

Summary

**The Ryan White CARE Act
Title I and II Regional Technical Assistance Meetings**

Estimating Unmet Need for HIV Primary Care

**July 21-22, August 4-5 2003
Washington, DC**

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Introduction

In July and August of 2003, the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) held trainings for Title I and II grantees of the Ryan White CARE Act. The purpose was to train grantees in the use of a framework for estimating the unmet need for HIV primary care of those individuals who know their HIV status, but are not receiving care. Grantees from the Eastern region met in July, while grantees from the Western region met in August.

The impetus for development of the framework was passage of CARE Act Amendments of 2000 that emphasized the need to enhance access to care for those individuals living with HIV who are not receiving care. The estimates will also assist the Centers for Disease Control and Prevention (CDC) in focusing more resources on prevention with HIV-positive individuals.

It is HAB's expectation that unmet need estimates will be part of an overall needs assessment process that supports comprehensive service planning. FY 2004 Guidances will require Title I and II grantees to provide information on the resources, personnel and timelines they will use in completing their unmet need estimates using the framework. Grantees will also be able to request technical assistance (TA) throughout 2003-2004 to help them use the framework effectively. In their FY 2005 applications, grantees will be expected to use the framework to estimate unmet need by State and Eligible Metropolitan Area (EMA), and will be scored on their efforts.

The framework was developed by staff of the Institute for Health Policy Studies at the University of California, San Francisco (UCSF). The Institute developed the framework under a contract with HAB. UCSF project staff gave presentations on the use of the framework, required data inputs, and limitations.

Large and small EMAs that had participated in a "dry-run" of the framework provided insights on their experiences with trying to estimate unmet need. These presentations highlighted the impact of diverse data sources and resource levels on grantees' abilities to accurately estimate unmet need. Grantees also reported on the challenges of using the framework, benefits of the approach, and lessons learned.

Participants received a presentation on guidelines developed by HRSA and CDC to assist grantees in conducting joint epidemiological profiles for prevention and care planning. Presenters discussed the relationship of the joint profile to efforts to assess unmet need.

A presentation was given on the Rapid Assessment, Response, and Evaluation (RARE) methodology, which convenes local stakeholders in the assessment of factors contributing to the spread of HIV in minority communities, and uses that information to identify interventions that enhance and sustain prevention, treatment and care activities. Chief characteristics of the RARE methodology are a focus on local decision-making, cost-effectiveness and rapid development and deployment of interventions. HAB is modifying the approach to assess disparities in access to, and use of, care services, and is piloting this approach in four EMAs over a two-year period.

Finally, participants heard from CDC representatives about a new initiative to focus prevention efforts on HIV-positive individuals, in an effort to reduce the number of new HIV infections. Currently, more than 40,000 new HIV infections occur each year. CDC presenters stated that the new effort would be part of an overall prevention portfolio, which would continue to include established, science-based prevention interventions that focus efforts on HIV-negative individuals in high risk areas. CDC staff also emphasized the inclusion of HIV screening as a routine part of primary care.

Welcome and Agenda Review

Douglas Morgan, Director, Division of Service Systems (DSS), HAB
Sonya Hunt Gray, Project Officer, DSS

Ms. Hunt Gray welcomed grantees to the regional training and introduced Mr. Morgan. He said the goal of the training was to help grantees become familiar with the framework so that they could begin implementing it as soon as possible - and report on results for their FY 2005 CARE Act grant applications. Additionally, the meeting would help HAB identify potential TA needs related to grantees' use of the framework.

REMINDER: Grantees can request technical assistance on the unmet need framework by contacting their project officers.

Mr. Morgan explained that unmet need estimates would be helpful in documenting the true extent of the HIV epidemic, and the level of resources necessary to mount an effective response. He said based on grantee findings, HRSA could make the case that greater resources are needed to provide quality care and services to those who are infected with HIV, and to implement effective prevention activities to halt further spread of the virus. **He emphasized that the intent was not to compare grantee estimates of unmet need.**

He also announced a one-hour caucus session scheduled for the first hour of the second day of the meeting, during which grantees could speak with their colleagues who have tested the framework and discuss other, related issues.

Mr. Morgan made the following announcements:

- The Title I guidance would be mailed on Friday, July 26. The due date for the application will be October 24.
- The Title II guidance would be out in late September, and due in February.
- Title I FY 2004 applications would be reviewed externally.

The application review process will be led by the newly established HRSA Division of Internal Review, which includes former staff of DSS. The goal is to coordinate all HRSA external reviews and standardize the review process. DSS will work closely with the Division to ensure appropriate review of CARE Act grant applications. As grantees prepare their applications, Mr. Morgan said, they should consider that those reviewing their applications will not be familiar with their programs. He urged participants to be clear and comprehensive in describing their activities.

Unmet Need : An Overview

Emily Gantz McKay

President, Mosaica, The Center for NonProfit Development and Pluralism

(See Training Manual for full presentation)

For the purposes of meeting HAB's expectations, unmet need refers to the HIV primary care needs of those who know their HIV status but are not receiving care. CDC estimates that of the 850,000 – 900,000 people living with HIV, at least 230,000 know they are infected but are not in care.

The goal of the CARE Act is to identify these individuals and get them into care. This will require effective use of early intervention resources and coordination across CARE Act programs, as well as between CARE Act providers and other health care systems. Heightened emphasis is placed on needs assessment and comprehensive planning.

Assessing vs. Estimating Unmet Need

Estimating unmet need requires determining the approximate number of individuals with HIV in a service area that know they are HIV-positive, but are not receiving primary care services.

Assessing unmet need involves determining the service gaps, barriers and needs of individuals who are not in care.

Highlights of Ms. Gantz McKay's presentation included the following.

- Unmet need activities should be incorporated into overall needs assessment activities.
- The accuracy of the framework depends on the quality of surveillance data.
- Epidemiologists are central to the process and can help grantees apply the framework, obtain additional supplemental data, unduplicate data, and explain the process to planning body members.
- Challenges include: how to effectively link databases

without duplicating data; how to compensate for lack of data or quality of data; the limitations of qualitative data; the costs of large-scale surveys; limited resources; the difficulties in getting access to some databases; and the confidentiality issues inherent in data sharing (HIPAA).

- Planning body buy-in is critical to the process and EMAs should work to help planning bodies understand the usefulness of the process to their needs assessment and resource allocation efforts.
- Consumer involvement is important and helpful in determining data for use in estimates.
- The joint epidemiological profile will generate important data for use in estimating unmet need, and the terminology and categories used for both instruments should be consistent.
- Grantees must have unmet need estimates for their FY 2005 grant applications.

HAB is continuing to work on efforts to assist grantees with the following issues related to estimating and assessing unmet need:

- How to account for people living with HIV who are in jails and prisons;
- How to account for those who live in a service area but get their care outside the service area;
- How to account for people living with HIV who have private insurance; and
- How to account for people living with HIV that receive primary care from providers that do not report to CARE Act systems.

Ms. Gantz McKay said she would try to get State-by-State information on the numbers of HIV-positive people in prison from the Department of Justice.

Unmet Need Overview: Questions and Answers (Eastern Region Training):

Question: Many documents required by HRSA seem to be asking for the same information, such as the Statewide Coordinated Statement of Need (SCSN), the grant applications, and others. Has HAB thought about this?

Mr. Morgan: Actually, many of the documents do request different pieces of information. We are looking at ways to simplify the administrative requirements, including the possibility of having a bi-annual application. At this time, we only require a comprehensive plan every three years, with annual updates.

Question: How can we account for migration of clients in and out of our service areas when we estimate unmet need?

Mr. Morgan: We recognize that will be impossible to determine unless we have a uniform name-reporting system for the whole country. However, CDC has done some work around this, and has funded some limited studies.

Question: Is HRSA going to make CAREWare data from Titles III and IV available so that we can integrate into estimates and planning?

Mr. Morgan: I will talk to the Office of Science and Epidemiology (OSE) about that.

Irum Zaidi, CDC: The CDC is conducting evaluations of studies on migration and will have protocols out within the next year.

Question: I am concerned about the need to unduplicate supplemental surveillance data?

Ms. Gantz McKay: You are not expected to unduplicate the data, rather to get a sense of where your HIV population is getting care.

Question: Is there a training to help us do data matching? Also will there be money for data people to do this work?

Mr. Morgan: I will speak to the Centers for Medicare and Medicaid Services (CMS) about the training. Also, CDC has provided some money. HRSA money is limited, but there is money available in the quality management category if you can prove a connection.

Question: How often will we be expected to estimate unmet need – every year, every 5 years?

