

Recommended Protocol for HIV/AIDS Health Care Area Needs Assessments in Florida

Submitted by:

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Contents

	<u>Page</u>
Introduction	3
HRSA Guidelines	
Local Area Needs Assessments	
Assumptions	
Organization of Reports	6
Epidemiologic Profile	
Resource Inventory & Profile of Provider Capacity and Capability	
Estimating Unmet Need	
Types Data Collection	10
Consumer Survey	
Provider Survey	
Outreach Survey	
Focus Group Interviews	
Guides to Implementing Data Collection	14
Conducting a Consumer Survey	
Conducting Focus Groups	
Conducting a Provider Survey	
Conclusion	21
Appendices	22
A. Sample Epidemiological Tables	
B. Consumer Survey Sample (Long Form)	
C. Consumer Survey Sample (Short Form)	
D. Provider Survey Sample (Long Form)	
E. Provider Survey Sample (Short Form)	
F. Focus Group Facilitator's Guide	
G. Sample Focus Group Questions	
H. Provider Inventory Sample	
I. Definition of Terms	

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Introduction

The Area Needs Assessment is an important process used to identify gaps in care by identifying the needs of people living with HIV (PLWH), both those receiving care and those not in care, and what services are available to meet those needs. According to the U.S Department of Health and Human Services, Health Resources and Services Administration (HRSA), “needs assessment provides the information required to develop a service plan, set priorities, and allocate available resources appropriately-across a Title I eligible metropolitan area (EMA), Title II State, or within a Title III or Title IV project.” In late 1999, HRSA presented a six-section document that detailed for all grantees a guideline for conducting a comprehensive needs assessment (<http://hab.hrsa.gov/tools/needs.htm>). A more updated manual was released in 2003 for Title I and Title II grantees (<http://hab.hrsa.gov/tools/granteemanuals.htm>).

The Florida Department of Health Bureau of HIV/AIDS recognized the need for consistent reporting within the state and requested recommendations for a consistent protocol and related instruments. As a result, two major sources of data were analyzed for insights concerning recommendations for a needs assessment protocol and instruments: HRSA guidelines and local area needs assessment conducted in Florida during 2001. The following is a tool book for creating a needs assessment that provides a framework for consistent reporting thereby facilitating the development of consistent local needs assessments. This document reviews the HRSA guidelines, lessons learned from previous needs assessments, reporting recommendations and primary data collection methods.

HRSA Guidelines

According to HRSA, the comprehensive needs assessment should have at least five important components: 1) an epidemiologic profile, 2) an assessment of service needs, 3)

a resource inventory describing services available, 4) a profile of provider capacity and capability, and 5) an assessment of service gaps and unmet need based on an analysis of the aforementioned information. The epidemiological profile describes the current status of the epidemic in the service area. AIDS prevalence data and HIV prevalence data are used to document the status and impact of HIV/AIDS among defined subpopulations and trends in the epidemic. The second section, the assessment of service needs, includes identifying those barriers that prevent PLWH from receiving needed services. The third recommended component is a resource inventory which provides a comprehensive depiction of the continuum of care. This resource inventory should include a description of the types of services provided by each provider, the number of clients served, and funding levels and their sources. A profile of provider capacity and capability, the fourth section, should describe the extent to which the services in the resource inventory are offered by providers, are accessible to populations in need of services, and are appropriate for PLWH and specific subpopulations. This section relies heavily upon the information provided by the providers in the previous section in addition to data from sources that provide insight on access and appropriateness. The final component of the comprehensive needs assessment is an assessment of service gaps and unmet need. This is based on all of the data about service needs, resources, and barriers already ascertained in the other portions of the needs assessment.

Local Area Needs Assessments

Upon review of the needs assessment provided by the local service areas, it is apparent that content of any one report was determined by that individual area. For instance, some areas had the resources to provide extensive follow-up as part of their data collection methods, while others were forced to rely on scanty response rates. High non-response and poor response rates limited the validity of findings in all areas. Additionally, use of terms seemed to vary from area to area. Clarification of a few common terms (e.g. met needs, unmet needs) would facilitate greater uniformity of the local area needs assessments.

Assumptions

Several basic assumptions were made when developing the guidelines that follow. These included having hardware and software capacity to handle rich text format (.rtf) files and the ability to handle these files as email attachments. Also assumed was that in highly multi-cultural environment, foreign language translation services are available. A result of the previous needs assessments was a need for more culturally sensitive providers and products, which should also apply to needs assessment data collection. Due to the large number of data that is available on the Internet, areas should also have access to the World Wide Web.

