the descriptions of each database.

Casewatch

This system, which is produced by the private vendor Automated Case Management Systems (ACMS), Inc., based in North Hollywood, California, is currently in use in Miami, Florida, and in Los Angeles County. Currently a text-based DOS system, Casewatch is migrating to a graphic user interface Visual Basic and the Caché database, which is known for its ability to coordinate complex interactive transactions.

Approximately 40 providers, including social service agencies, outpatient medical clinics and hospitals, link into the central Casewatch system. In Los Angeles, more than 80 agencies are connected into the central server.

Casewatch includes a registration screen that can be customized to meet the data needs of individual agencies, with options for pre-registration, short registration, extended registration, case status changes and registration log reports. There also are modules for progress notes, client service plans, fiscal functions, contract and grant management, medical records, appointment scheduling, administration, service delivery and in-house services. Casewatch produces several

¹ The Central Patient Care Data Management System, reviewed under 'basic systems' is a centralized "real-time" client tracking system. However, it is essentially a data collection system, with little interactive prompting for eligibility, treatment protocols, or services. The developers say it could be modified to be more interactive.



federal and state reports, including the AAR for Title I providers. User defined reports can be generated using two report writers and SQL server calls.

Given the complexity of the database and its interactive structure, the system requires intensive technical support. In Miami, two full-time ACMS employees supply this technical assistance. Expenses for system support are steep: the EMA's administrators spent \$620,000 in 1999 for licensing and support. The cost of technical assistance was offset by the fact that the ACMS staff members provide service bureau follow-up for billing. Miami administrators report that the revenues generated by the database system have been a powerful incentive for agencies to implement and maintain it.

Casewatch offers multiple security features, including passwords that limit a user to specific functions, "field blinding" (the blocking of certain fields from the view of agencies and users), and reports tracking invalid log-ins. The system also forces mandatory periodic password changes – the only database we saw that does this – and screen timeouts. In other words, if an agency staff member leaves a computer unattended, the screen will black out. This is an important security feature. From past experience, it is known that most HIV database security breaches have taken place when agency employees have failed to exit their applications when going on break, thus leaving confidential data on screen and within sight of unauthorized visitors.

Provide

Provide is a Lotus Notes based interactive database system that pools information into Lotus Domino server. It initially was developed on a pro bono basis by Groupware Technologies, Inc. in Wisconsin, then was launched as a commercial venture after its initial success. The system has won the Lotus Beacon Award for Best Philanthropic Solution.

It currently is in use in the Detroit, Kansas City, Tampa, Fort Lauderdale and Seattle EMAs. It links a statewide network of HIV and AIDS providers in South Carolina. Currently, a prototype version is in testing at the Multnomah Department of Aging; and its nutritional module is in use at Loaves and Fishes in Portland.

Provide has been thoughtfully engineered by a team that includes former HIV administrators and case managers. Intake and assessment forms are filled out by a staff member; and, based on the information collected there, the software automatically generates a list of eligible services for the client. The system will then follow up with emailed referrals to other linked agencies, and produces agency defined Microsoft Word forms with data from the client file. Another feature is a documentation archive, which can be customized by a system administrator to store support documents that address a client's issues.

Other features include graphics that document outcome trends, a drug reference library, a community service program directory and a medical test reference library. The case management software produces Ryan White Care Act, HOPWA and Title XIX reports and can be used for user defined reports. It does not do billing. However, Grouptech has worked with agencies in the past to develop middleware that will bridge Provide data into commonly used accounting and billing applications.



Provide also offers a coordinated care management module that integrates inpatient and outpatient tracking. The care management module includes the Provide Pathways database, which can be populated with agency-defined or pre-configured pathways. When diagnosis and procedure codes have been assigned to a patient, the software will create defined pathways with anticipated outcomes and will automatically generate care plans with recommended interventions. The Care Management module also has two customizable Java based middleware components that can link the database to existing systems.

Provide's staff will do on-site technical assistance and training work at the cost of \$1000 per day, plus transportation. But the bulk of its technical assistance is engineered through its Wisconsin office. The staff there will analyze troubleshooting databases replicated from a provider site and claim to resolve most issues within 24 hours.

Provide's recommendation, however, is that its EMAs hire a full-time Lotus Notes administrator who can implement, maintain and train providers on the database.

Provide's security measures include user password protection linked to groups with varying management, design, editing and reading rights, document level access rights, and database and communications encryption capabilities.



6. RECOMMENDATIONS

The goal of this review is to recommend a standardized system of intake, monitoring, and assessment. The recommended system will, at a minimum:

- Determine clients' eligibility to receive different RWCA funded services;
- Track clients' status; and
- Provide data for evaluation of services.

After reviewing eight systems and interviewing ten providers and administrative agents, PCH finds that no single solution stands out as the obvious choice for an "off-the-shelf" system for the Oregon EMA.

The major finding from this survey of available systems is that the greatest predictor of success in adopting a common automated system for an EMA is not the database technology. Rather, predictors of success are:

- Having well defined goals for the system.
- Having a clear road-map for the system.
- Developing specifications with providers, clients, and administrative agents.
- Designing a phased implementation with specific deliverables.
- Providing substantial technical assistance to providers for adopting and maintaining the system, including system consulting, workflow analysis, and training.

Having Well Defined Goals

The overall goal of any system is the improvement of services to PLWH/A.

For the client, systems can improve services by:

- Cutting red tape by having common intake forms, eligibility criteria, and having clinical and service data on file to reduce the need for reporting history both within and between agencies.
- Improving linkages to additional service providers.
- Providing health care information that helps make informed decisions about a continuum of care.
- Assisting agencies to improve efficiency in backoffice requirements and enabling them to focus more on providing services.

Unanticipated consequences of badly implemented systems can be poor access to stored information, reduced time with agency personnel who have been mandated additional data entry or analysis tasks, and breach of confidentiality unless proper security measures are implemented.



For agencies, systems can improve their efficiency and effectiveness by:

- Providing case histories of clients that can be used in making treatment plans.
- Enabling agencies to produce unduplicated counts and reporting necessary data for AAR and other reports.
- Providing data for making informed management and planning decisions.
- Increasing communication/coordination and lessening duplication among departments and other providers by making linkage expectations more explicit.
- Providing data for analysis of process and outcomes assessments.
- Providing essential data for linking to billing systems and facilitating third party reimbursement.
- Facilitating the creation and use of linkages with other service providers.
- Providing data for developing unit costs.

The undesirable outcomes that sometimes follow the attempt to automate are:

- Less personalized service.
- Additional resources spent on technology.
- Running multiple, partially redundant reporting systems.
- Dedicating more time to support functions and less time to providing direct services.

For administrative agents, an automated system that determines eligibility, provides common intake, and provides information for assessment can:

- Greatly increase the ease and accuracy of reporting.
- Allow accurate unit cost comparisons.
- Provide data for regional planning.
- Provide data for contract monitoring and quality control.

Some notable disadvantages for administrative agents can be a great dissension among providers and clients. This may be a result of a considerable amount of resources spent on the development and support of systems that do not have universal use and therefore cannot provide system wide data.

Unfortunately, not all the goals are compatible; and many reflect conflicting views of the different parties. For example, better tracking of clients may be the goal of administrative agents and providers, but may not be the objective of some clients. Having comparable assessment data across agencies may be desirable for the administrative agent but not for the provider. Improving linkages may be desirable for the clients but not for some providers.

In developing an automated system, it is advantageous to establish consensus around a set of goals that providers, consumers, and administrative agents find acceptable.



Developing a Clear Roadmap

Key Destinations

Where should the system's final destination be? What are the intermediate stops?

In the opinion of PCH, major goals of the system should be to provide:

- A reduction in red tape for clients.
- More coordinated services for clients.
- Screening for eligibility.
- Improved provider's ability to balance reporting requirements, client tracking and service delivery.
- Greater accuracy in reporting by providers and administrative agents.
- Better data for decision making for providers and administrative agents.

Modular Development

To achieve these goals, it is recommended that the system have six modules:

1. Eligibility that contains a common intake form that will allow assessment of eligibility and key demographics for reporting.
2. Service tracking and reporting (mandatory and pre-designed reports as well as ad-hoc reporting).
3. Linkages to billing systems for third party reimbursement.
4. Assessment of demand and unmet need that contains a common set of questions for each service and permits an assessment of demand and capacity.
5. Linkages to relevant services.
6. Quality assurance that contains measurement of key indicators that minimum requirements are met for each service.

Essential Criteria

Without deciding on the specific system, the Portland EMA should establish a committee with representatives of administrators, providers and consumers to develop specifications for the desired system. They should:

- Agree upon criteria for eligibility that are programmed into the system.
- Agree upon a tracking module that provides information for mandatory and desired reports, such as the AAR and other reports that of use the providers and administrative agents.
- Document links to billing systems.
- Determine what service linkages exist in the system.
- Document what data is needed for assessing need for each service.
- Determine the minimum standards for quality of care for each service and measurable indicators for quality.



Intermediate Destinations

The intermediate destinations along the way are:

1. Agreed upon eligibility criteria that set clear limits on the access to specific services that match the systems capacity to provide those services.
2. Agreed upon essential data elements to track services provided and produce required reports.
3. Agreed upon measures of quality assurance.
4. Report specifications that can be used for monitoring, planning, quality assurance and outcome assessment.
5. Data dictionary of mandatory and desired fields to be captured by the system.

The process should help establish buy-in as well as defining key outcomes for the system. At the end of this process, there should be a clear roadmap that can be compared to existing systems to determine which system is best for the Portland EMA.

Modules

Eligibility Module

It is recommended that this process start with the limited objective of providing the eligibility module where a uniform intake process captures information to assist in the determination of eligibility for all services in the system at the point of intake. This common eligibility system would be the operationalization of the continuum of care where clients can enter the system at any service and get linked to the appropriate service. Equally important, it would require updates of persons' status as they continue to use the care system and provide updates on eligibility over time.

The eligibility module would be an enhancement to the care system in the Portland EMA, thus would not be perceived as being redundant; and it would explicitly require sharing of basic information between agencies. In order to share information on eligibility, the system has to contain a centralized database built on either a centralized real-time system or distributive decentralized system where every agency runs its own database and synchronizes with a central database. Finally, it will require the development of security and designated access to information both in and between agencies.

Once an eligibility system is operational, other modules can be added. It is recommended that they be developed in the following order:

1. Service tracking and reporting (mandatory and ad-hoc).
2. Links to billing.
3. Individual needs assessment.
4. Linkages.
5. Quality assurance.



Service Tracking and Reporting

To develop this module, an initial task is to determine what agencies have existing automated systems and what data elements are already being captured. Where there is no system or they do not include key elements, paper and pencil forms that reflect these data elements can be created and used to capture essential data.

Tracking the number, types of clients and units of service provided are key to providing basic reports. Some information will be available through the intake and some will be provided by persons providing the service. The process of developing the criteria and key elements, however, is the same as for the eligibility module. Before an automated system is in place, the ability to produce reports from existing systems supplemented by data collected by paper and pencil and entered into a database should be established.