Mr. Morgan: We'd like to see everyone up to speed, so maybe after a couple of years, if we are comfortable with the estimates, we may request them every 2-3 years. We are using this process to answer critics of the CARE Act and to document the need for additional resources for the program.

Question: What about people coming out of jail?

Ms. Gantz McKay: It is important to know who they are so you can count them.

Question: When will there be an initiative to de-stigmatize HIV/AIDS?

Mr. Morgan: HAB has funded studies looking at this issue and we recognize how important it is. This comes up a lot in our discussions, including in our deliberations around reauthorization.

Question: I am concerned that HIPAA restrictions severely limit our access to information.

Mr. Morgan: We are working on how to give you guidance on getting information while meeting HIPAA requirements.

Question: What's being done to clean up surveillance systems and clear out data on those who have died?

Mr. Morgan: CDC is working with the States to update surveillance data and I will follow up with them.

Unmet Need Overview: Questions and Answers (Western Meeting)

Question: Is there a way for HRSA to tell grantees about the importance of sharing data? We are having trouble getting information from Titles III and IV.

Mr. Morgan: We have discussed this with OSE and are working to make sure your colleagues in other Titles share the information. I also want to mention that several years ago, we worked on a data-sharing agreement with Medicaid. Information on this agreement is on the CMS Web site at <http://cms.hhs.gov/states/letters/smd10228.asp>.

Question: Does that apply to the Veterans Administration (VA) as well?

Mr. Morgan: We will have to work to re-engage the VA in this effort.

Question: Are we using a 6- or 12-month timeframe for out of care? In Austin, Texas we have been using 6 months.

Ms. Janney: For the purposes of the framework, we decided to use the least common denominator — 12 months — that would allow all grantees to use existing data. You can do both if you have the capacity.

Six Steps to Estimating Unmet Need

Dr. James Kahn, Jays Janney and Katie Ikard of the Institute for Health Policy Studies at UCSF outlined the six steps for estimating unmet need in accordance with the framework they had developed.

Step 1: Review your objectives, which include calculating an estimate of unmet need for primary HIV care for the entire population of individuals living with HIV, and for selected sub-populations.

Step 2: Review and select among options for estimating unmet need. This involves assessing data inputs in accordance with the “operational definition” of being in care: 1) Has the person had a viral load test in the past 12 months; and/or 2) has the person had a CD4 count in the past 12 months; and/or 3) was the person on antiretroviral therapy (ART). If any one of the criteria has been met, then a person is considered to be in care.

Step 3: Develop a workplan. This includes identifying a team, agreeing on data inputs, estimating the effort required to conduct the estimate, and developing a timeline with benchmarks. **Title I and II coordination in this effort is strongly recommended.**

Step 4: Implement the workplan. This includes: 1) collecting, analyzing and interpreting data; 2) regularly reassessing and refining your strategy; 3) meeting regularly to assess progress and challenges; 4) reporting back to Title I and II planning bodies; and 5) refining data inputs as needed.

Step 5: Prepare a report that outlines how estimates were obtained, the limitations of the data used, the reasons for choosing certain data sources and the overall strategy. The report should also address the implications of estimates for the jurisdiction’s efforts to meet unmet need.

Step 6: Disseminate the report broadly, to planning body members, providers, community members, elected officials and others. Title I and II grantees will be required to report the information in their CARE Act grant applications.

UCSF has created a *Practical Guide to Measuring Unmet Need for HIV-Related Primary Care — Using the Unmet Need Framework*, which was included in the meeting manual and is available on the HAB Web site at <http://hab.hrsa.gov/tools/unmetneed/>.

Six Steps to Estimating Unmet Need: Questions and Answers (Eastern Meeting)

Question: Can the unmet need team include planning council members?

Ms. Janney: Absolutely, they should be involved.

Question: What is the framework for assessing service gaps and how will this process aid reauthorization?

Dr. Kahn: This is a solid first step, and it was designed to be the floor for what PLWH should be receiving in terms of care. As a next step we may look at a broader category of services, but I can't say when that would be.

Question: How can we pay consultants to work on this with us?

Dr. Kahn: I'd refer that question to Mr. Morgan, but I think it would be best to look at how current needs assessment activities are being paid for in your program, and to look at your quality management budget for any leeway there.

Question: Can you elaborate on common ratios as a data source?

Dr. Kahn: For states that don't have HIV reporting data, CDC data can be used in conjunction with the ratios. Additionally, it is best to go with ranges on your estimate.

Question: What is a good cutoff for CD4 counts?

Dr. Kahn: We think a CD4 of less than 200 can be used to monitor care patterns for people with AIDS, but not for people with HIV (non-AIDS). Furthermore, we will follow up with HAB on the usefulness of having 500 as a cut off point.

Question: Has there been any effort to get Medicaid and the VA to participate in this activity?

Dr. Kahn: We are asking them to provide us with the number of people in their systems that are HIV-positive, as well as information on the CD4, viral load and ART measures we are using. With the VA, since they have a national system, it's possible that they could provide the data once. For Medicare, since there is no drug data or national data set, obtaining local data is difficult.

Mr. Morgan: Medicare data is handled by intermediaries, which makes it difficult to obtain. Medicaid is a better way to go. We will work with our colleagues in the Bureau to get Title III and IV data, so that grantees can unduplicate the data.

Question: What is the rationale for the operational definition of in care? I am concerned that one CD4 or viral load count would significantly underestimate unmet need?

Dr. Kahn: We agree with you, and debated about whether to narrow the definition. I encourage you to make your own definition based on what your data can support.

Ms. Janney: During the field testing process, the rationale for using 12 months was that it would give all jurisdictions the opportunity to calculate unmet need using a basic, but common denominator – an operational definition. It is not, however, meant to convey a standard of care.

Question: We have access to a database that reports on case management encounters, and I know if a person is in case management, he or she is getting care. How strict is the data use?

Dr. Kahn: I would err on the side of being stricter.

Ms. Janney: Also, if a person with HIV is going to the doctor, it doesn't mean that they are getting regular primary care, because maybe they are going for some other reason.

Question: So you don't want data on opportunistic infections?

Dr. Kahn: We could add that as a standard embellishment.

Question: From our experiences in New York State, I have some concern about the operational definition. In New York, Medicaid data is used for billing, but not for procedure codes. So how can we capture the information for the operational definition?

Dr. Kahn: You could work with the State to discern some of that data for operational purposes.

Question: I have not heard mention of taking into account post-test counseling rates for population data. We have these in our reporting system, even though they don't come back for results. Sixty percent of those who test positive come back for their results.

Dr. Kahn: We'll need to think about that and a possible adjustment. It would probably lead to a low estimate for unmet need.

Ms. Janney: You can't use a high population number for funding purposes and a lower number when it looks better. The number should be consistent, so think about what the data means and how you want to adjust it.

Data Inputs for the Unmet Need Framework

Jays Janney of UCSF described data inputs for the unmet need framework. These included data for population size and for care patterns. **Population size data** includes all people diagnosed with AIDS and HIV (non-AIDS) living in a jurisdiction.

Care pattern data includes how many people are receiving HIV primary care under the operational definition. This includes the number/percent of PLWA with met need and the number of PLWH who know their status and have met need.

The framework is flexible, allowing for the use of various data sources in calculating unmet need. Dr. Kahn of UCSF provided examples of how the framework would be used with one data source, such as the HIV/AIDS Reporting System (HARS), or with multiple data sources, which could include HARS, surveys, and local estimates.

In choosing data, grantees should consider the following:

- Estimates of people in care should be either the percent in care in a representative sample (survey) or the number in care across all care settings;
- Data should represent the entire population of interest, and therefore sample sizes must be representative;
- Sampling should not depend on those in care, so as to minimize data bias;
- Aiming for mid-range estimates with known upper or lower bounds is best;
- Unavoidable biases should be understood and described;
- Variables must be valid indicators of the provision of CD4, viral load and/or ART;
- When calculating in-care data across databases, comprehensiveness and non-duplication is important;
- Good, rather than perfect, estimates should be the goal;
- Consistent data and methods permit tracking over time;
- Reasons for data selection should be documented;
- Confidentiality is key; and

Data Inputs for the Unmet Need Framework: Questions and Answers (Western Meeting)

Question: How do you account for people who die during the 12-month period. Should we just use information on those who receive care during any point in the 12-month period?

Dr. Kahn: Yes.

Question: Does the definition of being in care mean those who are in primary medical care?

Ms. Janney: It has to be HIV primary medical care. For instance, a woman who is treated for reoccurring yeast infections, but is not receiving HIV primary medical care, would not be considered “in care.”