Organization of Reports

A clear structure is emerging for Patient Care Area Needs Assessment Reports. The following sections are recommended by HRSA and proved feasible for many Areas in Florida during 2001.

Epidemiological Profile

The Epidemiological Profile is used to report the status of the HIV/AIDS epidemic of the service area. Different CARE Act titles will generally have different reporting needs, but it is useful for all service areas to collect a common set of data to facilitate benchmarking, comparisons, and compilation of a statewide report. The two major sources of data for this segment are HIV case surveillance and AIDS case surveillance data sources. The CDC has HIV/AIDS surveillance reports for states and EMAs. Total HIV prevalence is not provided by CDC however since not all states report HIV. The CDC also publishes a National HIV Serosurveillance Summary periodically. This summary provides information on the level of HIV infection among selected populations. Other sources of HIV data may include those from local and state health departments, vital statistics reports, clinics, drug treatment centers and correctional facilities. A list of the strengths and weaknesses of each data type is provided on the HRSA website.

Data is readily available in Florida from such sources as the Florida Department of Health, Bureau of HIV/AIDS, the Agency for Health Care Administration (AHCA) and the regional health planning councils in Florida. The Bureau of HIV/AIDS has surveillance data in unidentifiable aggregate form. The Bureau also provides an annual service area-specific epi profile that should be utilized. Medicaid and other insurance data are available from AHCA and frequently accessible from regional health planning councils in Florida. Counties also have access to AIDS Area offices, which house data for that area.

The steps to follow when preparing the HIV/AIDS Epi profile are first to plan the scope of the profile and decide what information is needed. Secondly, identify data sources and

collect the HIV/AIDS data for the local service area. Third, using that data, perform analyses that address the requirements of the Care Act title and program for the area. HRSA provides information on how to outsource the analysis task. Lastly, prepare the written epi profile and present the analyzed data.

According to HRSA, the narrative portion of the profile should include an explanation of the purpose of the needs assessment process, including providing a history of the epidemic in the service area. The methodology for how data was collected and/or analyzed should also be included especially if it varies from the state reporting system (HIV/AIDS Reporting System [HARS]). Sociodemographic information that describes the service area in terms of geography and population is also useful for planning purposes. Reporting of the demographics of high-risk subpopulations would be included in this section. Additionally, an analysis of the trends in the epidemic over time and possible projections may be included.

Service areas should also seek to describe the demographics of the HIV/AIDS cases in relation to the total population and the State's population. Beyond a general description of subpopulations, areas should comment upon any disproportionate impact upon these special populations that can be observed. In addition, a statement of how the State's HIV/AIDS epidemic impacts the cost and complexity of service delivery should be included. Any identified rate of increase in the number of reported cases should be noted. Specifically, emerging populations most heavily impacted should be identified. Special populations to be considered for evaluation include: racial/ethnic minorities, white gay and bisexual men, gay and bisexual men of color, injecting drug users, women, pregnant females, infants and children, adolescents, the elderly, recently diagnosed individuals, incarcerated populations, migrant workers and other transient populations. High-risk groups identified at the local level should also be evaluated.

Sociodemographic measures provide a framework for assessing the impact of HIV on a particular area or population. At the same time, various title application guidances have different requirements for reporting poverty, insurance status, surrogate marker and co-

morbidity data. In order to create a comprehensive report, information that is specific to PLWH in the service area as well as from the general population of the service area should be reported. All titles should report information on co-morbidities, in particular tuberculosis infection, and any general information that is available on surrogate markers. Other co-morbidities and surrogate markers of interest include syphilis, gonorrhea, other STDs, intravenous drug use, homelessness, etc. The Bureau of the Census has some of this sociodemographic information and other offices such as the Departments of Commerce, Welfare or Human Services should be able to provide other data.

The tables in the epidemiologic profile should include reported AIDS cases, reported HIV cases, and projected HIV and AIDS cases. Data or estimates related to specific subpopulations (e.g., injecting drug users, African-Americans, or women) and specific geographic areas (e.g., three counties in the eastern part of the State) should also be included. The CDC produces national data on new and cumulative reported AIDS cases which be obtained from the CDC Prevention Information Network (formerly the CDC National AIDS Clearinghouse) or through the CDC National Center for HIV/STD/TB Prevention website (www.cdc.gov/nchstp/od/nchstp.html). The limitations of the secondary data used should be noted so that others can judge the validity of presented data and conclusions. Epi profile specific tools are provided in Appendix A.