For tracking to be useful for the administrative agent, there has to be universal use of the system. An effort to bring all providers online, or using forms that can be entered in the system, will be required.

Billing Linkages

The next module that would be developed is the link to billing. For most agencies, this would be a useful add-on. And, because third party reimbursement is used by many agencies, the ability to interface tracking services with billing would probably be perceived as useful.

Individual Needs Assessment and Treatment Plans

The module on individual needs assessments is a feature of ECHO, one of the systems reviewed. It is also used in other health care systems and can be used in developing measures of acuity related to services. The use of these types of assessments would require agreement on stage of infection and treatments linked to health and psychological status that could be collected. While in the Portland EMA case management assessment and referral for services are not a prerequisite for accessing services, standardization of the questions used to determine whether a client needs a particular service can be useful in documenting current service utilization and anticipated need.

Quality Assurance

The quality assurance module can be created after there is agreement on the indicators of quality of each service. The data would allow providers and administrators to monitor the quality of services, based on established criteria.

Implementation

The process suggested is a phased development and implementation of a centralized or distributive client tracking system. The first step is determining the needs of providers, administrators, and clients. The second step is adopting and supplementing current systems.



Data entry protocols would be established at each agency that minimize a burden to line staff, but provide high quality data entry.

System Specifications

During this period of reviewing current systems and determining criteria, a separate assessment must be made of whether to adopt a centralized or distributive system that can aggregate data. A centralized information system offers the potential of real time access to data and data sharing.

An advantage of the centralized system would be that the system is maintained centrally and each provider is required to have a link to the main program and database. It would have greater capacity and reduce development costs, and reduce training costs. Finally, a centralized system would allow development and beta testing with a minimal amount of disruption to the providers.

The disadvantages of a centralized system are that it removes some control from each agency and that, if there is a problem with the system or communications, it will affect all agencies. It would require that everyone would use the same system, or that the current system be adapted to export relevant data to the central system.

Another option is a distributive system where each agency houses its own database and maintains it. Data is uploaded and there is some time lag when accessing the central database. The advantages would be greater agency control and less dependence on a centralized data operation. The disadvantages would be redundant system maintenance, more difficult updates and greater agency system implementation costs and training costs.

Regardless of a distributive or centralized system, the ability to download data and do analysis locally should be a feature of the system.

Confidentiality

In any system of shared data, confidentiality is a major concern; and strict confidentiality rules must be established. However, a system can be designed which provides equal or better security than paper records and forms. At a minimum, full names and contact information should be in a separate database; and a unique identifier has to be encoded, encrypted, and have the highest level of security.

Program persons should be involved in developing what information is needed to perform different tasks, and password access to different parts of the database can be established so that information is available on a "need to know" basis. Clear protocols and staff training on passwords and access to names are an essential part of adopting an automated system. There is generally agreement in systems that the consumer should give permission for the access of his/her data. Once permission is granted, it is the obligation of the system to allow access to information on an "as needed" basis.



Assessing the System

Once the system is being utilized, ongoing assessment is needed to assure that it meets the needs of clients, providers, and administrators. A number of questions should be answered:

- Is the intake process able to adequately determine eligibility?
- Does the system produce valid unduplicated counts of clients in the aggregate and for each service?
- Are eligibility requirements being adhered to at the agency level?
- What are the pluses and minuses associated with the established eligibility requirements? Are the requirements too limiting? Are they resulting in too few or too many persons accessing each service?
- Does the service tracking and assessment module reflect client needs and utilization of the care system?
- Are the quality assessment indicators valid?
- Are the program outcomes being measured, and are they valid?

Outcomes for the system should be monitored. They include:

- Does the system reduce red tape for the client?
- Does the system cut duplication of efforts in determining client eligibility and obtaining client history?
- Do PLWH/A have a greater access to services?
- Are there improved linkages between providers?
- Does the system record accurate counts of clients and units of service delivered?
- Is client confidentiality assured? Do all system users follow the protocols that assure confidentiality?
- Are providers adequately trained?
- Is the data being entered valid?
- Do providers know how to run reports and use them in monitoring and planning?

Selecting A System

The systems reviewed range from the most basic to relatively complex systems. One option would be to select a simple database, such as HRSA's RWCAREware, that requires only the entry of basic data elements for the generation of Title I reports. The system has a utility for EMA-wide unduplication of clients. The drawback of the CAREware package is that it does not determine eligibility, archive case management progress notes, generate billing data, or provide a mechanism for sharing referrals with other agencies.

A second option would be to adopt a new database, such as the Central Patient Care Data Management System in Houston, and pay to customize the database to meet Portland's data collection goals. This system is non-interactive and does not determine eligibility. However, it captures most of the essential fields and could be programmed to do most necessary functions. It is untried to date; but since the program is being developed, the developers will most likely be



more open to modifying it. One advantage for the CPCDMS would be that Houston has paid for basic programming costs, and Portland would pay only for the cost of customization or added features for the software.

A third option would be to adopt an existing database, such as Abilitech's HIVCMS or New York's State's AIDS Institute URS, and pay to customize the database to meet Portland's data collection goals. HIVCMS is a smaller, more case management oriented database. The AIDS Institute's database is a comprehensive database that collects and processes information on a wide range of demographic, medical, referral and service functions. It is comparable to COMPIS or the system being developed in Houston. The COMPIS system is not designed for windows and the interface makes it more difficult to use than graphic or windows based systems. New York's URS has the added feature of having a module for billing and it also captures anonymous prevention and outreach information.

A fourth option would be to implement an interactive database that enables Portland's providers to collect and share data in a "real time" mode. Two systems that have been reviewed might be choices here, the Casewatch and the Provide databases. This option has some significant benefits: 1) it requires clients to document basic eligibility only once; 2) it allows providers to share referral information; and 3) with authorized access, providers can see whether a client is receiving specified services at another agency.

An interactive system also has significant drawbacks, including:

- "Real time" data entry often is seen as intrusive on a staff member's time with a client.
- An interactive data system requires extensive cooperation among agencies which often has been difficult to achieve in other EMAs, and it suggests the acceptance of a model of care where the system recommends treatment options.
- Interactive data systems often are difficult to implement within individual agencies because of infrastructure, data collection and political issues.
- All interactive systems that pool information carry risks of security breaches. Therefore, security issues must be of paramount concern to any EMA considering the implementation of a "live" system that shares data.

When assessing the systems, purchase price and maintenance are key considerations. At the upper end are large health care tracking systems like ECHO, and at the lower end are systems like the RWCareware, which is free. For systems already developed, like URS with the AIDS Institute, fees can be negotiated.

Other systems like PROVIDE and Casewatch have established pricing based on the number of users, and they offer basic support packages.



Conclusion

After reviewing the systems and talking to providers, administrators, and clients in the Portland EMA, PCH's recommendation is:

1. Get consensus about what the system should do. PCH recommends developing the system in a modular format.
2. Start by knowing the outputs that are desired.
3. Go slow. Do a detailed specification before selecting a system. See if data can be collected using existing systems to assure they can produce the desired outputs.
4. Select a system that can meet the specifications and where the developer(s) are willing to help customize it to Portland's needs.
5. Provide exceptional technical assistance during and following implementation, including transfer of data from old to new systems.
6. Make the system mandatory and provide both incentives for use and disincentives for noncompliance.



7. WORKSHOP FEEDBACK

On March 8, 2000, PCH presented this report to providers. Dr. Mitchell Cohen made the presentation, and Ms. Lucia Orellana and Ms. Peggy Marion presented an assessment of different systems through a teleconference link.

There were twenty participants representing fifteen providers. The list of participants are shown in Attachment C. A PowerPoint presentation (available by request) reviewed the goals, methodology, findings, and recommendations. A discussion of the findings and concerns of the providers followed the presentation.

In discussion, the following issues were raised:

1. The need to assure that client confidentiality was protected.
2. Confirmation that there was little data sharing among providers, but the feeling it could be useful to enhance linkages and reduce red-tape.
3. The general lack of computer sophistication by providers, particularly case managers and the probability that most providers would be hesitant to have real-time data entry.
4. Concern that existing efforts and development costs for agency databases would be overlooked and discarded.
5. Concern about development costs and availability of technical assistance.

The provider group offered neither a strong statement of need for a centralized system nor a strong resistance to establishing a common database system that determines eligibility, tracks clients and services, and assists in providing treatment information.

ATTACHMENTS



A.

Attachment A In-Depth Interviews – Protocol

PROTOCOL FOR INTERVIEWS WITH COUNCIL/ADMINISTRATIVE AGENTS

Oregon Standardized Client Eligibility
February 8, 2000

Objective:

- Identification of systems of intake, tracking and assessment used in different EMAs.
 - Identification of the problems encountered in implementing the models and how the problems were or are being resolved.
 - Identify any problems in determining and enforcing eligibility criteria.
1. What is the current system of intake, tracking and assessment used by your agency? (probe for name of database system/vendor). Is it centralized, or distributive? Who maintains and updates the system?
 2. How is eligibility for your agency's services verified & documented? Do you have any specific acuity measures used to determine client eligibility? How often is the information updated? Does your system capture eligibility information?
 3. What is the system used for, what are the goals? Does your system have the capability to perform any of the following?

Function/Tasks	Capability	Is it used by agency?
Note taking		
Mail lists and mailings		
Correspondence / letter writing		
Client information / data entry		
Assessment / evaluation (surveys)		
Data analysis		
Accounting / Book-keeping / billing		
Faxing		
Internal E-mail		
External E-mail		
Web based information		
Making and tracking appointment		
Duplication checks		
Levels of access (security measures)		
Shared/ centralized system		
All required RW reporting fields		
Billing (Medicaid, insurance, other 3 rd party)		



Function/Tasks	Capability	Is it used by agency?
Grant tracking		
Referral library		
Referral making & tracking		
Scheduling		
Medications		
E-mail/ communication		
Coordinate/ track services		
Evaluate client outcomes		
Assess provider performance		
Assess costs of care		
Determine units of services received		
Assess health service utilization		
Report on network of care		
Monitor multiple patient services		
Writing proposals		

4. How is data collected & entered (real time?), amount of personnel time required/ in-house staff or consultant
5. How does data validation occur?
6. Degree of client data sharing, biggest obstacles.
7. How are levels of access determined? Client or agency driven?
8. How did you go about choosing this system?
9. What are the strengths/advantages of the system?
10. What are the limitations?
11. Are you satisfied with your current system?
12. Comments/Recommendations



B.

Attachment B In- Depth Interviews – Summaries

The Austin EMA

Current System of Intake, Tracking and Assessment

COMPIS is the standard program for Texas for data system – mandated by the State of Texas, Texas Department of Health (TDH). According to the grants manager in Austin, all RW Title I providers are using the same system. It tracks the demographic information for a client and tracks the numbers of kinds of services that are entered. TDH has contrived a set of 38 different codes – an expansion of the 22 HRSA codes. There may be 2-3 TDH codes that are equivalent or converge to one HRSA code, and this is because different people talk about different kinds of services. COMPIS was designed to assist in reporting. It is not a good system for case management.