Question: There must be evidence of ART, CD4 counts or viral load testing, correct?

Ms. Janney: Yes. If you do not have that data, you can use upper- and lower-bound estimates as a temporary measure until you have access to that data.

Question: Our ADAP program in San Francisco will not be providing viral load testing to some clients, due to budget constraints. What should we do?

Ms. Janney: I would evaluate all your data sources and see if you can use lab-based reporting to get information on care patterns. Also, I want to clarify that “met need” involves meeting only one of the three criteria — viral load testing, and/or CD4 counts, and/or ART.

Question: Have you looked at estimating the number of people in care by choice? Also, are you looking at the capacity of a system in meeting care needs?

Dr. Kahn: The latter question is not addressed in our estimate, but it is very important. If we can document need, we can possibly get additional support for programs to address the second point you raised.

Question: Would you assume someone on ADAP is in care?

Dr. Kahn: Again, you need to look at specific data. Just because someone is eligible for a service, doesn’t mean they are getting it. If a person is getting prescriptions, then we would consider them to be in care.

Question: In our EMA, we have access to Medicaid data, but I don’t think there is much unduplicated data available?

Dr. Kahn: There must be a system for unduplicating the data. If you can’t unduplicate, that’s a big problem.

Question: Since CD4 counts can be used for multiple diagnoses, how should we adjust for those that are related to HIV?

Ms. Janney: You can count the number of people with HIV in the Medicaid database, for example, and within that subset you can look for CD4 counts. We can provide the codes to you for identifying someone who is HIV-positive, as opposed to having another illness for which a CD4 count would be taken. Please e-mail us and we will provide you with the information.

Question: This framework does not address the needs of those who don’t know their status.

Mr. Morgan: That's right and the justification is that in order to receive HIV primary medical care, someone has to have a confirmed diagnosis of HIV. However, HIV prevalence estimates are important in the overall needs assessment and priority setting processes.

The legislation addresses the need to identify those who are aware of their status but not in care. **As part of the new CDC initiative, you will have to start finding people, including those who don't know they are HIV-positive.** We also understand that you may have to reallocate dollars to meet demands of the legislation, and some other support services will have to be lower on the priority list.

Question: Should we count people who test positive but don't return for their test results.

Dr. Kahn: We will have to work in the next few weeks to determine how to address high rates of non-return.

Comment: It would be important to involve public health department staff that are knowledgeable about rates of those who do not return for their HIV test results.

Question: With respect to Title I and II coordination, are there any plans to get more collaboration from the State and making this a mandate?

Mr. Morgan: The Statewide Coordinated Statement of Need (SCSN), which came out of the 1996 CARE Act amendments, was the first attempt to have coordination across all Titles. Over the last three to four years, it has become clear that as dollars flatten out, there must be enhanced coordination. That's why we created the joint epidemiological profile guidance, and other initiatives. At HAB, we walk a fine line between being prescriptive and allowing for flexibility. I think it is clear that you need to work together, that you can go further with your resources if you do. We will not be sending out a mandate, but we think it only makes sense for you to work together.

Question: Can you submit CARE Act Data Report (CADR) data back to us in a data set format, and unduplicated?

Mr. Morgan: We have talked to OSE and will follow up.

Question: At what point will you evaluate this process to see if it's working?

Mr. Morgan: We will be evaluating the process, but we believe it will be long-term.

Ms. Janney: The estimates provide an impetus to look at what's going on. It is an issue of access to services, and data quality.

Measuring Unmet Need for Primary Care In Louisiana

***M. Beth Scalco, Administrative Director
Louisiana Office of Public Health
New Orleans, Louisiana***

Ms. Scalco discussed Louisiana's approach to estimating unmet need, using a surveillance-based model. She said that having worked on the unmet need project for a while, she has found that the data is useful, but also raises more questions as to why PLWH are not in care.

Louisiana has had AIDS case surveillance since 1984, and confidential name-based HIV reporting since 1993. All AIDS and HIV cases are reported to HARS. In 1996, the State also started conducting lab surveillance for results indicative of HIV, so they could track the data over time. In 2001, the state started using an ancillary lab database to maintain all lab results for each person with HIV. Lab and HARS data for 2002 were used to estimate unmet need. Any individual who had a CD4 or viral load test during 2002 was considered to be in care.

Using these data, the State found that of the 14,650 persons living with HIV/AIDS in 2002, 67% of PLWA were in care, 43% of PLWH were in care, and 55% had at least one lab test during the year. Those with AIDS were more likely to be in care.

In conducting a sub-group analysis of the data, the State found that 60% of females and 53% of males had a lab test during the year, that pediatric clients were most likely to be in care (70%), that 29% of those under age 13 were not in care, and that 32% of 13-19-year-olds were not in care.

Regional breakdowns of the data revealed some regions with high estimates of unmet need. It was discovered that one of those regions did not report lab data, and so the unmet need estimate was adjusted. Another region was close to the Texas border, so the State surmised that perhaps PLWH in that area were going to Texas for care. Louisiana also discovered that there were a number of people in its surveillance system that had moved out of State.

The following questions have been raised during Louisiana's work on estimating unmet need.

- How complete is lab-reporting data?
- What is the underestimation of those in care due to moving, death, and deportation?
- What is the validity of using CD4 and viral load tests as a marker for a care visit?
- How can you ensure that labs are associated with a care visit and not a diagnostic test?

In determining the feasibility of using Louisiana's approach to measuring unmet need, grantees would need to determine if they have reliable lab data available, how timely their data is, whether they have electronic lab reporting, and what programs are used to match and import electronic lab data, among other considerations.

Louisiana found that their use of the framework helped them produce a helpful estimate of unmet need in a cost-effective manner. The approach uses data from all systems of care, and once it is

set up will support sub-population analyses. The big challenge in using the approach is that many jurisdictions do not have lab-reporting systems in place.

Ms. Scalco also outlined some of the staffing and resource needs that the State had in order to meet their goals for estimating unmet need.

She ended by saying that the Title II grantee will work closely with the Title I program on this effort, and will provide Title I with guidance in estimating unmet need for their use in the CARE Act grant application and other areas. She stressed the importance, and benefits, of Title I and Title II collaboration in this effort.

Louisiana plans to use its unmet need data for the following:

- An analysis of the relationship between labs and care visits;
- An assessment of the completeness of lab reporting;
- Matching the HARS and ADAP/CAREWare databases to determine if people living with HIV/AIDS are getting ART, but not lab measurements;
- Matching data with the national death index (NDI) to determine who might have left the State or who has died;
- An analysis of the Interstate Duplication Evaluation Project results to determine who's living in the State with HIV/AIDS; and
- Additional information on ART from other sources, such as Medicaid, Labtracker, the Adult Spectrum of Disease (ASD) and CAREWare.

Questions on Louisiana's Unmet Need Work (Eastern Region Training)

Question: Is there a plan in place to address the 30% of pediatric cases not in care?

Ms. Scalco: A frustration with our surveillance data is that I can't use it to send a case manager out to a client's house. I will be consulting with Title IV on the issue.

Question: How accurate do you think your geographic breakdown is?

Ms. Scalco: We are constantly updating our information. It is not exact, but it is useful.

Question: How do you know that your CD4 data is only for HIV, not another disease?

Ms. Scalco: Because we are using HARS data.

Question: Have you looked at waiting lists or agency funding in the context of those not in care?

Ms. Scalco: I am not sure what we will be doing about that. We have used all of our ADAP funding and, with our current resource levels, we won't be able to provide care for the individuals we are identifying through this process.

Question: What about confidentiality?

Ms. Scalco: With all CD4s being reported, it's not really an issue.

Question: Is Louisiana capturing data about those who take the rapid test?

Ms. Scalco: We are just beginning to get that data, but the downfall is that it will only provide us with information on individuals who test positive for HIV.

Questions on Louisiana's Unmet Need Work (Western Region Training)

(Note: For the Western Region Training, the UCSF team presented on Louisiana's experience with estimating unmet need because Ms. Scalco was unable to attend.)

Question: In Wisconsin, we feel confident in our population data because we have had HIV reporting for a long time. However, we are concerned about care data. We only have data on individuals with CD4 counts under 200 and the completeness of our viral load data is questionable. In addition, we have no access to Medicaid data.

Ms. Janney: You could look at ancillary databases, as well as dates on which CD4 and viral load data are reported.

Question: Will there be any discussion around the qualitative piece of doing this work?

Mr. Morgan: I urge you to speak to your project officer about that. The presentations you've heard today have been given to all project officers so they will be a first-line resource.

Ms. Janney: We are also hoping that you see through the presentations that developing these estimates can help direct you in other activities. For example, Louisiana is now doing some work with Houston.