Resource Inventory & Profile of Provider Capacity and Capability

The resource inventory describes current HIV services in the service area, regardless of funding source. The profile of provider capacity and capability on the other hand builds upon the resource inventory by providing additional information about the availability, accessibility and appropriateness of services for PLWH. While these can be conducted separately, it is more efficient to conduct them simultaneously as they require many of the same contacts and approaches.

While the provider profile builds on the resource inventory, it is not necessary to include all providers from the inventory. This is especially true if a provider profile already exists. When focusing on the needs of special needs populations however, it may be

prudent to provide the details for all providers. The profile should not only include individual provider information, but also aggregated information, dependent upon title requirements. From the provider profile, areas should be able to estimate partially met and unmet need for services overall and for subpopulations. In addition, areas should report gaps in early intervention and primary care. From the findings, areas will be able to develop a service plan and a provider network to fill the identified gaps.

Estimating Unmet Need

In order to identify met and unmet service needs, an analysis of the epi profile, co-morbidity data, primary data, resource inventory, and profile of provider capacity/capability needs to be performed. Title I and Title II grantees are required to perform qualitative gap analysis overall and for specific populations and summarize the data in both a table and a narrative part of their applications. The qualitative gap analysis helps determine population and geographic specific needs. In this case, a qualitative analysis refers to the review of narrative and other non-quantitative and in some cases quantitative information to draw inferences and conclusions. The HRSA website only refers to requirements as of FY 2000, so the most current guidelines will need to be consulted.

EMAs should have sufficient data and resources to use quantitative methods to determine the gap analysis (the difference between met and unmet or partially met needs). This analysis should estimate the number of PLWH in a given area, document available services, and determine the number or proportion of PLWH receiving specific services and the number indicating a need for those specific services. These data can be obtained through the consumer and provider surveys, described in the following section. Challenges and assumptions made when conducting the analysis should be noted in the report.

Types of Data Collection

Consumer Survey

Beyond the use of secondary data, needs assessments also require the use of primary data collected via surveys, key person interviews, focus groups and community forums. The primary focus of the PLWH needs assessment client survey is to determine met and unmet service needs. Service areas will need to determine in advance what types of information will be collected through the survey. Surveying client satisfaction via this tool can also be performed. Sampling strategies that enable areas to ensure that the sample is representative of the population of interest are essential to interpret results.

After the survey has been developed, translation into another language should be done if necessary. Those who will conduct the survey will need to be identified and trained. Pilot-testing and adjusting the survey as necessary follows. Distributing and collecting the data is followed by analysis and development of the report described in the previous section. The survey that is provided in this tool book consists mainly of closed-ended questions, however open-ended (qualitative) questions may be developed and added to fit the needs of individual service areas. A sample consumer survey is available in Appendix B.

HRSA recommends conducting in-person consumer interviews. Use of mail surveys with a self-addressed stamped envelope is considered acceptable. The survey envelope or the return address envelope should not use the words HIV or AIDS or use any words or symbols that might identify the nature of the correspondence. Follow up reminder letters can help improve response rates. Non-respondent (abbreviated survey) should be considered when response rates fall below fifty percent. Sampling methods that ensure representation of the communities of concern are critical for the results to be most meaningful.

One of the disadvantages to using the mail survey is that language requirements cannot be ascertained beforehand. Therefore, it may be advisable to distribute the survey

instrument in multiple languages dependent upon the population of the service area. A Spanish/English version is appropriate for areas with large Hispanic populations. Similarly, surveys in Haitian-Creole/English would be appropriate for areas with large Haitian populations.

Provider Survey

HRSA recommends that provider surveys be conducted via mail-in surveys. However, if response rates were particularly low, it would be advisable to follow up with a reminder phone call and if necessary, develop a provider non-respondent short-form interview to conduct via telephone. The respondent survey should be used to provide a formulation for interpreting results, particularly when response rates are low. Also, in cases where providers fail to divulge certain information follow up telephone calls to obtain this information may be warranted. A sample long-form survey is included in Appendix C.