COMPIS is a distributive system in that each of the twelve vendors (service providers) has a computer and the program that operates autonomously. They put all their data in; and, once a month, the grants office collects the data through a download process, brings it through to their own central site, and merges the data. Analysis is run on each of the individual sites. The grants office does standard reporting and custom reporting to solicit information out of the database. The data is merged to create the annual administrative report (AAR) and the semi annual URS report. The data can also be merged at anytime to analyze it at various time periods. By custom reporting, they can design a query that will solicit any information that has been put in, even though it's not part of a standard AAR.

Maintaining and Updating the System

The system is updated by each provider, and all data is merged at one central site. There is a data manager trained in data management software programs and techniques. Currently, the grants office is looking to reclassify that position as a research analyst to take the data and get more out of it than what they have been able to get so far. They're looking for a person who's skilled in analysis techniques and determining the type of data that would have to be entered. This would be in addition to having a technical person.

Verification and Documentation of Client Eligibility

All of the providers are challenged when they bring their clients in for services to make the determination to ensure eligibility. At the same time, they are required to look for other eligibility such as Medicaid, Private Insurance, and so forth. Providers can discover that, if there's a third party payor available, they have to exhaust all other resources before they are allowed to expend any Title I or II Ryan White funds, etc...

Specific Acuity Measures Used to Determine Client Eligibility



There are no acuity measures used. Each agency queries their clients through the intake system, the first time when they arrive for services and periodically thereafter.

Capabilities and Functions of System

The grants manager feels that they need to get as much useful information out of the existing data as possible. He has mentioned to both the TDH, who provides some of their grant funding, and HRSA, who provides Title I&III, that they have not had an analyst look at their data. He feels that they have had no guidance from HRSA in regards to what constitutes good data analysis, what kinds of things to look for, and what types of analyses to do with the available data. What other data should they be collecting in order to look at certain trends – whatever they are. Also, he feels that there should be valid data ranges. If the value is outside that range, the system should alert you that it's questionable in order to ascertain why it's outside the range and to determine if there's something that demands attention that hasn't been intuitively obvious – either to the provider at an individual site or to the grants manager.

Determining Levels of Access

In Austin, within the COMPIS system, if providers have a need to know, they can access data. However, there's only one computer at each of the 12 sites, and it's used primarily for data entry. Usually the provider will request a COMPIS printout on an individual and they are given a hard copy of that information. But it's not an online system where 14 different case managers and 5 providers (doctors, nurses, etc) can get on an online system at any one site to simultaneously look up at records from various clients. It's one computer, one data entry person; and that one person generates reports, logs the day's productivity into the system, and updates client demographics or updates clients services received.

The system is password protected, and all users require a password to get into the program. Some of the providers have a computer in a locked room. There are physical and electronic security measures in place.

Providers could have a local area network at their location, but agencies have not asked for that. In Austin, they have briefly looked at the feasibility of each of the agencies being connected to a master computer located at the health department – via modem. It is technically feasible to have them transfer information to the grants office, but it is not a truly online system where they would have continuous access. Three years ago, Austin looked at that possibility and decided it wasn't worth the effort considering what COMPIS could do.

Currently, data is downloaded on a ZIP disk which accommodates all information from any one provider. The data manager physically drives to each provider site, runs the program, runs data checks for quality insurance, downloads to a zip disk, and brings it to the grants office.

The system collects all the data necessary for a RW AAR. It also generates a Title II report which goes back to the feds. The grants manager also needs to produce a Title III report. He is unaware of whether COMPIS has the capability to run a Title III report or not. He has



never been able to figure it or get someone to show him how to do it. They end up creating the report, some by what they get from COMPIS and the other from manual collection of data.

Data Entry Process

Data entry at most of the agency sites is handled by a part time person, e.g., an administrative assistant who answers telephones or pulls charts. Many of the agencies are so small that they only take a couple of hours a month. For instance, all that is required for housing services is to enter the client's name and all thirty days of housing in one set of keystrokes.

Currently, the data manager is operating at half time by running reports, collecting data, and also keeping the machines running. He analyzes the technical symptoms of a system and gets it running. The COMPIS system does tend to lock up, and a general data entry person is not skilled enough to resolve the situation. Additional time would have to be added for data analysis.

Data Validation

The data manager runs QHX to look for fields that are abnormally high with unknowns. The unduplicating of clients occurs at this level. The grants office does not attempt to second guess the validation of client's eligibility or types of service they are getting. If it's entered, it's assumed to be valid. There are another set of contract monitors who are embarking on doing some of these eligibility checks and verifying individual client eligibility to receive services – but that's more of a contract monitoring function than a data management function. The data manager looks for the obvious things with the problems of the systems or the data while making sure that the data adds up. There is no requirement put on the provider regarding data validation.

Client Data Sharing

Providers submit all their data to the grants office. This includes not only Title I funded services but also Title III, agency fundraising and other grants.

The only thing that agencies have been adamant about not doing is providing the client's name. When the health department downloads the data, they can only retrieve the URN of the client.

Strengths/Advantages of the System

In the grants manager's opinion, one of the limitations of COMPIS is that it is Dbase4, which nobody really knows. He feels that trying to get any kind of programming done represents a big challenge. He says:

“It has bugs that do weird things some times. Our agencies would like to know more about the system if it was a more up to date computer language – but they don't want to know



anything about Dbase 4. It's okay for the stuff that it collects but it has its limitations. I don't know if an ACCESS system would do anything better – but it has potential to be better. Part of it is that we have to realize what is good data analysis such that we collect the data that will allow us to do the analysis. So we have to collect data in an easy access fashion. We haven't had the time to quantify this. A lot of it is being driven by HRSA wanting an AAR and TDH wanting us to use COMPIS. So we stayed with COMPIS. And it just got so painful that we wanted to at least explore the options of an alternative system. It would probably not do a whole lot more than what the AAR requires, but we wanted to at least do some sorting out in that regard and see what else we don't know.”



The Houston EMA

Choosing a System

For the new system, the Planning Council determined that we needed something better. Because we had the CM system for so many years, it had a component that the people in Houston really liked – real time. They evaluated previous and current models – like COMPIS – but it was rejected for something better. They wrote down a wish list that they wanted and came to a conclusion that there was no product already in use by other EMAs that had what they wanted. With the assistance of a consultant (high level system designer) they developed a set of criteria that became specifications, which became a request for proposals. We went from wish list to what we have to have. We did two RFPs. The first only had one applicant, and that one was unacceptable. The second RFP said this is what we want to accomplish and you tell us how you can do it. We selected a vendor and only in last October got the contract. It's a custom developed application.

Current System of Intake, Tracking and Assessment

We in Title I in Houston don't use COMPIS. Agencies who get Title II in Houston use COMPIS, but that is a different administrative agency. It's people who get money from the State of Texas who have to use that. Since we don't administer any Title II or state monies, we were able to avoid the unpleasant responsibility of using COMPIS. Universally, the providers here in Houston loathe that system.

We are in the process of starting out a brand new data collection system—the Centralized Patient Care Data System (CPCDS). We are implementing it as of March 1st --a new data system which will be rolled out the first couple of months of the grant year to all of our agencies.

Our past system? We essentially allowed agencies to use their own data collection methods, and then we would tell them what information they were supposed to report to us and they would submit it in paper form and then we compile it, primitive. So for an agency that's been using COMPIS, they could use it to collect the information that they send to us. Many have had their own database put together. Medical providers tend to have systems that they use to bill which they can run reports. But we haven't been telling them exactly what to do; hence, we've problems coming up with good data. That's the goal of the new systems, to correct those deficiencies. We are one of the original 8 cities – and have had this system for about 9 years. We are starting our new data system at the beginning of our 10th year.

The old system really isn't sophisticated. We get in information: we've had aggregate level reporting, not client level. With one exception, we've had client level reporting for case managed clients. But when you want to get information from a provider, most providers have more than one service; so, while we could get very good information about case management (e.g., unduplicated counts), for any other service category there really isn't a mechanism to unduplicate. So agencies could use COMPIS or their own systems, and they



would answer our questions. But we couldn't compile that data in any form other than aggregated.

The case management database system we used to use was called URS (a much used acronym in AIDS reporting) which was a FOX PRO system. It connected all case management agencies in real time; therefore, we always had an unduplicated client count and there was no duplication of case management among agencies that did that service. It was an old DOS based system.

We essentially kept some of the concepts that we liked about that system: real time, and there's only a single record for a client. Rather than the COMPIS scenario which is sort of like CAREWare from HRSA.

16 providers participated in the old case management system. It was updated daily, real time. The database was at our site, and the agency simply connected over phone lines to it.

Verification and Documentation of Client Eligibility

Up until now, the only eligibility criteria for case management services in the Houston EMA was that you were HIV+. You then presented it in the form of needs. There was no financial eligibility. There's been efforts periodically within those nine years to put in severity of need scales. But the truth is, there has never been one that anyone felt was very good. From 1990-95, mostly you got case managed with people who were very sick and consequently died. They needed services to help them transition from a healthy person to a sick person to eventual death. 1995, those kind of scales disappeared because there was no longer that transition occurring.

Data Entry Process

Regarding input, it is the number of case managers. As far as at the central site, we had a contract programmer. We had someone responsible for the application, the other helped with the connectivity because it was an analog dial up system so there was a hosting situation (CARBON COPY, now obsolete). There was always maintenance to make sure the host and the remotes could connect – and analog phone lines were always being screwed up. There were two contract people at a cost of \$25,000 a year and maybe half of an FTE over the course of a year. Not a very expensive system to run.

Data Validation

Automatic validation existed to make sure that elements were within ranges – that you couldn't enter illogical information. At our side, we pretty much lived with what they put in because we didn't trust this database a lot.

Determining Levels of Access

For the new system, (to be rolled out in March 2000) first the concept, it has been improved in that there's one record for a client. You have a database running to a central site: when a



new client accesses the system, it goes through a registration process. All their new information is obtained except identifying information. If 30 agencies are connected, the new client is registered; and only one record is used. After that, if the client goes and accesses services from anyone in our EMA, those agencies add to the client's log of services they are getting those encounters. So there's a record for a client, and we track all the services they are getting. And for each different service category, that encounter information is customized to reflect the type of service it was. In case management, you would indicate whether it was face-to-face and how long the visit was. For transportation, you would enter the date, from what zip code to what zip code and the mileage of that trip.

There's a security matrix – we assign to each person who becomes a user of the system and fills out the information to access the system. Who has the right to sign to them – what they could not enter, what they could not read/write, or whether they could change the information.

Another good feature, we did not want a system that had client names in it. But the provider wanted the names. So while the database runs in two places (central and providers), at each agency there is a part of the database where they could enter personal private information that does not get to the centralized database yet this record is synchronized. Classes or levels can be developed for further security measures (Supervisors, managers, data entry person, etc...)

One agency (a service provider) gets the payment for doing the registration and then is responsible in doing the updates in whatever intervals our policies and procedures dictate. If the client gets case management, then that agency is the record owner. If they don't get case management, then it's their primary care provider. And the other agencies use that same information for their purposes, but all agencies are adding to the list of services that the client is receiving. So two pieces: registration information and the encounters.