Question: Are there examples of doing analyses at the aggregate level to estimate unmet need?

Dr. Kahn: In general, we would urge caution around that. In New York, however, we made assumptions that people in the VA system were not getting CARE Act services. If you are looking to adjust for those who are privately insured, you can look at hospital discharge data files and for those with an HIV diagnosis, you can exclude those with private insurance. These are imperfect approaches, but they can yield some information.

Question: Is there an imperative to break out HIV from AIDS? Will there be other things HRSA wants to know? Will we be providing estimates by race, ethnicity, gender, etc in near future?

Dr. Kahn: You should be looking at Table 6. This year we will do additional field tests in Louisiana, Atlanta and San Francisco to examine the feasibility of doing subpopulation analyses. Further, it is desirable to keep separate estimates for HIV and AIDS

Mr. Morgan: Information by race, sex, and subpopulations will be helpful as we try to get additional support for our programs.

Question: Do you want information on everyone with HIV living in our State?

Mr. Morgan: I will be attending a CDC meeting on in and out migration and I will carry that question forward. The answer for now is “yes.”

Ms. Janney: Also, if you do adjustments for migration, do it in both directions.

Question: Will we, at some point, be looking at who is in Medicaid vs. receiving services under the CARE Act vs. who is being served through the VA system?

Mr. Morgan: It is not inconceivable that we would go down that path, but we need to start where we are first and see where that leads us.

Measuring Unmet Need for Primary Care In Atlanta

Eastern Meeting Presenters:

***Kandace Boyd, Assistant Director
Ryan White Projects
Fulton County Board of Commissioners***

***Linda Beer, Research Associate
Center for Applied Research and Evaluation
Southeast AIDS Education and Training Center (SEATEC)***

Western Meeting Presenter:

***Debbie Isenberg, Director
Center for Applied Research and Evaluation Studies
Southeast AIDS Education and Training Center (SEATEC)***

Ms. Boyd said that the Atlanta EMA decided to contract its project out using funds from the Planning Council support category. The city decided to work with the Southeast AIDS Education and Training Center (SEATEC) at Emory University, based on a prior working relationship and a knowledge of SEATEC's capabilities.

The city began to assemble its unmet need team, including staff of the health department, ADAP program, and those working with the supplemental HIV/AIDS surveillance (SHAS) data. Thirteen individuals participated in a workplan session, bringing various data sets from their programs. The core group made a commitment to participate in the project for its duration.

Ms. Boyd emphasized the importance of keeping the Planning Council updated on the progress of the unmet need work. In Atlanta, the Planning Council has received presentations on the methodology, as well as initial results of the analysis of unmet need.

Dr. Beer described the method — termed the “linked-database method” — used by Atlanta to estimate unmet need. From the outset, SEATEC, working in collaboration with the grantee, identified other types of information they could pull from the data they'd be using to estimate unmet need.

Considerations for the databases used to estimate unmet need included:

- Types of data available;
- Representativeness of the data;
- Limitations of the data set; and
- Sustainability of the database over time.

Atlanta modified the operational definition of “in care” to include a category of “intermittent care.” Those individuals who had received a CD4 test, viral load test, or ART in a 12-month

period were considered to be in “intermittent” care. Individuals in “regular care” had more than one of the three measures in a 12-month period. Consistent with the operational definition, those without one of the three measures in a 12-month period comprised the population of individuals with unmet need.

Population inputs used by the city included:

- HARS for AIDS cases; and
- Mid-point of the CDC estimate, because Georgia does not have HIV reporting;
- Medicaid data;
- CARE Act data;
- VA data; and
- The Health Cost and Utilization Inpatient Sample, which was adjusted using data from private providers.

In addition, Atlanta looked at the data to determine service gaps for meal delivery, transportation, child care, client advocacy, foster care and education/risk reduction activities. Substance abuse and mental health diagnoses for those in public health care programs were also reviewed.

The project was conducted in two stages. The first stage involved creation of a crude estimate, based on unique cases within databases, duplicated data across databases, and unmet need for HIV primary care only. A refined estimate was then calculated. It included:

- Unique cases within databases;
- Unduplicated data across the Annual Administrative Report (AAR) and Medicaid databases;
- Unmet need for primary care and service gaps for other medical care and support services;
- Cases 13 and older; and
- Information on co-morbidity and patterns of care among subpopulations (gender, race, etc.).

Dr. Beer explained that because there was no data from a main provider of pediatric care in the EMA, the estimate did not include any information for those individuals younger than 13.

By using the unmet need framework, the Atlanta EMA discovered that:

- 5458 (86%) individuals with AIDS were receiving primary care;
- 3284 PLWH were receiving primary care;
- 32% of PLWH were covered by private insurance;
- 34% of PLWH with private insurance were receiving primary care;
- 2591 PLWA with private insurance had an unmet need for primary care;
- 2416 PLWH with private insurance were not receiving primary care;
- 86% of PLWA were receiving primary care; and
- Overall, 3800 people with HIV in the EMA had an unmet need for primary care.

The EMA used the data to calculate racial breakdowns of those in care with unmet need for mental health and substance abuse services. (See Training Manual)

The EMA found the framework to be a flexible methodology that enables the use of local data sources. Atlanta used the activity to increase collaboration and coordination with other entities. Further, the EMA was able to broaden the framework's application to get additional information about PLWH. The effort helped Atlanta highlight issues with its data collections systems that might not have been otherwise known.

Atlanta also discovered the importance of database management and having someone with statistical skills involved in doing the unmet need estimates.

Some of the lessons learned include:

- The framework relies heavily on data quality and comparability;
- The lack of participation from private insurers necessitated an indirect way of estimating care patterns;
- Unduplication across data sets was difficult to achieve due to lack of common data elements and confidentiality issues;
- Confidentiality issues play a big role in gaining access to data for conducting the unmet need estimate; and
- Staff turnover is a challenge that has to be addressed in performing this work.

Next steps for Atlanta include working to refine their estimate even further, and presenting the data to the Planning Council for integration into the comprehensive plan.

Questions on Atlanta's Unmet Need Work (Eastern Region Training)

Question: How did you unduplicate Medicaid and AAR data?

Dr. Beer: We used an algorithm based on race and zip code. We ran into some difficulty, but were able to generate a unique identifier for Medicaid. Still, 20% of the AAR data was not unduplicated and we continue to look at this issue.

Question: Should each of the numbers in your graphs add to 100%?

Dr. Beer: No, because it is percent use for each service category.

Questions on Atlanta's Unmet Need Work (Western Region Training)

Question: Where did you get data on individuals with mental health and substance abuse diagnoses that were not getting care?

Ms. Isenberg: We looked at individuals with a current HIV diagnosis, then went through and got codes for the services they received.

Question: You said you developed an algorithm for linking AAR to Medicaid?

Ms. Isenberg: Yes, it's client level and unduplicated.

Question: How hard was it to work with Medicaid?

Ms. Isenberg: Not too difficult. In part because Georgia had applied for a Medicaid waiver and there was precedence for collaboration. It was hard when the data manager left. And what took a long time was Medicaid's legal review of the collaboration agreement.

Question: Did you share information with private insurers as a way of getting them to participate?

Ms. Isenberg: We are sending a preliminary report to those who participated, but we could think about sharing with others. It's not that they didn't want to participate, they didn't have time.

Question: Can you say more about the technical challenges you encountered?

Ms. Isenberg: The biggest challenge was that we do not have HIV reporting. It was also difficult to find commonalities between our data and Medicaid data. Medicaid created the algorithm for us and was very willing to help. I highly encourage the use of surveillance data, which was not an option in Atlanta.

SPECIAL GRANTEE PRESENTATIONS: EASTERN REGION TRAINING

Estimating Unmet Need for HIV Primary Medical Care in New Jersey: A Proposal for Statewide Collaboration

Karen Dodge
Public Health Planner
Palm Beach County Title I Program, FL

Carmine Grasso
Director of Care and Treatment – AIDS Division
State of New Jersey

New Jersey reported on a proposed approach for collaboration across jurisdictions and CARE Act Titles in estimating unmet need. Six EMAs, 4 consortia, 9 Title III sites and 7 Title IV sites will be involved in the project. The rationale for the collaboration is that it is geographically manageable, will save time and resources, and will ensure an accurate estimate. Further, the project will benefit from existing collaborations in place from the State's efforts around the SCSN. The SCSN forum will be used to conduct the State's work on unmet need.

In New Jersey, all laboratory activity is reported to the HIV/AIDS surveillance system: there is an internal mechanism in place to indicate viral load and CD4 counts at the State level. Additionally, all payers of pharmacy benefits use the same electronic reimbursement system, so information on all public ART providers is available.