The minimum information to be collected for the resource inventory include: name, address and other contact information for the organization being surveyed, funding amount, funding sources, program focus, services provided, geographic project area, target population, and number of individuals served in a year. This information can be gathered through providers, consumers and secondary data sources such as provider directories. The inventory compilation should be organized by types of services provided, target populations and/or geographic service area. A sample data collection tool is available in Appendix E.

Service areas often neglect the resource inventory and provider profile due to data collection problems. HRSA suggests collecting provider information through in-person and telephone interviews. However, budget and time constraints may make it more feasible to mail out surveys, with follow up reminder cards, via mail or fax. When response rates are too low, follow up reminders may also need to be conducted via telephone.

Outreach Survey

Service areas will need to ascertain the extent to which PLWH are not in care and the

barriers, if any, to being in care. Per HRSA, “PLWH not in care need to be sought out at a variety of locations, using a mix of street, service provider, and media outreach techniques.” Providers can be a resource friendly means for surveying PLWH in care. However HIV/AIDS Care providers are not as likely to provide access to PLWH not in care. Primary data collection with PLWH not in care may need to include purposeful sampling of PLWH who have been out of care for the past two years and key informant interviews with selected providers such as outreach workers, case managers and substance abuse treatment providers.

In previous needs assessments, some service areas interviewed and/or surveyed case managers. Interviewing this group of people proved a valuable supplement to what consumers were identifying as barriers to care. Key informant interviews can be used to obtain qualitative information from knowledgeable individuals about service gaps, needs and barriers. Like focus groups, however, information from key informant interviews should be used to supplement primary data already gathered and not used as primary, generalizable data.

Quantitative versus Qualitative Data

Quantitative data collection such as closed ended interviews or surveys are valuable for generalizing results across populations when scientific sampling and good response rates are attainable. These data are not very effective in clarifying complexity or context. Qualitative techniques such as focus groups and open-ended semi-structured interviews may be best for developing insights concerning issues of complexity and context. However focus groups are not as useful for quantifying results or generalizing results although scientific sampling methods can improve the generalizability.

Focus Group Interviews

A focus group is a discussion between a small group of people of similar backgrounds or characteristics. A trained moderator who is free of bias related to the service or activity being discussed usually facilitates the discussion. The results of the focus group discussion often provide valuable insights but generally cannot be assumed to represent

the views of a broader population. The initial steps for conducting a focus group are to determine the characteristics of the participants and a method for recruiting them. Next, train or recruit a trained moderator in the area of HIV/AIDS and develop a script(s) for the facilitator to follow. Logistics (e.g. time and location) should be set, the focus group conducted and information on incentives disseminated. Make any necessary changes prior to the next focus group and when all results are collected, prepare a focus group report. A moderator's tool for conducting a focus group is located in Appendix D.

In the past PLWA were used to conduct focus groups in a few service areas. This was an opportunity for these people to earn money. Consumers may also be more comfortable discussing HIV/AIDS issues with their peers. However, when PLWA facilitators have personal agendas, bias may undermine the focus group results. PLWAs can have strong opinions and biases about issues since they have personal involvement. Unbiased facilitators of focus groups may be necessary to effectively use the focus group as a source of valid information.

Incentives can be an important part of obtaining valid results. Incentives increase response rates. Scientific sampling, reinforced by incentives for participation, is likely to produce the most valid results if issues of anonymity and confidentiality are effectively addressed. Incentives were often motivation for participating in the focus groups. Ten dollars, \$25, \$25 plus reimbursement for transportation or childcare, and food gift certificates have been offered.

HRSA suggests selecting consumers for the focus groups on basic parameters (e.g. age) and then sorting them into groups based on other parameters. These other sampling parameters include gender, family status, ethnicity, education, residency, client status, co-morbidities and sexual orientation. Each group should have no less than 6 people. In order to obtain an optimum number of participants, over-recruiting is recommended. A brief participant questionnaire can be utilized to collect descriptive information. The facilitator's guide that is presented here is taken directly from the HRSA website.

Guides to Implementing Data Collection

Conducting A Consumer Survey

1. Define and Understand Your Objectives

The primary focus of the PLWH needs assessment client survey is to determine met and unmet needs. However, some areas may also be interested in assessing client satisfaction with the consumer survey. This will require adjustments/additions to the basic survey provided in the Appendix.