Strengths/Advantages of the System

MACRO enterprises is developing the new system. Things we have done in our own experience you have to support this type of initiative to the max. All of the software, hardware, and support for this endeavor is provided by us; the Council allocates the money. Every agency gets a fileserver, x number of workstations; we handle all of that. We have help desks, technical support goes to their agency. Ongoing training because there is lots of turnover of staff in this field. We are building in a lot of business rules – like you can't get three of a certain type of services within a 30 day period. Anything you have decided as a business rule of how clients access and use services, you can automate it to the system.

It's been an expensive project if you heard the dollar amount – but it's been spread over three grant years and a lot of it is because we are investing in the providers. It has to be something that works: quick, fast, reliable, and well supported.

Our provider base is about 30 agencies. Some of them have multiple sites. Some of them serve a couple of dozen clients a year, some of them serve several thousands a year. The



provider gets the base system which is fileserver, workstation, router plus the training component – provider gets everything. The only thing they have to pay for is the data entry. We cover all costs because any burden put on the provider makes the project much more difficult to be successful.

It is able to collect clinical information like viral loads and CD4 counts on clients. It doesn't do billing – or not on the core product but it can definitely be included (enhanced).

There has been an issue about network security. Because this system operates over their existing networks, hence anybody on their site can access the network.



The Miami Dade EMA

Current System of Intake, Tracking and Assessment

For the past seven years, Miami Dade has been using a centralized system developed by Automated Case Management (ACMS) Inc called Casewatch. This is a character driven database system which has served as a major tool for needs assessment. The system is used to report on client counts, demographics of those receiving services, units of service, cost, linkages, and gaps in services.

Before going with Casewatch, the Miami EMA looked at various systems and found that none focused on coordination of services. They were also interested in monitoring and reducing duplication of efforts, both duplication in clients and services. They, however, did not want to reinvent the wheel.

They found that Casewatch was comprehensive and offered modules for case management and referral tracking. Other systems were more data driven and not service delivery driven.

Casewatch has expanded their capacity. For \$620,000 a year, Casewatch provides two full time support staff paid, partial payment of developer's time, software, hardware, training; technical support, and programming.

Currently all Title I providers (over 30 providers) use the Casewatch system.

Verification and Documentation of Client Eligibility

The Planning Council determines the eligibility criteria per service which is in turn programmed into the system. For instance, there is a \$100 limit for grocery vouchers. The system will track how much each client has received and will prompt the provider when the limit has been reached.

As of May 1, 2000, the system will not allow entry of clients where one of the criteria has not been verified.

Acuity scales are not used at EMA level. However, written guidelines exist stating that eligibility should be based on relative need, i.e. PLWH/A with children or substance abuse have greater need than others.

Data Entry Process

It's not done in real time because providers are concerned that they don't have the knowledge to navigate through system quickly enough not to interfere with the client's time. Entry usually takes place shortly after the interaction, and a concern is the lack of time to dedicate to data entry process.



Data Validation

Casewatch updates information every 6 months and random checks are conducted periodically by grantees and ACMSinc. Validation is important as it is used for needs assessment uses as a primary tool.

Levels of Access

Levels of access are programmed into the system based on client consent. The client can limit the type of service or provider who has access to his/her information.

Strengths/Advantages of the System

The billing capability of the system was very appealing to agencies. With exception of the large CBOs that already had complex billing systems in place, other agencies do daily transfers of data to the central server. Large CBOs upload information from their own systems at the end of the month.

In Miami, as in all of the other EMAs, client confidentiality was a main concern. So before any system was adopted, all consent procedures were reviewed and approved by lawyers, consumers and the Planning Council. The agreed upon procedure gives clients' complete control over who uses their information.

Intake process is centralized and shared. Over 99% of clients don't care if their information is shared. Instead they appreciate it because they don't have to go through intake again. The system allows the EMA and service providers to coordinate system and to communicate across providers. This results in a great benefit to client, and they have seen it.

While competition for clients may exist among providers, providers get paid on number of units of service provided, not on whether the initial client intake was done at their site.

Limitations of the system are that it is not very user friendly, requires extensive training, the cost to move to a windows application would be very high; documentation is lacking, and system fields need updating.



The San Francisco EMA

Choosing a System

In San Francisco, they first started using uniform reporting in 1994. Early in 1994, they were part of a pilot project for URS in which they developed a small database installed at five different agencies. It was a Paradox for DOS database. They found that it really didn't get any good data because of the software, and there was no training and support for the agencies.

For the agencies, it meant doing double data entry--entering service and client data in another database which provided no value to them. Each agency had their own software. Some agencies used spreadsheets while others did most of their data gathering on paper. The URS did not serve as primary record keeping system. It contained many data fields which did not really mean anything to users.

A major limitation was that the agencies were not involved in design of the database. There was no needs assessment done to ask how to make the database useful for them. The design of the database was just based on HRSA requirements.

Some time after, the San Francisco EMA won a grant to continue to use URS. They were to do a full-blown URS to try to get all care-funded agencies to submit data. The initial approach was to go out to the agencies and help modify the existing system and incorporate HRSA data elements for URS—instead of asking them to enter data into a system that was not useful. In a couple of cases, it was necessary to help agencies develop new databases. The end result was that every agency had their own custom database, but every database included required HRSA elements. Some databases had “supersets,” which had more data than HRSA required...

With three consultants and 1.5 to 2 full-time equivalents at the end of 2 years, 13 out of 65 agencies are on board. It's been a pretty costly process with URS requiring two submissions per year. The data administrator was actually processing the back end as well when agencies would submit data that would be put together and unduplicated.

Current System of Intake, Tracking and Assessment Used by Agency

San Francisco administrators decided that as long as they put resources into EMA wide data collection, they wanted to get data useful to the data administrators. They extended the HRSA data set and added questions, e.g., sexual orientation. They clarified and extended the data set and added new data so they could get data valuable for their own planning purposes. It was a great opportunity to do local evaluation, yet it required tremendous effort to define a good set of questions. They spent six months bringing a lot of people to define data set, including the epidemiologists, the database developers, medical providers who really understood questions about TB and exposure, and the front line staff who understood what it would be like to ask a client those questions and how to make it useful and workable.



According to the data administrator, one of the critical things in defining a data set is to keep it lean. In his opinion, *“It’s expensive to collect data; and when you ask too many questions, the quality of everything drops. Asking 50 questions is so burdensome for providers, and it’s hard to collect as well. Sometimes it’s better to ask 20 questions than 50 questions.”*

They asked more questions of case managers and medical providers than supportive service providers and core providers. According to the data administrator, it’s important to break down questions by type of provider.

They defined their own data set and put that out there. They felt they were getting pretty useful data. The data administrator said that one thing to keep in mind for planning and evaluation is that it’s hard to study data when you don’t have all the providers on board. He felt that it hurt them that only 22 of 65 providers were on board. He felt that it was important to strategize about who to bring on first, and it probably takes a few years to bring everybody on. They went after large providers and also picked providers who could give them a good cross section so when they looked at the data, they wouldn’t leave out entire communities.

They did a needs assessment as to what the barriers were for clients getting served. Two things came out: repeated registration and eligibility processes were a big barrier for most marginalized groups, really a barrier for everyone; and for high functioning clients, the repeated questions were invasive. Clients wanted to see a coordinated or integrated system of care. The thought was that a shared client registration system would provide an infrastructure for coordinated care.

They proceeded in three phases: First phase, standalone database; second phase, custom data base; and third phase, centralized client registration system, the Reggie system.

The Reggie system is an Enterprise database and application that agencies around the city connect to live, and register clients live.

They wanted to use the system to do citywide client level data collection. Reggie is a WAN. There are different ways of connecting: the most common ways are modem, ISDN, T1 and some agencies that are part of the Department of Public Health are connected to the Public Health Dept.’s network.

Verification and Documentation of Client Eligibility

The data administrator felt that it was challenging to get agencies to trust each other on eligibility and data collection. The Reggie system was set-up to capture this information. However, providers still needed to rely on each other to verify the information.

Data Validation

The database administrator worked with each agency to develop extraction tools. This is a piece of software that pulls HRSA elements out of custom databases and puts them into a



standard format. An important thing to note is that the extraction tool was different at every agency. Each agency developed a custom tool for doing extraction. Yet, they still had the data administrator send extracted data, validate it and process it for HRSA.

They started running into problems with quality of data, i.e., errors needed to be corrected at source and resubmitted and turnaround was unmanageable. It took too long to be effective. The data administrator stated that one of the first things they learned was that validation should be done on site, at agency site, making the agency then responsible for validation of data. Agency personnel felt that once they submitted the data, they were done with it; and all quality assurance problems were the administrator's problems.

They developed a validation tool which was installed at agencies. It required the agency to process the data through the tool before they could submit it. What that meant was they could do repeated extractions and validations with turnaround of hours instead of weeks. What that meant is that agencies really owned the validation work because they couldn't submit the data until it passed validation.

Levels of Access

They gave clients the choice of sharing or not sharing in the system. When clients share in the system, only providers who give them services are allowed to see information. Each provider can see their own information and others within the system. If the client doesn't agree to share, each provider has a completely different copy of that client's record. Clients make the choice to consciously value confidence more than convenience. Ten percent of clients choose not to share. According to the data administrator, *"People concerned about confidentiality are a vocal but small minority. Other EMAs run roughshod over confidentiality concerns. If a client is getting public funding they don't have any rights.... That wouldn't wash in San Francisco."*

If a client doesn't share information, they are still unduplicated in the system. The system knows that it's one client through the URN.

Safeguards? Each provider has a log-in and password. That log-in is connected to a specific agency. It allows providers to view clients at an agency who were registered by that agency. There are different levels of users that allow them to see different amounts of information. You can hide any individual fields for any group of users.... This is because you may have some data entry users who you don't want to allow see certain fields.

They also have auditing. This allows them to know which user viewed or modified each client. They can track which user viewed a client and agencies can call the system administrator to produce auditing reports of which users were looking at which clients...

Strengths/Advantages of the System

One lesson they learned is you've got to give agencies good feedback on data to convince them the data is actually being used. The data administrator described this as follows,



“Providers were putting a lot of effort into reporting, and felt they’re dumping data into a black hole which meant nothing ever came out. Agencies learned with the department in San Francisco that they could submit garbage data and it was not detected because nobody was really looking at the data.”

The data administrator developed a lot of statistics on the data, e.g., statistics and demographics among agencies. Among 13 agencies, that kind of feedback served as a big motivator. They also wanted to be accurate; it motivated them to get data in completely and accurately.

Confidentiality was a huge issue for San Francisco. The CBOs are very strong there. There were a lot of CBOs serving people with AIDS long before the department. The confidentiality issue was a huge issue every step along the way. Providers wanted them to take huge precautions because “though clients are somewhat anonymous with the URS, they were still concerned; and I think legitimately so, that there were ways clients can be linked back. If you know the name, DOB and gender, you can find out with some certainty if the client is in the database.”

Confidentiality was a main concern. The data administrator took lot of measures to make sure the system was very secure. They actually guaranteed to commit that they would never allow the data to be subpoenaed. They also took advantage of the certificate of confidentiality from HRSA which protects data indefinitely during a certain time period. All data in the time period was protected indefinitely against subpoenas. It helped give them more legal standing.