The State's plan involves caucusing with participants at the DSS Regional Training to further discuss implementation of the approach and solicit participation and comments. The AETC will also be invited to participate in the initiative. Additional steps will include identifying members for enhanced SCSN membership, and strengthening working relationships with the Medicaid and VA programs to gain access to data.

New Jersey plans to request TA from HRSA and recommendations from the Governor's AIDS Advisory Council for a Statewide unmet need initiative. An SCSN meeting in Trenton in November will be used to implement unmet need activities.

Mr. Grasso also provided information about proposed population sizes, care patterns, and data sources for both (See Training Manual). He said the State was considering the use of either a linked database model, or taking data from the HARS database.

Questions on New Jersey's Proposed Approach

Comment: I applaud the State for taking this effort on, and hope the EMAs and consumers are engaged in the process.

Mr. Grasso: We are responding to what is a requirement for all of us. We look at this as a first step in estimating unmet need and providing us with enough resources to continue to provide the services.

Question: How can we pay for this work?

Mr. Morgan: Under administrative or Planning Council support. You should look at those categories to see if you have room in the budget for these activities. Also, the kind of partnership outlined by Mr. Grasso is an option.

Question: Why is the focus on primary care?

Mr. Morgan: There are clear PHS guidelines on primary care and this is basically what the CARE Act should be paying for. Appropriations are increasing for ADAP and primary care. At the same time, there are some who are concerned about CARE Act funding being used for services such as dog walking and buddy support. HAB must respond to OMB and Congress, and those kinds of services will not drive the appropriations process.

Question: Where do we need to focus for the SCSN, on primary care or service gaps for case management, transportation, etc?

Mr. Morgan: The SCSN brings people together to look at what is being done about all needed services. You can use the SCSN for the planning process for the comprehensive plan and to meet locally on the unmet need framework.

Question: Are there examples from pilot projects of approaches that weren't successful?

Dr. Kahn: Mississippi, which has few AIDS cases and providers, may be a good model for a low impact State. San Francisco used a combination of two methods to look at care patterns. The health department conducts chart reviews on PLWA, which produces excellent information, but is a time consuming process. The city used an AIDS progression study for PLWH to do estimates of prevalence. The disadvantage of this was that it was a one-time study. The challenge for San Francisco now is that HIV reporting data is code-based and only 50% complete.

New York has a well-established research program and an excellent linked database that combines Medicaid and ADAP. Their process focused on linking databases. Some challenges included reimbursement databases that provided information on service packages.

Question: Should we expect that databases are available to the public, because public dollars pay for them?

Mr. Morgan: A lot of this requires you to have a relationship with the person who maintains the database and is dependent on your ability to prove the benefits of using the data.

Dr. Kahn: The feedback we've received is that this project has brought people together in collaboration to address the issue.

SPECIAL GRANTEE PRESENTATION: WESTERN REGION TRAINING

Estimating Unmet Need in Washington State

Mark Stenger, Epidemiologist
Office of Infectious Disease & Reproductive Health Assessment
Washington State Department of Health

There is good collaboration between Titles I and II in Washington State. Both programs share epidemiological resources, staff, and other resources as well. The State has a name-based reporting system, which involves keeping the name of the person for 90 days, and then supplanting it with a unique identifier.

Mr. Stenger said that Washington began to look at unmet need in January. The first step was to come to consensus about how the unmet need framework would be implemented and used. The framework is viewed as a mechanism for establishing replicable methods for identifying unmet need. The operational definition for "in care" was used by the State, with the exception of data on ART.

The next step involved establishing criteria for including data sources. Lab reporting data was used, but the State only reports CD4 counts below 200 and does not report undetectable viral load levels.

Findings revealed an unmet need estimate of 28%. Data was then examined individually for the State and the EMA. When looking across Title II, there are higher estimates of unmet need for rural consortia (63.3% in care for rural populations). The data revealed no significant differences between gender, race and ethnicity in terms of unmet need, said Mr. Stenger, so the State will be taking another look at the data. The most significant differences in estimates were between Titles I and II.

The State has come up with mid-point estimates for 2001, using confidence levels and lower- and upper-bound estimates. Confidence levels will be reviewed again.

Washington State views this as a new initiative subject to possible, significant changes in the way it arrives at estimates of unmet need. The biggest concern is that there may be a loss of funding for the ASD, which is data that the State depends on.

In closing, Washington State feels like it needs to do a lot more work in refining the estimates of unmet need. The process will be ongoing.

Questions On Washington State's Unmet Need Work

Question: What about ART?

Mr. Stenger: Washington State did not look at that. We only used CD4 and viral load measures as predictors of care.

Question: Did you consider looking at mental health or substance abuse diagnoses as part of your analysis?

Mr. Stenger: Our data sets do not support that. What we could do is take what we've learned and begin to match across other data sets.

Question: When you talk about HARS data, are you talking about those with HIV/AIDS living in your State, or those diagnosed in your State?

Mr. Stenger: We track all HIV/AIDS cases, irrespective of where individuals were diagnosed.

Question: Did you break out who was in care for different systems?

Mr. Stenger: No, we did not match across care systems, but we could look at provider sources to determine who is paying for care.

Question: Does a name vs. a unique identifier have an impact on data quality?

Mr. Stenger: You can match across to other public health data sets.

Question: Do you have access to all lab data?

Mr. Stenger: Yes, for all patients living in Washington.

Opening Remarks – Day 2

Deborah Parham
Associate Administrator
HIV/AIDS Bureau
HRSA

Dr. Parham thanked HAB's Unmet Need Workgroup for spearheading efforts in meeting the unmet need requirements of the 2000 CARE Act amendments, and for organizing the grantee training. Workgroup members include: Sonya Hunt Gray; Doug Morgan; Yukiko Tani; Sheila McCarthy; Johanne Messoro; Donna Phillips; Hushel Coates; Celia Hayes; Steven Young; Katherine Marconi; Mary Vienna; Tanesha Burley; Paul Beasley; Emily Gantz McKay; and Alan Gambrell. In particular, she acknowledged the work of Ms. Hunt Gray for coordinating the training, and also thanked grantees for "all their good work in identifying people with HIV/AIDS and providing them with quality care."

She then discussed the new CDC prevention initiative focused on HIV-positive individuals, and expressed HAB's concern over the implications of what the potential influx of new clients will mean for the CARE Act service delivery system. She added that the new CDC initiative will require grantees to deliver vital services in an even more cost effective manner, because the 2004 budget does not provide any significant increases for the CARE Act.

HAB is constantly trying to understand the changing nature of the epidemic in terms of the following:

- Financing issues, such as the fact that in many States Medicaid is contracting with managed care providers, that State budget shortfalls have caused waiting lists on ADAP, and as people fall off other systems they turn to the CARE Act for services;
- The development of new drugs that enable people with HIV to live longer and healthier lives, which increases the number of people living with the disease and the need for CARE Act services; and
- An increased emphasis on accountability and the implications for future program funding.

In particular, Dr. Parham noted a recent assessment of the CARE Act program conducted by OMB using the newly developed Performance Assessment Rating Tool (PART). She said the tool was being used to grade program effectiveness in several areas, and that the results would be used in part to determine how much money would be allocated to which programs. She voiced concern over the CARE Act's receipt of a medium grade from the assessment, and said HAB is seriously working to implement OMB recommendations for improvement.

Finally, she said that while HAB has been able to share resources and expertise that have been useful in global AIDS efforts, the agency wants to continue to emphasize the severity of the epidemic at home and the need for an effective response that incorporates both prevention and care activities.

Rapid Assessment, Response, and Evaluation (RARE) Project

*Christopher Bates, Acting Director
Office of HIV/AIDS Policy
Department of Health and Human Services (HHS)*

Mr. Bates said he appreciated the work of CARE Act grantees, especially as a former Planning Council member and as the former Executive Director of the Title II consortia in Washington, DC. He thanked grantees for their work and for “walking through the community and talking about a topic that most don’t want to talk about.”

He then provided background on the RARE approach. Three years ago, HHS met with the World Health Organization (WHO), which had developed a rapid assessment methodology to respond to the AIDS crisis in international communities with little infrastructure in place.

In the United States, assessments tended to be long and resource intensive and did not allow for quick responses to shifts in the HIV epidemic. HHS was interested in adopting the rapid assessment approach for resource-poor communities in the States, in an effort to make HIV services more accessible, available and culturally responsive.

Care, said Mr. Bates, in many ways is about personal relationships with clients and treating people with dignity and respect. RARE is a qualitative assessment that asks communities “what do you think and feel and know” about the HIV epidemic. RARE takes into consideration the context and environment and how that impacts on HIV. People do not spread the virus based on one activity, he said, you have to consider the person as a whole.

“RARE is about speed – what drugs are in use today, what they cost, what area is hot today, what park or bath house is hot today. RARE involves letting hypotheses evolve based on the local experience, and local feedback.”

*-- Christopher Bates
Acting Director
HHS Office of HIV/AIDS Policy*

The four stages of RARE are:

- Assessment;
- Intervention Development;
- Implementation; and
- Evaluation.

Mr. Bates stressed that evaluation is a critical component of RARE, and citing Dr. Parham’s earlier comments on accountability, he stressed

the importance of evaluation in efforts to secure additional resources for HIV/ AIDS programs.

RARE projects are generally 3-4 months long and involve decision making by the local community. This is critical to getting local buy-in and establishing trust, said Mr. Bates.

RARE convenes community working groups, comprised of local government officials, planning groups, CBO representatives, consumers, mental health providers, the media and others. A Field Coordinator is recruited from the community, whenever possible, to hire Field Team

Investigators, provide ongoing training for the Field Team, and interact with the community work group.

The methodology for collecting data includes:

- Focus groups;
- Cultural expert interviews;
- Street surveys;
- Mapping; and
- Observation, which means watching people engage in activities and understanding how they use their physical environment.

Because RARE uses small sample sizes, it is a very doable method. Further, the interventions are affordable to produce and do yield outcomes.

Mr. Bates provided one example of how RARE was able to identify and implement an effective intervention in one community within a short period of time using minimal resources. In this particular community, RARE found that HIV prevention providers worked during the day, whereas women who were having sex for crack and for money were doing most of their work at night. Part of the intervention involved rearranging the hours that prevention staff worked and setting up a storefront in the community, with a washer and dryer, phones, etc., an approach that has brought more than 60 people in for services.

(See Training Manual for more details on the RARE Project)

Questions on RARE (Eastern Region Training)

Question: Do you need a certain population level to use this methodology?

Mr. Bates: No, it's very flexible.

Question: What are some other obstacles you've found in doing this work?

Mr. Bates: Trust. Many health departments don't have good relationships with local communities. Many AIDS service organizations (ASOs) have not been well connected to the communities they are trying to serve.

Question: In Orlando, we have a situation where our police department now wants to interview our field interviewers.

Mr. Bates: That is a cause for concern. In Miami, the police started arresting male prostitutes and used the possession of more than one condom as evidence that they were selling sex. It had taken RARE teams in that community 9 months to get these men to carry condoms. So, it's

tricky, because you want the police to be involved, but you need to be clear of their mission and make sure you don't expose your clients.

Question: What is youngest age group with which you have worked?

Mr. Bates: In Baltimore, we are working with 18-24 year olds and can't really go much lower than that because of parental consent issues.

Question: How would we work on a Statewide level?

Mr. Bates: In Florida, they have conducted training for trainers, and are working with the State health department on that effort.

(Note: Mr. Bates was unable to attend the Western Region Training, so his presentation was given by Moses Pounds and Richard Conviser of OSE)

To find out more about how you can participate in a RARE project, contact Sheila Merriweather in the Office of Minority Health at smerriweather@sosphs.dhhs.gov or at **301.443.9923**

Using RARE for Care Initiatives

*Richard Conviser, Chief
Service Evaluation and Research Branch
Office of Science and Epidemiology
HAB*

*Moses Pounds, Deputy Chief
Service Evaluation and Research Branch
Office of Science and Epidemiology
HAB*

Dr. Conviser stated that he worked in 1994 doing needs assessments in Portland, Oregon and later in Kentucky. He said these experiences helped expose him to the issues of disparities in the provision of HIV care services.

To address this issue, HAB is in the process of adapting RARE methods for care services planning. HAB's efforts are being funded through the Special Projects of National Significance (SPNS) program and will include pilot efforts in: Orange County, California; Palm Beach, Florida; San Diego, California; and Minneapolis, Minnesota. EMAs are being targeted for the study, said Dr. Conviser, but the approach could be used at the State level as well. In choosing communities in which to pilot the project, HAB looked at diversity in size, populations to be served, and location.

The approach will analyze the care system in each community to determine how comprehensive and coordinated it is, who is providing services, and what additional providers can be incorporated into the HIV care system. The goal is to provide recommendations to planning bodies and grantees for use in care services planning.

Some of the issues in health services planning that RARE will attempt to address include:

- Funding of the same organizations each year, even though they may not be the ones providing the bulk of services to affected communities;
- Care service systems are not evolving in line with the HIV epidemic; and
- Needs assessments tend to use samples of clients who are in care, and do not, therefore, yield information about the needs of those not in care.

Dr. Conviser said that RARE is being re-tooled by HAB to identify the needs of those not in care, and to determine the factors that influence which individuals are in and out of care in a particular community. The project will also look at where people live, their risk behaviors, health insurance status, and health-seeking behaviors as those factors impact on a person's likelihood of being in care. Further, the goal is to look at the cultural dimensions of service provision, such as service acceptability, provider knowledge and skill base, and client-centeredness of services, and how these characteristics impact on who's in care.

The following populations will be the focus of the pilot activities:

- African refugees (Minneapolis);
- African Americans (Orange County);
- Haitians (Palm Beach); and
- MSM of color, African American women, and non-IDU drug users (San Diego).

Data collection sites for the projects will include:

- Emergency rooms;
- Primary care sites;
- Adult and juvenile detention centers;
- STD clinics;
- Substance abuse clinics;
- Case management agencies;
- CDC prevention sites;
- HIV testing sites; and
- Bars, clubs, and social organizations.

National project staff will guide the work of each project site. However, all on-site work will be done by individuals from the community, hired by the community.

With this process, said Dr. Conviser, HAB hopes to discover what the care system looks like to people who are not in it and how the system measures up against their needs. Before turning the presentation over to Dr. Pounds, he acknowledged the following HAB staff for their help in adapting the RARE methodology for use by the CARE Act program: Alice Kroliczak of OSE; Ginny Bourassa of the Division of Training and Technical Assistance; and Jo Messoro of DSS.

RARE for Care Project Goals

- 1) Contribute to the decision making process for developing and managing the HIV care system
 - 2) Complement current procedures with evidence-based approaches
 - 3) Improve access for people not in care
 - 4) Institutionalize ability to reassess entry and retention progress
 - 5) Institutionalize involvement of affected communities
-

Dr. Pounds explained that the process will involve a local team at each site who will analyze the care system. This analysis will examine current and potential providers, assess how and which aspects of the system may act as access barriers, and make recommendations for how to correct problems.

Each project will be two years long and will include the training of local teams in project implementation. Local findings will be analyzed and integrated into services planning. HAB will also evaluate whether recommendations from the project actually lead to positive changes in

the system, once they are incorporated. Longer-term SPNS projects may examine how service changes have impacted on disparities in service access.

Dr. Pounds said that HAB has hired a principal investigator, Leah Kedar, who has already begun to meet with staff of local project sites. HAB is also in the process of hiring an evaluator, Luis Mejia. In October 2003, HAB will bring the local teams to Washington to train them.

As a final point, Dr. Conviser noted that while the unmet need framework is about quantifying unmet need, the RARE for care project is about all of the factors that impact on unmet need.

Questions on the RARE for Care Initiatives can be e-mailed to Richard Conviser at **Rconviser@hrsa.gov** or to Moses Pounds at **Mpounds@hrsa.gov**.

Questions on RARE for Care Initiatives (Eastern Region Training)

Question: When will the information from this project be available for use by local communities in the planning process?

Dr. Pounds: The plan is to share our findings in two years, and we will try to share as much information about our progress as the project comes online.

Question: How will this apply to Title II?

Dr. Conviser: We think this approach is applicable to all CARE Act programs. We have chosen to pilot the project with EMAs, but we will be developing tools for use by other CARE Act grantees.

Question: Will you be collecting any information on staff training? Are you going to survey providers?

Dr. Pounds: The characterization of the care system will include looking at where service providers are and how local funds are allocated by service type.

Dr. Conviser: We will be fleshing out how we collect the data, but have not done so yet.

Question: I would like to see cultural competence built into standards of care. I don't think many organizations go that far. Further, I am from the Washington, DC EMA, which is very complex, includes rural and urban areas, and crosses State lines. I am not sure how useful this information will be for our EMA.

Dr. Pounds: We are focusing on methods that should be relevant to all grantees. I think the tools will be helpful, if not the findings. We also hope that there is peer-to-peer assistance between you.