Participation has been the Achilles heel of their project. Using the Reggie system was incredibly beneficial to some agencies, but to other agencies it was burdensome in the sense that it increased their work. It makes a major difference whether an agency can use the system as a primary data entry system or whether they will do double and triple data entry. The EMA has not provided funding for data entry costs. That has made some agencies very uncooperative. There’s a necessity to provide agencies with staff resources to do registration and data entry.

The data team has given agencies equipment but made them responsible for maintaining it. A lot of agencies don’t have resources for maintaining the system. The reality is that some CBOs can’t do that; some need more technical support or staff training. The larger agencies are able to maintain the system, but the smaller agencies don’t have the ability. According to the data administrator, the reality is that if you don’t do it for them or support them, it doesn’t happen. He said, “We do a lot of technical support. We support 60 agencies. It’s very expensive with 3 or 4 computers per agency.”

He also feels that one thing to do to ease the burden on providers is to do monthly uploads of service data. However, batch upload from hospital systems is a lot harder than it sounds. It’s a lot of work, and hospitals can’t deal with batch upload for client data. It requires client data within 24 hrs.



Comments

In the opinion of the data administrator, “ *The participation in the system has to be truly mandatory. The system is officially required, but there are no consequences for not doing it. Basically, if it’s not tied to funding, it’s not going to happen. Some agencies are great at follow-through; but the word around the community is that you don’t have to do it, so they won’t do it. It’s got be tied to funding so you can’t get paid if you don’t follow through. Somehow agencies have be motivated to follow through. Some agencies see the benefits to clients or benefits to themselves if they see the system as a primary registration system. However, if care funded systems are part of a larger system like a hospital system which has got a system for registration and billing, then it’s just double data entry.*”



The Seattle EMA

Current System of Intake, Tracking and Assessment Used by Agency

Seattle has been using Provide for the past two and half years. They use it exclusively as a case management tool with all four case management agencies using the system.

Initially, the system was adopted because the Planning Council recommended implementation for reporting, tracking demographics and reducing duplication of clients.

Site administration and technicians came together; and with extra money allocated by the Planning Council to each agency, they decided to go with Provide.

The information is centralized, but client level data is not shared among providers. The system replicates with server and checks to see if client already is in the system. However, because each of the four case management agencies target different populations, it does not eliminate the need for additional assessment intake.

Verification and Documentation of Client Eligibility

Since the case management program is part of a community hospital, all case management clients must receive care in hospital. All clients must be HIV+ and verified either with lab slip or retested at the clinic. There is no income requirement since not all funding comes from Ryan White. Acuity scales were too complicated to implement and are therefore not used.

Data Entry Process

Each case manager has to carve out at least 30-45 minutes of her/his time to enter the assessment. This is in addition to time spent with client.

Data Validation

The case manager supervisor reviews charts periodically but does not review data entry.

Levels of Access

Levels of access can be programmed into the system and firewalls built to assure confidentiality. However, through a recent experience with an insurance continuation service provider, it was found that firewalls did not work.

Strengths/Advantages of the System

One of the advantages and lessons learned is that a centralized system forces collaboration and agreement on common definitions. The experience with one system has educated providers about what a system can and cannot do for them.



A big disadvantage of the system was that the West Coast is Microsoft Country, and no one knew about Lotus Notes.

Also, over the past two years, Provide has expanded to respond to needs of other cities and has gotten too complex to meet the needs of Seattle. There are fields that never get populated, yet the case manager has to bounce from one to the other.

The reminders in Provide don't tell you what to do. There are no logical links.

Although the system has email capabilities, staff don't use it because they already had an e-mail system in place.

Provide has many bells and whistles, but they are not reflective of the day to day activities of a case manager.

The system is too slow and not easy to navigate. Getting in and out of systems is too slow from screen to screen – have to go from one to another, does not allow skips.

Also, it only allows you to access one record at a time. This comes into play when a client calls, and the case manager is in the middle of entering another record. They need to abandon the current record in order to pull up another record.

The system is prescriptive and inflexible. Case managers have gone back and forth to request modifications and have been denied. They have been told no, that is not the way to do case management.

Another limitation is that they have been unable to do case management outcomes because of their own lack of technical knowledge. The information is there, but they don't know how to use it.



The Portland EMA (Five Interviews): Cascade AIDS Project (CAP)

Current System of Intake, Tracking and Assessment; Maintaining and Updating System

CAP is currently using a privately developed database system on ACCESS. Have had the ACCESS system for a couple of years. The previous database system wasn't ACCESS; but it was very much like it, so it was easy to transfer the data over. CAP has about 25 computers hooked up for ACCESS. The centralized database is available on their network and allows real time data entry. The operations manager and the program manager are in charge of any changes in the database or maintaining the operation. Information going into the database is maintained by all of client service staff (about 20 people) who have access to enter data – about 20 people.

The frequency of a client's data being updated varies depending on whether someone is actively getting services and/or how often they may come in for one of CAP's services. If someone initially comes in for services, it's possible to get all needed information. But there's no guarantee that the information gets updated – even if they are coming in pretty regularly. CAP is planning to try a new centralized intake in order to have updates happen on active clients at least every six months or annually. One of the limitations of the database is that some fields do not generate updated information. CAP is currently in the process of contracting \$10,000 to have the entire database updated and a lot of areas fixed.

Verification and Documentation of Client Eligibility

CAP requests written verification of health status from a medical provider. There are various ways CAP tries to verify people's income status, including talking to Social Security and working with the client's case manager. Up until now, staff in each program did a standard intake and could open a new client's file. A new technique is not fully implemented, but CAP has one department have responsibility in doing a standardized and comprehensive intake and then develop a service plan which would then call for referrals to other programs within CAP as well as out of CAP.

The database does capture eligibility information and allows the service provider to ask about and update information that needs to be done during an intake. They can always add information around those fields, for instance around health status. One of the areas being redesigned on the database is making it much more user friendly and more specific. Take medical condition as an example: rather than just having a field to enter if the person has HIV or AIDS, being added will be fields to say if the person is symptomatic or asymptomatic.

Specific Acuity Measures Used to Determine Client Eligibility

CAP does not have an acuity measurement for its service, but the program manager has requested such at the Title I council all the time. Most of CAP's programs now, like emergency financial assistance (EFA), have the client's request for services go through a finance committee meeting to determine the level of need. Part of what they look at is someone's health condition, as well as other eligibility, because of limited resources for



EFA; and it's also compared to what other requests are made for the same service. CAP has wanted to create a form of acuity measurement, but the Council has felt that something like that should be developed by the Council.

Capabilities and Functions of System

The Access system does not include billing. CAP uses a program called MIPS. "It works fine; it's as good as any accounting system." Last year, there was a staff person employed half time, working mainly on bookkeeping and accounting for housing services because these services are the most complicated for billing.

The system does include the following functions: note taking, mailings, assessment/evaluation, data analysis, duplication checks, security measures, shared/centralized system, all required RW reporting fields, grant tracking, referral making and tracking, medication history, tracking of services, determination of units of services received, assess health service utilization, the monitoring of multiple patient services, and the ability to assist in writing proposals.

Determining Levels of Access

There are staff working at the client service sites that have passwords and icons on their computers to use the database system. Staff in prevention and education don't have access to that because it's not part of their daily work. There are a couple of staff members as executive level people and a system administrator that are given levels of access to go in and change the database. The people who have access to the system are people with whom we don't have concerns about the privacy of the client.

Data Entry Process; Data Validation

The twenty staff members collect and enter the data. There are a couple of staff members that are responsible to make sure the database is there and that it's meeting the needs of the programs. Intakes do not occur at the computer; instead, it's done on the hard copy assessment tool that is used as a tool for conversation.

Data validation has been very sporadic. The reason for doing the centralized and standardized intake is to implement regular (at least monthly) random checks of their files and to see that all the information is entered and that it's comprehensive and that all the fields have been looked at. In the new design, it will make some of the fields mandatory, so that further information will not be accepted until you fill in certain fields. Lastly, part of the central intake will be providing for follow up. Once information is entered in, we want to make sure that information was followed up on.

Client Data Sharing

Internally, because there are so many programs, there is no centralized approach. Someone may be working in one program, and another staff member doesn't know it. That doesn't



happen too often, because the notes and the encounter that they enter would be visible to others when reviewing a record. Also, unfortunately, someone may come in for a visit, and the staff member may not have reviewed their file before meeting with them; but that's something that was more procedural that we worked on quite a bit.

Outside the agency, CAP has been encouraging Partnership Project (PP), a centralized case management provider, to share their database with them. CAP wants to share, actually swap, client information. With access to PP database, CAP hopes to get more of a client's history and background, family relationships, their whole situation. For instance, if PP did an intake with a client, CAP would just assume not to do an intake with the client. PP has been extremely reluctant and not wanted to do that. Currently established is a referral sheet of CAP referring to Partnership and vice versa which has some basic information but does not go very far.

CAP is a multi service agency that does not offer case management but has about 15 programs in client service where there is a need to have a service plan and be able to offer clients as much support as we can if they are eligible. Plus we are seeing a client population that is much more complex and diverse in terms of multiple diagnosis. We have found that, over the last couple of years, we need more and more information to be effectively serving clients. We have the housing program here that is a full wrap around service program. CAP feels the frustration from clients and from service providers because it hasn't been okay, or people are being reluctant, to share information that can be really helpful.

Strengths/Advantages of the System

The database actually is very helpful, user friendly and pretty comprehensive. It's set up to report for AAR reports. Also, CAP is able to put together specific queries to get at some other information or to analyze some other aspects of the client population.

Limitations of the System

The area for updating information is badly programmed, but it can be changed. Another limitation, the lack of in-house expertise to update and change the database when you see a problem. The last time CAP hired a programmer was 4-5 years ago. For instance, in the AAR a couple of years ago, they changed the age range. CAP is still operating with the old age ranges because they have not had anybody to come in and change them because of the resources available as well as lack of technical assistance in the community to help us do that. CAP is also trying to address being able to use the system much more to be able to identify the population that we are working with. Also needed is if the system could notify them of a need to update client data that has been neglected. They do a couple of client mailings a year, and it is a sign to them that the addresses are no longer valid when the mail is returned.



Multnomah County Health Department, Portland

Current System of Intake, Tracking and Assessment; Maintaining and Updating System

Three different systems coexist: the organization's Health Information System (HIS), the Partnership Project (PP) database, and the social workers have their own database for content of visits and referrals. The most consistent is the HIS database, but it is used by the entire Health Department; it's not just for this site. The three systems are not electronically connected.

The HIS data system is an electronic system for all appointments, demographics, billing, coding, and information of all the services the client is receiving. The client is entered the first time they enter the Health Department system. It's primarily for demographics so it collects the age, birth date, race, and ethnicity of the client. The Health Department primarily wants medically based data from medical visits – so it doesn't have a lot of information on social/economic factors.