Comment: We used the methodology in Detroit to conduct a service system analysis for the Hispanic community, injection drug users (IDUs), and commercial sex workers. We found the methods very useful.

Dr. Pounds: We worked two-three years ago with the Lewin Group on candidate indicators of cultural competence. Those of you interested in incorporating those into your services can find them on the HRSA Web site at www.hrsa.gov.

Questions on the RARE for Care Initiative (Western Region Training)

Comment: I am from Los Angeles County and I like that RARE uses local analysis. I wanted to also say about your use of an example from our community, that your geomapping efforts are inaccurate. They suggest that services are not located where the clients are, and that is not true. That's why we think local analysis is such an important component of RARE.

Question: I am from a Title II program. Is there an opportunity for small, rural communities to be involved in this initiative?

Dr. Conviser: There will be several products emanating from process. One will be guidance on doing this intervention. While our initial pilot tests are being conducted in EMAs, I see no reason why this process couldn't be implemented in rural communities, or at the State level. In fact, Palm Beach County, which has many rural areas, has used the RARE for prevention methodology.

Comment: I am from the Los Angeles Planning Council. I really like the RARE project because it is fast and works with providers. I hope to see more use of this methodology to educate consumers and others on Planning Councils. I think the project provides a great opportunity to bring new people to the table and bring them quickly up to speed on community needs.

Dr. Conviser: I want to emphasize that the learning will be done at the HAB level as well. This methodology seems like a wonderful opportunity to improve responsiveness of the care system to needs of communities.

Unmet Need in a Small EMA

*Lisa Cardinale, Quality Management Manager
Dutchess County EMA
Dutchess County, New York*

Ms. Cardinale started her presentation by saying that even with limited resources it is possible to estimate unmet need in a jurisdiction. In Dutchess County, she explained, she is the only full-time staff person on the program, but was able to get support from others in undertaking activities to determine how many people in the service area have an unmet need for HIV primary care.

She provided some information on the EMA:

- The population is 280,000.
- The EMA is located between New York City and Albany.
- The area is home to many prisons.
- The biggest cities in the area are Poughkeepsie and Beacon, and these are the epicenters of the HIV epidemic.
- HIV data indicates that African Americans are disproportionately impacted by HIV.
- Men account for 75% of all HIV cases and 80% of all AIDS cases. IDU comprise the largest number of both HIV and AIDS cases by risk category.

Ms. Cardinale said that Dutchess County actually began to think about estimating unmet need a few years earlier. With limited resources, she said, the county needed additional lead time, and anticipated that there would be a need to respond to the issue sooner or later.

She outlines some of the advantages of being a small EMA.

- There are fewer decision makers.
- There are limited data sets to collect and unduplicate.
- There are limited numbers of providers to track utilization of services.
- Integration of services is easier to achieve.

She also outlined some of the disadvantages of being small.

- There are limited resources.
- There are fewer experienced planners in the process.
- There are fewer providers and potential contractors to choose from.
- There is limited technological capacity in small agencies.
- There are power issues around having only one provider for certain services.
- Limited dollars preclude in-depth strategic planning.
- It is difficult to decide how to use limited funds — for capacity building or service provision.

The EMA submitted a TA request to HRSA. The county received some training for Planning Council members, grantee staff, consumers and stakeholders. Ms. Cardinale said the TA was instrumental in helping the EMA begin to look at calculating unmet need.

Dutchess County realized that its HIV surveillance system was new and unreliable and that data from the system would not be extremely useful. Further, there is no linked utilization data between Title I providers, and the county, being small, does not have many special studies. So where did they look for data? They began with the following sources:

- Local provider databases;
- Data from prisons and jails;
- Medicaid;
- ADAP;
- AAR;
- Other CARE Act Titles; and
- The EIS out-of-care survey.

Ms. Cardinale said that the flexibility of the unmet need framework was helpful in allowing the EMA to begin to calculate an estimate based on what was available locally, in terms of data. However, she said the program did encounter some major challenges, such as:

- Lack of access to information on PLWH/A with private insurance and on those in prison;
- Unduplicated data for those seeking treatment outside the EMA;
- Insufficient resources and time;
- No unique identifier; and
- Limited unduplicated data between systems.

How has work on unmet need benefited Dutchess County?

- The EMA has a better sense of what HAB is looking for in terms of unmet need.
- The program has identified and is planning to address data and capacity challenges and is effectively selling the importance of doing this work to stakeholders.
- The Planning Council is a better-informed partner.
- The EMA has increased communication with Title II.
- The department of health supports the process.
- The EMA feels good about its progress in preparing for its FY 2005 funding application.

In particular, Ms. Cardinale cited the accuracy of prison data as a big challenge to estimating unmet need because patterns of care within the prison system are difficult to determine and prisoners are often reluctant to disclose their status. Both of these factors contribute to wide variations in HIV estimates. In comparing data from the National Institute of Justice, the Bureau of Prisons, and New York State, the EMA wound up with widely disparate estimates of those in

care — between 105 and 654. Since the EMA has only 1200 HIV-positive people, this variation was too big.

Given some of the challenges, the EMA has been able to come up with ranges of unmet need, but is working to refine and narrow the estimates. What the county has identified is the need for a long-term assessment of who has HIV but is not receiving care, and why those individuals are not in a system of care. Part of the data collection efforts will include administration of a survey during routine EIS outreach and engagement. Questions in the survey ask a person if they have HIV, when they were diagnosed, if they were ever in care, and what they would need to be in care. Ms. Cardinale said that providers have been given the flexibility to use terminology and approaches that resonate with individual clients. The EMA is hopeful that this survey will yield some useful data for the estimation of unmet need.

Recommendations from the EMA include:

- Provide Federal funding for use in making State and local data systems compatible, or postpone unmet need requirements until capacity is in place;
- Grantees should start data collection efforts early;
- Don't hesitate to request TA; and
- Integrate unmet need data collection into other activities.

Questions on Dutchess County Unmet Need Work (Eastern Region Training)

Question: We have a county with a large prison in our EMA and are wondering how to adjust for migration, and for prison populations?

Ms. Cardinale: I am hoping to get some of this information through the efforts that I mentioned. Make sure you do describe your rationale to HRSA, especially when you don't have strong data sets.

Question: How did you unduplicate your data?

Ms. Cardinale: We can't, so we examined clients of an infectious disease doctor, who is the only other provider of HIV primary care in our county. We are also requesting that our case management and nutritional service providers collect information on their clients.

Special CDC Presentation

Dr. Patrick Sullivan, Chief of the Surveillance Branch in CDC's Division of HIV/AIDS Prevention, addressed participants during lunch on CDC's new strategy "Advancing HIV Prevention: New Strategies for a Changing Epidemic." The initiative focuses prevention efforts on HIV-positive individuals as part of an overall CDC prevention portfolio that will continue to

include prevention interventions with HIV-negative individuals in high-risk populations. A copy of Dr. Sullivan's presentation was provided to all participants.

HRSA/CDC Joint Epidemiological Profile

***Celia Hayes, Senior Program Analyst
Office of Science and Epidemiology
HAB***

***Irum Zaidi, Epidemiologist
CDC Division of HIV/AIDS Prevention***

Ms. Hayes described the use of an epidemiological profile as a planning and evaluation tool. She said the goals of a profile are to describe the current HIV epidemic in a local area, understand possible future trends and identify characteristics of affected populations.

Ms. Hayes said that HRSA moved forward with development of guidance for a joint HIV prevention and care profile based on grantee requests for streamlined processes and guidelines. The profile was developed with grantee input and incorporates common data sources for CDC and HRSA. The benefits of a joint profile include increased utility and application, enhanced data sharing at all levels, easy interpretation and application to local needs, enhanced possibility of using it in planning processes, and effective use of local resources.

Ms. Hayes provided background on the process of developing the epi profile guidance (See Training Manual) and invited grantee feedback on its usefulness and length. She acknowledged the support of Katherine Marconi and Steven Young from OSE in developing the profile guidance, and thanked grantees that provided valuable feedback during the guidance draft stages. She added that TA will be available from HRSA for grantees that need help in creating a joint profile.

5 Core Epi Questions to be Answered Using the Joint Profile

- 1) What are the socio-demographic characteristics of the general population in the service area?
- 2) What is the scope of the HIV epidemic locally?
- 3) What are the risk indicators for HIV infection?
- 4) What are the patterns of service utilization in the service area?
- 5) What are the number and characteristics of persons who know they are HIV-positive but are not receiving primary medical care?