The PP database is of the case management network in Portland and has been used for about 3 ½ years. It allows the Health Department's three social workers and one nurse case manager full access to the PP database. The PP intake form contains a lot of the same information as the HIS; but there is no way at this point for that data to be downloaded into the PP database, so the information is entered twice. The PP allows the gathering of more social situation information such as mental and emotional situations, medical status, and referrals. It's more of a case management data system and has a lot more information in it than the more general management stuff in HIS.

Separate to all of that, a really simple Access database is maintained by the social workers. It is used for end of the month tallies, e.g., there were this many contacts made by the case management staff, this many were face-to-face, this many were by phone, this many were made in the hospital. The database is more text rich and is primarily just like a hatch mark for the primary reason for the contact.

The case managers have access to all three of these. The medical staff have access directly to the HIS system; but if they need information, they go to the chart because the notes that the social workers keep are kept in the clients' medical charts. When there is a need to report to somebody on how many clients are being seen by social workers or case managers around drug/alcohol problems or how many clients are homeless, the PP database is used because it has much more information.

Verification and Documentation of Client Eligibility

For each new client that comes in, they have an appointment with an eligibility screener; and that appointment includes bringing proof of residency, income information, or social security card. Eligibility is essentially that they have to live within the 6 county EMA area. There are no eligibility criteria regarding incomes.



Specific Acuity Measures Used to Determine Client Eligibility

There are no acuity measures for the HIS database because the only requirement for services is an HIV diagnosis. The PP database does have an area that assigns acuity by requiring a CD4 count at each visit and a notation if the client is symptomatic or not. Identification of the level of HIV staging of clients is possible in the PP database.

Capabilities and Functions of System

The three systems offer a variety of functions and tasks such as note taking and the capability to do mailing lists and mailings. Data analysis regarding their collected data is possible, but requests have to be made to the Health Department. The HIS database does offer accounting and billing. Internal and external email, as well as web access is offered by a network in the agency but not available through any of the above mentioned systems.

Also available on their systems: making and tracking appointments; duplication checks on each individual system; security measures for levels of access; billing; referral making and tracking; scheduling; determination of units of services received; report on network of care (if it's within the Health Department); and monitor multiple patient services.

Most of all billing is done electronically. Tapes are sent weekly to Medicaid, Medicare, and to the billing arm of our managed care group. I don't know the details, but as long as we have the insurance info updated on our system, it is done automatically. Then the payments come in and are credited to the appropriate places, and I get a report once a month that says you billed this much to Medicare and you get this much back.

Data Entry Process; Data Validation, and Levels of Access

For HIS, most of the data entry is handled by the three employees of the front desk who check people in and out with their individual computers. The client is given an encounter form that travels with them through the clinic where the providers and the nurses indicate the diagnosis, length of visit, and what was done during the visit. The client then takes that back up to the front desk when they check out, and there their information is entered into the system by the front staff again. Everybody in the clinic has access to the computers to see a client's record.

With the HIS database, data is not available locally. It's downloaded into an Access file monthly, and we have one data analyst assigned to our division. When information for reports is needed, it has to be requested from the data analyst; he/she does the pulling of the data. This system is not really handy because the time it takes to get the data depends on how many grants are being written and how many reports are needed. Usually it takes 2-3 days to get the information and occasionally on the same day.

The PP database allows the 3 social workers and one nurse case manager to record their data directly into the system. They each have their own computer. With the social work database, the social workers do not enter data. Everything is entered onto the encounter form



which is also data entered by the front desk staff. Everybody except for the front desk staff makes their data entry onto the form, and that is transferred up front to the database.

Data validation has not been instituted with the case management/social workers systems. It is part of the protocol of the medical side of our services. There is a medical records technician who takes the encounter form of the client and does a random sample of those encounter forms and checks the data entry screen to make sure it was data entered correctly.

Strengths/Advantages of the System

No strengths in what we currently have. The social work database will eventually be integrated with a revised HIS database. I don't think we will get to a point where the county will allow us to import another agency's database onto that HIS system. The PP database will always have to be a standalone.

RFPs for the HIS have been put out now for a new health information system that is going to be more of a medical management system or client management system that we have now. We are going to be able to link it with the lab, link it with the pharmacy, and track outcomes and all of that. But it will be at least a year before it is completed. It won't bring together the HIS and the PP databases. We are hoping that we can put into the new system the social worker based info, like reason for the visit, that is not currently in the medical management database. We are looking at the new system as being a little more comprehensive than what we currently have.

Limitations of the System

Big limitation is the technology expertise needed to consider intergrating the three systems, particularly when different agencies have different capabilities and different systems to support them. The PP database has a huge database, and they have just one guy that is an independent consultant available for technical support. You may or may not get hold of him, and he may or may not call you back.

Waiting for data information is a limitation by having to ask the HIS data analyst to do that work for us. Primarily, it is not possible to get the information needed in order to look at outcomes. The data is basic: it's really specific diagnoses, lab tests done but not the results, the fact that they had prescriptions filled but not what kind of prescriptions. It just doesn't have enough data in that system to allow us to do the monitoring and tracking we need to do, so we end up having to do chart audits and hand tally systems. A system is needed that gives us not just what was done in the visit but gives us objective and/or outcome based information.



Partnership Project, Portland

Current System of Intake, Tracking and Assessment Used by Agency

The current data management system used is a custom designed Access system. It was designed by a Case Management committee, and the process took about 6 months.

The system keeps a client master with a unique identifier which is agency generated. As part of their development process, they reviewed other existing data collection software, including Provide. However, they found that this particular system was based on a Wisconsin model of case management which they felt was a prescriptive model; and the cost was too high.

Verification and Documentation of Client Eligibility

HIV diagnosis is verifiable with a medical form to be completed upon intake. There are no income criteria, but the information is recorded in the system. There are no geographic criteria.

Data Entry Process

The data is entered by the case manager, not during client encounter. It takes about 25% of staff time to do data entry.

Data Validation

Validation occurs through client record audits. The software consultant checks system and looks for the completion of mandatory fields within system and productivity.

Levels of Access

This is an agency wide system; however, only case managers can access client files.

Strengths/Advantages of the System

The Executive Director felt that a system used must be user friendly, i.e., easy to navigate from one screen to next. The system should also address all reporting needs so it doesn't have to be done manually. It should have the ability to produce and track core plans, services, and tasks.

Currently they have been using their system for 2 years. There is some need for data changes, with emphasis on outcomes. One of the limitations is that it can't produce CM outcome.



The system is not set up to process billing. The organization has a contract for one registered nurse visit per month based on a Medicaid waiver. Billing is handled remotely by the Multnomah County Clinic.

Comments

Case management at this organization is based on a tiered system of services. The levels of case management are defined as follows:

- 1) Information and referral: services at this level are not formally viewed as contacts with clients.
- 2) Monitoring case management: There is a consenting process for services beyond information and referral. At the Monitoring level, case managers see clients once every 6 months. This maintains a connection with clients; however, clients are not tracked. These interactions are generally client initiated.
- 3) Basic case management: monthly on-going contacts
- 4) Intensive case management: at 4 hours of contact per month, acutely ill or multiple diagnoses.

Acuity is based on amount of services accessed during month – e.g. if more than 4 hours, move into intensive.



Central City Concern, Portland

Current System of Intake, Tracking and Assessment Used by Agency

Switching from R-base to a custom designed Access program. The system is maintained and updated inhouse and is used to address Ryan White Contract requirements and for outcome study tracking.

Verification and Documentation of Client Eligibility

Eligibility is determined by an enrollment specialist at time of enrollment. Income eligibility is confirmed after admission. The current system used captures eligibility information.

Data Entry Process

The data is entered everyday by a full time data entry person.

Data Validation

QA (Quality Assurance) process occurs at 3 different levels. Data entry is only garbage in garbage out. We have one case manager for 350 clients – she fills out a standard form, and the data entry person processes those forms and puts that data into our system.

Levels of Access

First of all, we'd have to get a release of information to share any data for any patient. But once getting that, there wouldn't be a problem with sharing the data. But timeliness is often a problem. The releases are filled out by the client and it takes 4-6 weeks before getting a response from the provider.

The client is often leery about sharing data. We have to have a signed release (not only because we are an HIV clinic, but because we are also an alcohol/drug program). We need releases on anything that touches anybody, HIV+ or not. So anything going out to anybody has to meet federal/state guidelines about confidentiality – up and beyond paranoia and stuff.

Levels of access are defined and determined by the agency.

Strengths/Advantages of the System

Some of the strengths of the system are that it is easy to interface with other Access programs, it is expandable, and it is in-house programmable.

Comments

Our quality assurance manager is doing the data analysis – we'd be dead without her. If you are really going to rely on data on a computer system, you need constant vigilance over the system. What the EMA wants to do is foolish at this time with the lack of sophistication. We



have one of the most sophisticated programs (computers and data wise) around, and we are far from perfect. And a lot of these agencies are small. Just getting computers – forget about systems – and think that we can go to a centralized data base system of any kind with sharing of information would be a big economical/costly mistake as well as from a policy standpoint.

I don't think it's needed. I am one of the dissenting votes on the Council on this. It would be one thing for client ease if they had a library card that had all of their eligibility and all of that stuff on it so they wouldn't have to fuss with paperwork when they came to another agency. For an agency, we could spend \$30,000 on a scanning device and give all these contracted agencies– that's doable. But to have a centralized database – no way. We are talking hundreds of thousands of dollars. The county has trouble monitoring their contracts let alone monitoring data.

It [the County] has all the information about a person utilizing RW funds. Now how accurate is their database – that's the major question. Because you want this in an infrastructure that has security, confidentiality and the where-with-all to handle this. I wouldn't bid this one out at all.

*This would be the responsibility of the contractors—**that** on an every six month basis, they would update data and submit any changes to the county. They are getting all of the provider information on those AARs – they get quarterly reports when people blew their nose last time.*

The county has already tried this – in another public health realm...Central Intake, called the IRMA system, and it was a failure that cost 11.5 million federal dollars. Remnants of it are still around. It was a huge waste of money and created a bureaucracy that is still striving. It did nothing to enhance client services; it did nothing to improve the quality of life for people with Chemical Dependency. And I think the same mistakes would happen all over again. It's a cost that doesn't do anything for the patient – so who is it serving?

Data entry happens by audit form – whether it's medical provider, or a case manager or a therapist, and they fill out an audit form at the end of the day and then that goes to the data entry person that goes into the computer database.



Administrative Agent – Title I Grantee, Portland

Current System of Intake, Tracking and Assessment Used by Agency

Currently, the Administrative Agent in Portland uses RWCare and in-house developed spreadsheets to track data. Using Excel, customized contract report forms are set up per provider for:

- Monthly reporting of service activities;
- Quarterly reporting of client/service data for the AAR; and
- Periodic reporting of outcome indicator data.

Providers submit reports either electronically or by paper (faxed). Data from the latter is entered by the Program Development Technician (PDT) for HIV Services Administration who oversees the current client/services data system. Initial quality assurance for the data is completed by the PDT, with subsequent review by the HIV Services Administrator and HIV Contracts Administrator for monitoring purposes. Data summary sheets are set up in Excel, and several standard spreadsheet reports have been set up to meet a variety of information needs.