Ms. Zaidi said that guidance would help identify information that could be used by both prevention and care planning bodies. The guidance provides new and recommended analyses, data sources, and examples to help grantees use it effectively.

She outlined possible uses for the joint profile, including:

- Development of comprehensive prevention or care plans;
- Setting population priorities for care and prevention resources;
- Framing research and evaluation questions;
- Producing information for use with the unmet need model; and
- Assessing the composition of planning groups.

She then reviewed with participants the major components of the joint epidemiological profile guidance (See Training Manual). Included in her presentation were examples of how to use the profile with varying types of data that may be available locally, such as AIDS data only, HIV and AIDS data. She also talked about how to make adjustments for time delays in data reporting.

Finally, Ms. Zaidi recommended that grantees complete a comprehensive epidemiological profile every five years. Updates of the executive summary and the core epi and care-related questions should be completed when new data is available.

Questions on the Joint Epidemiological Profile Guidance (Eastern Region Training)

Question: What if we only have 3 years of HIV data?

Ms. Zaidi: You should use the first method I described, because it generally takes about 6 years for old cases to come in.

Comment: In Massachusetts, people don't get reported to our system until they have had a clinical care visit, whereas your approach assumes that people are reported to the system when they are diagnosed. So in terms of estimating HIV prevalence, I don't think this methodology would work for Massachusetts.

Question: When do we need to incorporate this guidance?

Ms. Zaidi: It depends on where you are in your planning process. We would encourage you to incorporate as much of it as you can during your next planning cycle.

Ms. Hayes: HAB expects you to use this in response to your Title I and II 2004 application guidances.

Question: Because the CADR is duplicated, how do you use it to complete the profile?

Ms. Zaidi: You have to unduplicate the data prior to using it with surveillance data.

Question: It's my understanding that CADR data is unduplicated at the agency level, but duplicated at every other level, and that it's not able to be unduplicated at any level but at the agency level.

Ms. Hayes: At best, you can use it as a data source, because what it provides is a baseline for what is happening in the State. We also recommend using percentages rather than numbers. Please look at Appendices A and B of the guidance for State-specific listings of available data.

Questions On the Joint Epidemiological Profile Guidance (Western Region Training)

Question: Is the data sent to Title I EMAs by the CDC indicative of true HIV prevalence, or for the estimated number of individuals diagnosed with HIV?

Ms. Zaidi: The HIV data that was sent to Title I grantees was the prevalence of diagnosed HIV (not AIDS) cases for areas with confidential, HIV name-based reporting systems. These are estimates of the number of persons living with HIV (not AIDS) at the end of December 2002 by age, race/ethnicity, mode of exposure and sex for EMAs within 29 states and the U.S. Virgin Islands. The data has been statistically adjusted for delays in reporting and for unreported risk.

Dr. Marconi: This fall, we will be providing grantees with a data dictionary in MS Word, the CADR data they have submitted to us in a Word format, and an Excel spreadsheet. We'll also provide you with guidance on how to use provider-level data in conjunction with the development of the joint epidemiological profile.

We will have the epi profile on HAB's Web site in about a month.

Question: In your presentation, you included combined numbers for HIV and AIDS for those who are unaware of their HIV status. How can we tease out the number with HIV?

Ms. Zaidi: There is no way to know for sure. I will follow up on the aware/unaware ratio, specifically as it pertains to aware/unaware dependent on AIDS and non-AIDS.

Question: How do you define geographical boundaries when you have overlap of community planning groups, Title I programs and others.

Ms. Hayes: We are hopeful that you will be able to collaborate with other programs to present information for your entire State. The purpose of the effort is to avoid multiple profiles.

Question: What about the fact that programs have different deadlines for submitting information to HRSA?

Mr. Morgan: We recognize that this is an issue and in the epi profile guidance we request the data at the same time each year.

Dr. Marconi: In addition, we are planning by the fall to have a network version of CAREWare.

Question: We are a Title II grantee without access to client-level data. Will HRSA be recommending that grantees collect this data?

Mr. Morgan: We think that client-level data is most useful. While we have not mandated use of CAREWare, we have stated publicly that we recommend its use. If I were you, I would require providers to use it.

SPECIAL GRANTEE PRESENTATION: EASTERN REGION TRAINING

Louisiana Experience Using the Integrated Guidelines for Developing Epidemiological Profiles

***Kira Radtke, Services Manager
Louisiana Office of Public Health***

In April 2002, Louisiana was asked to produce a sample epidemiological profile using the integrated guidelines produced by HRSA and CDC. The State was interested in doing this because it had integrated its surveillance systems, as well as its prevention and care programs. A joint profile seemed like a logical next step.

Coordination was begun early with care and prevention programs. This was helpful in gaining access to data, ensuring appropriate interpretation of data and understanding the strengths and limitations of various data sets.

Louisiana also recommends engaging both prevention and care planning bodies early in the process, to gain their support and to get information about the kind of data that would best support their planning efforts.

Louisiana committed two, full-time epidemiologists to work on the profile from May-July 2002. CDC staff within the State also worked on various sections. Ms. Radtke said that the State's experience showed the importance of having someone with an epi background involved in the process. Additionally, she said that designating one person to oversee the process is important, as is staff assistance from both prevention and care programs. Technical readers and editors are also helpful.

The State set out a 6-month timeline for completion of the project (See Training Manual). Ms. Radtke said that the schedule underestimated the time needed to de-duplicate data on HIV counseling and testing. Some data sets were readily available, such as HARS, ADS, Census data, and results of local outreach surveys. Other data was more difficult to obtain, such as STD data, counseling and testing data, information from CDC's youth risk behavior survey (YRBS) and CAREWare.

Some of the issues that arose with the use of behavioral data included:

- The lack of this type of data for many areas outside New Orleans;
- Many surveys were conducted one time, precluding an examination of trends;
- State law did not permit questions on sexual behavior as part of the YRBS;
- Survey data could not be generalized; and
- Some surveys required more advanced statistical analysis.

The use of service data, said Ms. Radtke, also poses challenges, because it is sometimes difficult to access, the quality is often not the best, some States and EMAs do not have client-level data, and data expertise varies among Titles and staff.

In presenting the information to stakeholders and the public, Louisiana struggled with the size of the profile and how to make it useful for planning purposes. Ms. Radtke said that the State did summaries at the beginning of each section, which seemed to help. She said in presenting the profile, it is also useful to note important distinctions between prevention and care audiences, and to present the information for use by both.

The State has used the profile to prepare its CARE Act Title II application. It has also been used by the CDC prevention planning group in prevention funding applications. Additionally, the State has received numerous requests for presentations on the profile, and has disseminated it for use by other Statewide planning groups.

The State health department will continue its provision of TA for planning groups using the profile. Further, ongoing TA from HRSA will be requested. The State has also established a mechanism for care and prevention planners to provide feedback to the profile writers.

Ms. Radtke said that the State found the guidelines useful in providing a structure for creating the profile, and providing the State with flexibility in adapting the profile for local needs. Further, the process has helped the Title II program move beyond its reliance on HARS data to understand what is happening in the State with respect to the HIV epidemic.

Ms. Radtke shared some suggestions on developing the profile. She urged the use of readily available software, and said that creating a procedures manual is a helpful way to address staff turnover. The manual should list agency contacts, provide information on where to store the data, and include the timeline used to develop the profile.

She had some final thoughts on the development of the joint epidemiological profile.

- The first time producing the document is the most difficult.
- Be prepared to receive increased data requests once the profile is created.
- Use the information to provide insights on the local HIV epidemic, but not as your only source of data on the epidemic.
- The process should be ongoing.
- There will always be information to add to the profile— local data, density maps, unmet need data, etc. — and changes in Federal requirements around both care and prevention activities will create new challenges in development of the profile.

(Note: Ms. Radtke was unable to attend the Western Region Training, so Ms. Hayes and Ms. Zaidi gave her presentation)

Questions on Louisiana's experience with the Joint Epi Profile (Eastern Region Training)

Question: How do you think the profile would change if you included information from other Titles?

Ms. Radtke: In terms of unmet need, it would not change. In terms of service utilization, we would benefit from that additional data.

The HIV/AIDS Bureau of the Health Resources and Services Administration would like to thank the following people for their work in developing the Unmet Need Training:

- James Kahn, Jays Janney and Katie Ikard for their work in developing the unmet need framework and grantee self-assessment tool;
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- Emily Gantz McKay for her support in developing the training and her provision of technical assistance to individual grantees;
- All the grantee and Federal presenters who were willing to share their experiences and knowledge with attendees; and

CARE Act Title I and Title II grantees, for their participation in the unmet need training and their dedication to providing quality care and services to people living with HIV.