In the opinion of the Grantee, several contractors currently lack computer/data processing expertise. Ryan White funds have been used to build system capacity for automated data collection and reporting—including computer hardware, software, and technical assistance for providers. Additional technical assistance is needed for most of our providers.

The Title I Administrative Agent believes that centralization would benefit administration, providers, and clients. With a unique ID, it would not matter where the client enters the system. He believes that many people would like to move in that direction for data management, with unique client identification and standardized reporting requirements. However, how long would the information be retained? Confidentiality is a big concern.

An advantage of a centralized system would be a more integrated system of care. However, it would require money and significant staff training. It may be a huge hurdle for some providers—with such a broad range of technical expertise, ranging from low technical skills to more proficient users.

For any system to work, the planners must convince contractors and consumers that it is secure and that information is kept confidential. It would require provider sites to do data entry; and access to information would have to be determined, whether just for tracking or responding to client needs. Training would be needed for providers to understand confidentiality and measures.

In his opinion, the number of people that access services will grow dramatically. It would be great to streamline the intake process, to assess level of adherence to HRSA's stipulated eligibility, and to have unduplicated data across system.



C.

Attachment C Participants of Provider Workshop

1. Helene Rimberg	Cascade AIDS Project
2. Dan Bueling	Cascade AIDS Project
3. Julee Graven	Clackamas County Public Health Department
4. Louie Smith	HIV Services Planning Council – Portland EMA
5. Roy Cole	Metropolitan Community Church/Esther’s Pantry
6. Liz Fosterman	Multnomah County Health Department
7. Fred Butsch	Multnomah County Health Department HIV Clinic
8. Don Jarvi	Multnomah County Health Department HIV Clinic
9. Brandt Rigby	Network Behavioral HealthCare
10. Vic Fox	Oregon Health Division – HIV/STD/TB Program
11. Nancy Sellers	Our House of Portland
12. Sandra Holycross	Partnership Project
13. David Eisen	Portland Addictions Health Center/Central City Concern
14. Sia Lindstrom	Program Development and Evaluation Services
15. Renata Ackerman	Project Quest
16. Jody Howell	Southwest Washington Consortium
17. Dan Walz	Southwest Washington Consortium
18. Wendy Blenning	Women’s Intercommunity AIDS Resource
19. Catharine Keane	Women’s Intercommunity AIDS Resource
20. Carole Hansen	Yamhill County Public Health Department



D.

Attachment D Eligibility Matrix - Five EMAs

A description of each of the services funded by Ryan White is shown below. Notably, the description may vary slightly among the EMAs reviewed. The box that follows each description displays eligibility criteria. The eligibility criteria are self-reported by the providers and/or HIV/AIDS Councils and Consortia. When a box is blank, it means there was no specific eligibility requirement reported. In addition to the basic eligibility criteria listed below, the eligibility screening process includes collection of data about the client's access to other resources to ensure that the client has no other source of payment for the services provided (e.g., health insurance).

Ambulatory/Outpatient Medical Care

Definition

Outpatient care is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist or nurse practitioner in an outpatient community-based and/or office based setting. It is the provision of routine, non-emergency, non-inpatient, and non-specialized health services focusing on the prevention of illness and the ongoing management of chronic conditions and acute health problems.

Medical care includes:

- Diagnostic testing, early intervention, medical history taking, diagnosis and treatment of common physical and mental condition;
- Care of minor injuries;
- Education and counseling on health, nutritional and family planning issues;
- Well-baby care, continuing care and management of chronic conditions, and referral to specialty care;
- Prescribing and managing medication therapy.

Medications are dispensed or administered during the course of a regular medical visit(s) and are considered part of the services provided during that visit. It does not include the on-going provision of prescription or non-prescription drugs. Medical care may include access to new and innovative drug therapies which are the standard of care for HIV and which provide persons with HIV frequent medical monitoring and assessment by physicians and trained medical personnel.

Table 7 Ambulatory/Outpatient services

EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+		18 +	Must be case managed at Austin ASO.
Houston	500% of FPL	HIV+	Resident of HSDA	21+, <21 Teen Clinic	Must meet other Ryan White Title I requirements



EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Miami-Dade	300% of FPL	HIV+			
Portland	< 200% of FPL	HIV +	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Case Management

Case Management includes a range of client-centered services that link client and other significant members of the client's support system with health care and psycho/social services in a manner that ensures timely, coordinated access to medically appropriate levels of care and support services, and continuity of care. Key activities include:

- Assessment of the client's needs and personal support systems;
- Development of a comprehensive, individualized service plan;
- Coordination of the services required to implement the plan;
- Client monitoring to assess the efficacy of the plan; and periodic re-evaluation and adaptation of the plan as necessary.

These activities may include advocacy and/or review of utilization of services.

Table 8 Case Management Services

CASE MANAGEMENT SERVICES					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+	Resident of 10 county HSDA	18 +.	Uninsured or underinsured
Houston	300% of FPL	HIV+	Must live in Houston/ Harris Co.	all	
Miami-Dade	300% of FPL	HIV+			
Portland	N/A	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Complementary Treatment

Definition

Complementary treatment is defined as services designed to provide a comprehensive package of alternative health care services for HIV- infected persons. This service includes acupuncture treatments, naturopathic visits, massage treatments , naturopathic herbs and nutritional supplements.



Table 9 Complementary Treatment

COMPLEMENTARY TREATMENT					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+	Resident of 10 county HSDA		Also available for family members or partners living with client
Houston					
Miami- Dade					
Portland	200% of FPL	HIV+	Resident of EMA		Must be referred by primary care provider
San Francisco	Zero to low income	HIV+	San Francisco resident		

Counseling/Nutritional Education Conducted by a Peer or Non-licensed Counselor/Social Worker

Definition

Non-licensed counselors who provide individual and/or group counseling services, other than mental health therapy/counseling provide this service. It can include psychosocial, caregiver support, bereavement counseling, drop-in counseling, peer counseling, peer support groups, family support groups, spiritual counseling, nutritional and employment counseling. Intern or student counselors are included in this category.

Table 10 Counseling Conducted by a Peer or Non-licensed Counselor/Social Worker

OTHER COUNSELING					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+			
Houston		HIV+	Living in HSDA/EMA	Must be between ages 25-35	
Miami- Dade	300% of FPL	HIV+			
Portland	200% FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Day/Respite Care

Definition

Home or community-based non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client or the children of a client.



Table 11 Day/Respite Care

DAY/RESPIRE CARE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+	Resident of 10 county HSDA	0-12 years old	Must have dependent children. Children using the day or respite care services must have up to date immunization records.
Houston		HIV+		18 +	Can be a caregiver or family member
Miami-Dade	300% of FPL	AIDS			
Portland	200% of FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Dental Services

Definition

Dental services include diagnostic, prophylactic, and therapeutic services rendered by dentists, dental hygienists, and similar professional practitioners. Dental care includes medications that are dispensed or administered during the course of a regular dental visit(s), which are considered part of the services provided during that visit; it does not include the on-going provision of prescription or non-prescription drugs.

Table 12 Dental Services

DENTAL SERVICES					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV +			
Houston		HIV +		17+	Must be without dental insurance except for oral medicine
Miami-Dade	300% of FPL	HIV+			
Portland	200% of FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Direct Emergency Financial Assistance

Definition

Provision of short-term payments to agencies, or establishment of voucher programs, to assist with emergency expenses related to food, utilities, medications, or other critical needs. Agency is required to acknowledge receipt of the assistance request within 24 hours.



Emergency essential living needs include utilities, electricity, telephone, TTY, water and gas for HIV/AIDS infected individuals.

The following guidelines may exist in providing these services:

- Assistance must be in the form of vouchers made payable to vendors, merchants, landlords, etc. No payments may be made directly to individual clients or family members.

Table 13 Direct Financial Assistance

DIRECT FINANCIAL ASSISTANCE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin¹					
Houston		HIV +		17+	Must be an emergency need.
Miami-Dade	150% of FPL	AIDS			CM referral, Clients enrolled in HOPWA may receive TI utility assistance only if HOPWA funds may not be accessed. Clients must be screened for eligibility under the Life Line Program for telephone services
Portland	200% of FPL	HIV+	Resident of EMA		Maximum of \$500/year for EFA and emergency housing assistance (up to \$700 for PLWH/A with dependents)
San Francisco	Very low income	Disabling HIV/AIDS	San Francisco resident		

¹ Austin does not offer this service. Instead, it provides money for specific services, allocating money for specific services.

Drug Reimbursement

Definition

Drug reimbursement services pay for approved pharmaceuticals/medications for persons HIV positive whose drug therapeutic needs are not fully met by other payment sources.

Medications include prescription drugs to prolong or prevent the deterioration of health. The definition does not include medications that are dispensed or administered during the course of a regular medical visit, that are considered part of the services provided during that visit.

ADAP and Medicaid are the primary source for drug reimbursement. Many PLWH/A also obtain drugs through their private insurance or HMO. Because there are other channels for drug reimbursement, Ryan White Title I and II are not major contributors to drug reimbursement.



Table 14 Drug Reimbursement Services

DRUG REIMBURSEMENT SERVICES					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin	Follow the HRSA and TDH guidelines.	HIV +			Reimburses the clinic for the cost of medications that are given to the client while they're at their appt. Pays for approved pharmaceutical/medications when drug therapeutic needs are not fully met by other payment sources.
Houston	500% of FPL	HIV +	Must live in 6 county or 10 county	All ages eligible	Valid Rx from doctor
Miami-Dade	300% of FPL	HIV+			Physician's referral or prescription
Portland¹					
San Francisco	Zero to low income	HIV+	San Francisco resident		

¹ Solely funded out of Title II ADAP

Food Bank/ Home Delivered Meals

Definition

The Food Bank provides food, meals or nutritional supplements. Not nutritional education and counseling which is reported under the category “Counseling –other.”

Table 15 Food Bank Services

FOOD BANK SERVICES					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin	N/A	HIV+ .		none	Case managed through Austin ASO or with physician referral
Houston	150% of FPL	HIV+	Live in Houston EMA/HSDA	All ages are eligible	Must not be using another pantry and must get food stamps if eligible
Miami-Dade	150% of FPL	HIV+ symptomatic, AIDS			
Portland	200% of FPL	Disabled with AIDS	Resident of EMA		Requires documentation of disability
San Francisco	Zero to low income	HIV+	San Francisco resident		



Health Insurance Continuation

Definition

A program of financial assistance for eligible individuals with HIV disease to maintain continuity of health insurance or to receive medical benefits under a health insurance program, including risk pools. Program pays insurance premiums, co-pays and deductibles.

Table 16 Health Insurance Continuation

HEALTH INSURANCE CONTINUATION					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+	Resident of 10 county HSDA		Must be unemployed
Houston	250% of FPL	HIV+	Resident of 10 county Houston area	All ages eligible	Must have insurance already in place
Miami-Dade	300% of FPL	HIV+			
Portland	325% of FPL	HIV+	Clark County ¹		
San Francisco	Zero to low income	HIV+	S.F. resident		

¹ Other counties funded through Title II

Home Health Care

Definition

Therapeutic, nursing, supportive and/or compensatory health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professionals. The clients who receive this service are at different stages of HIV disease. Some are recently released from the hospital after having been acutely ill, many are in the end stages of HIV disease. Receiving the service allows the client the option of being in their own homes yet still maintaining a level of health care which is appropriate to the stage of their illness.

Case managers work closely with the client's primary health care provider to ensure that the referral for home health care is more appropriate than a referral for hospice care. Once that has been established, the service will be provided by a subcontracted firm. The case manager will re-evaluate the client's need for the service on an ongoing basis. Component services include:

1. Durable medical equipment;
2. Homemaker or home health aide services and personal care services furnished in the home of the individual;
3. Day treatment or other partial hospitalization services;



4. Home intravenous and aerosolized drug therapy;
5. Routine diagnostic testing administered in the home of the individual;
6. Appropriate mental health, developmental, and rehabilitation services.

Table 17 Home Health Care

HOME HEALTH CARE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin	low income	HIV+ symptomatic	Resident of 10 county HSDA		Does not have other funding to pay for home health care. Client needs a physician referral and eligibility determined through the case management program.
Houston		AIDS	Live in Harris Co.		Requires doctor's order
Miami-Dade	300% of FPL	AIDS			Physician's referral
Portland¹					
San Francisco	Zero to low income	HIV+	San Francisco resident		

¹ Not funded in Portland. Instead, Portland funds in-home care and support training program for Medicaid Program caregivers.

Hospice Care/Home Hospice Care

Definition

Residential Hospice Services

Room, board, nursing care, counseling services, bereavement services, and palliative therapeutics provided to residents in the terminal stages of an illness in a facility setting designated as a hospice through licensure.

Table 18 Residential Hospice

RESIDENTIAL HOSPICE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		A prognosis of six months or less to live	Resident of 10 county HSDA		Not able to maintain the level of care necessary to live in their own home. All clients must receive case management services through a community agency, have a primary physician who agrees to participate, and have a living will with a directive to physician.
Houston		Diagnosed with AIDS		18 +	Less than 6 months prognosis
Miami-Dade					



RESIDENTIAL HOSPICE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Portland ¹					
San Francisco	Zero to low income	HIV+	San Francisco resident		

¹ Not funded in Portland

Housing Assistance

Definition

Housing-Related Services

Includes assessment, search, placement, and advocacy services provided by professionals who possess an extensive knowledge of local, state, and federal housing programs and how they can be accessed.

Housing Assistance

Housing assistance is limited to short-term or emergency financial assistance to support temporary and/or transitional housing to enable the individual or family to gain and/or maintain medical care.

Table 19 Housing Assistance

HOUSING ASSISTANCE					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin			Resident of 10 county HSDA		Use HOPWA funds to provide service
Houston	Income eligibility is established by Housing Authority	HIV+	Live in HSDA/EMA		May be gender specific, depends on program.
Miami-Dade					
Portland	200% of FPL	HIV+	Resident of EMA		Various levels of services have additional criteria
San Francisco	Very low income	Disabling HIV/AIDS	San Francisco resident		Programs may included target populations, i.e., dual or triple diagnosed, people of color



Legal Services

Definition

Comprehensive legal assistance includes but is not limited to estate planning, permanency planning, discrimination, entitlement, and insurance disputes. Criminal matters are not eligible for Ryan White funded legal assistance.

Table 20 Legal Services

LEGAL SERVICES					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin¹					
Houston	300% of FPL	HIV +	Resident of Houston EMA Title II counties	All ages	The legal issue must be HIV related
Miami-Dade	200% of FPL	HIV+			
Portland	200% of FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

¹ Legal services are no longer funded by Austin.

Mental Health Therapy

Definition

Mental health therapy includes psychological and psychiatric treatment and counseling services, including individual and group counseling, provided by a mental health professional, licensed or authorized within the State, including psychiatrists, psychologists, clinical nurse specialists, social workers, and counselors.

Table 21 Mental Health Therapy

MENTAL HEALTH THERAPY					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+ or a significant other of PLWH/A			Also offers couple counseling
Houston	500% of FPL	HIV+			
Miami-Dade	200% of FPL	HIV+			
Portland	200% of FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		



Outreach

Definition

Outreach includes programs which have as their principal purpose identifying people with HIV disease so that they may become aware of and may be enrolled in care and treatment services. It does not include HIV counseling and testing nor HIV prevention education.

Outreach programs must be:

- Planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort;
- Targeted to populations known through local epidemiology data to be at a disproportionate risk of HIV infection;
- Be conducted at times and in places where there is a high probability that HIV-infected individuals will be reached;
- Be designed with quantified program reporting that will accommodate local effectiveness evaluation.

Table 22 Outreach

OUTREACH					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin ¹		HIV +/-		Over 18	Targets populations who have a disproportionate risk of being infected.
Houston		Must be at risk for HIV	Live in Houston EMA/HSDA	13 +	
Miami-Dade					
Portland	None	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

¹ Prevention is not funded with Ryan White. Also, Austin's Outreach program has been focused primarily on substance abuse but this year they are extending to general outreach as well.

Substance Abuse Treatment

Definitions

1. *Substance Abuse Treatment* may include treatment and/or counseling to address substance abuse (including alcohol) problems provided in an office-based health service or residential health services setting. Appropriate licensure by licensing authority is required to provide substance abuse treatment and counseling services.



2. *Alcohol and Drug Free Housing* provides housing for clients enrolled in outpatient substance abuse treatment.

Table 23 Substance Abuse Treatment

SUBSTANCE ABUSE TREATMENT					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+		18+	Chemically addicted (a needle user or the partner of a needle user).
Houston	300% of FPL	HIV+	Must live in Harris Co.	17 +	Have a history of substance abuse and dependency
Miami-Dade	300% of FPL	HIV+			
Portland	200% of FPL	HIV+	Resident of EMA		Client must meet OAR criterion for admission to chemical dependency treatment. For A/D free housing client must be enrolled in treatment
San Francisco	Zero to low income	HIV+	San Francisco resident		

Transportation

Definition

Transportation refers to services provided to a client in order to access health care or psycho/social support services. Transportation may be provided routinely or on an emergency basis.

Table 24 Client Transportation

CLIENT TRANSPORTATION					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin	Low income	HIV+	Resident of 10 county HSDA. There is urban and a rural service.		Only provided when no other viable alternative is available. Clients who have a car, yet fall below 300% of FPL are also eligible
Houston	Must have low income	AIDS	Must live in Houston EMA	0-70 years of age	Must agree to and sign consent for transportation, rights and responsibilities.
Miami-Dade	150% FPL	AIDS			Case Management Referral
Portland	200% of FPL	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		



Volunteer and Buddy/Companion

Volunteer, buddy/ companion services, provided by volunteers/peers, assist the client in performing household or personal tasks, and/or to provide mental and social support to combat the negative effects of loneliness and isolation. Volunteer assistance to support individuals and person/families with HIV may include employment of staff to recruit, train and coordinate volunteers.

Table 25 Volunteer and Buddy/Companion

VOLUNTEER AND BUDDY/COMPANION					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		Symptomatic AIDS	Must live in the Austin EMA		Referred by case manager
Houston		HIV+	Must live in HSDA or EMA.	All ages	Can be a caregiver or symptomatic / asymptomatic
Miami- Dade					
Portland	None	HIV+	Resident of EMA		
San Francisco	Zero to low income	HIV+	San Francisco resident		

Wellness Education/Risk Reduction / Information about Treatments & Medications

Definition

Wellness education, risk reduction provide information including information dissemination/outreach about medical and psycho/social support services and counseling designed to assist people in managing their illness or slowing the progression of illness. It can include wellness and exercise/fitness counseling.

It includes preparation/distribution of materials in the context of medical and psychosocial support services to educate clients with HIV about risk reduction methods to reduce the spread of HIV.



Table 26 Wellness Education/Risk Reduction

WELLNESS EDUCATION/RISK REDUCTION					
EMA	Income	HIV Status	Geographic/ Residence	Age	Other
Austin		HIV+	Living in 10 county HSDA	18+	Uninsured or underinsured
Houston	No restrictions	HIV+	Must live in Houston EMA/HSDA	16+	
Miami- Dade					
Portland					
San Francisco	Zero to low income	HIV+	San Francisco resident		



E.

Attachment E Acuity Assessment Tool

ACTION AIDS ACUITY ASSESSMENT TOOL

Category	3 Points	2 Points	1 point
Medical Needs	<p>Numerous or rapidly fluctuating medical needs such as: home health care, medical supplies, medication, nutritionals, medically related transportation</p> <p>Frequently misses medical appointments, medications, and/or treatments</p> <p>Hospitalization in last 30 days</p> <p>Needs LAMP/MA Waiver assessment</p> <p>Needs significant assistance with ADL's</p>	<p>Intermittent fluctuating medical needs, such as: home health care, medical supplies, medication, nutritionals, medically related transportation</p> <p>Occasionally misses medical appointments, medications, and/or treatments</p> <p>Active OI's</p> <p>Needs some assistance with ADL's</p>	<p>Monthly monitoring to ensure access to health care</p> <p>Medically stable</p> <p>In long-term care facility all basic medical/physical needs are met</p>
Mental Health	<p>Active chaos or disruption due to violence/abuse</p> <p>Death in family in last month</p> <p>Acute dementia/psychiatric problems</p> <p>Active D&A abuse non-compliance psychiatric medications</p> <p>Requires significant emotional support</p>	<p>Sporadic chaos or disruption due to violence/abuse</p> <p>Intermittent dementia or psychiatric problems</p> <p>Sporadic D&A abuse</p> <p>Occasional emotional support needed</p>	<p>Stable M/H</p> <p>No D&A issues</p> <p>No violence/abuse issues</p> <p>Minimal emotional support needed</p>
Life Management	<p>Basic benefits incomplete, applications in progress</p> <p>Homeless</p>	<p>Benefit applications completed and pending</p> <p>Intermediate</p>	<p>Minimal assistance with parenting and/or life management skills</p> <p>Regular school</p>



Category	3 Points	2 Points	1 point
	Significant deficit in parenting and/or life management skills No income or benefits Frequent school absence/problems Significant communication barriers	assistance with parenting and/or life management skills needed Intermittent school absences/problems Some communication barriers	attendance/no problems In long-term care facility, basic concrete needs met
Availability to case management and involvement in service care plan	No contact in last 6 weeks <u>(Give NO POINTS in any other category)</u> Frequently does not return cm calls, often misses appointments and follow-up activities, not interested in service care plan	Occasionally does not return cm calls, sometimes misses appointments and follow-up activities, some investment in service car plan	Usually returns cm calls, keeps appointments, good follow-up activities, invested in service care plan In long-term care facility
Support Systems	Absent or overburdened support system	Inconsistent or not dependable support system	Intact support system In long-term care facility
Households with dependent children <u>(Enter "0" if not applicable)</u>	Person in parental role is chronically ill; dependent children in home	Presence of one or more dependent children under 18 years of age	

Client Interventions Worksheet

On the worksheet, write the client's name and estimate the number of client related interventions you have had in the last 30 days: direct client contact and collateral contract only.