2. Select Study Population and Develop Sampling Process

Eligibility criteria for participants will need to be determined. For example, are clients of a particular provider to be included or excluded? Which subpopulations (or special needs populations) will be sampled? At a minimum, women, adolescents, and the elderly should be considered. Additional populations to be considered are migrant workers, commercial sex workers, the homeless and, when available, speakers of other languages. In the latter case, consideration will need to be given to translation and the reverse translation of the survey instrument. Once the study population (s) has been determined you need to develop a process for contacting the population. If the survey is to be mailed, you need a list of the members of the population. If the survey is to be personally distributed, then a systematic process for accessing the population needs to be developed. Remember to emphasize what is already known about the population while developing this systematic process.

3. Determine Your Sample Size

In some cases, the population of interest will be so small that it is possible to attempt to survey everyone. Generally however, this is not feasible and a sample of the population will need to be used.

- If you want to generalize your results to the whole population of interest, appropriate randomized sampling techniques should be used.
- It may be necessary to consider oversampling a specific sub- or special needs

population to ensure appropriate representation of unique views or for analysis purposes.

- In order to generalize results adequate response rates will need to be achieved. For example, if the desired number of completed surveys is 30, areas should plan on distributing at least 65 surveys. When surveying a larger number of consumers, it is important to reach a response rate of at least 60 percent. If despite attempts at improvement response rates still tend to be low, reports of these assessments will need to document the limitations of having a low response rate (include a discussion about the non-generalizability of results).

4. Pilot Test the Survey

If time and budget allow, the survey that is intended for mailing out should be tested on a few individuals who have not been involved in the development of the instrument and who are similar to the population of interest. This will help to ensure that all questions are easily read and interpreted. This is a last check for reading levels, grammar, difficulty in using your answering scheme and typographical errors. Allow participants to comment on the survey itself and note these comments. It can be helpful to ask those piloting the survey to tell you in their own words what they think your question is asking. This will ensure that the survey is measuring what you think it is measuring. Incorporate any changes in the original document prior to distributing the survey to the larger sample. It is also important to describe the process of pilot testing of the instrument in your assessment report.

5. Collect the Data

Surveys should be mailed to potential participants in an envelope without the words HIV or AIDS or other words or symbols that might identify the nature of the correspondence. A stamped, self-addressed envelope of a similar bare nature should be provided to return the completed survey instrument in. Supply a return-by date. Also, use a non-obtrusive method of keeping track of the surveys. For example, put a number in the middle of the second page. If response rates are inadequate, follow up letter use is appropriate. If the

problem persists, an abbreviated form of the survey can be mailed instead. One way of encouraging participation is by offering incentives that potential respondents value upon return of the completed survey.

6. Analyze Data

A simple quantitative analysis of the survey responses is acceptable (i.e. frequencies, percentages, etc.). More complex cross-tabulations of the responses are also warranted if resources are available to conduct the analyses. These cross-tabulations are particularly of importance when analyzing the results of special needs populations. Cross-tabulations to be performed include met and unmet needs of males vs. females; met and unmet needs of English vs. non-English speakers; and met and unmet needs of each racial/ethnic group. Tables are an effective format for reporting these types of results.

7. Make Recommendations/Disseminate Findings

Audience specific reports can each be created for the state, EMA and survey respondents. In it, make recommendations for improvement as well as request technical assistance when necessary.

Conducting Focus Groups

1. Preparing for the Focus Group

Initially, the logistics of the focus group must be decided. These include when the focus group will occur, the length of the session and what topics will be covered. After the topics have been decided upon, specific questions to be asked will need to be developed.

Group characteristics also need to be established. Basic parameters such as age, gender, ethnicity, etc. can be used for initial selection criteria. The groups can then further be broken down based on other criteria. In order to ensure at least six people are present in each focus group, over-recruiting is recommended. Recruitment can occur via a variety of methods, including selection from community nominations or from invitations.

Incentives are an appropriate way to increase participation levels.

Moderators who are not connected with the service area or the participants should be chosen to lead the focus groups. Preferably, people with experience in conducting focus groups should be chosen. Otherwise, appropriate training should be offered. Topics to be covered during training include when to maintain 'low' or 'high' control, probing, avoiding judgmental statements and how to deal with potential problem participants.

2. Conducting the Focus Group

To promote a relaxed atmosphere include an acquaintance-making period as part of the beginning of the focus group. After this time period, have the group sign-in and distribute consent and data collection forms. Provide an explanation of the purpose and the importance of the focus group, with emphasis on encouraging members to participate. Interaction rules and limitations should also be discussed.

Ideally, focus group interviews should not include more than 8 to 10 questions.

Preliminary questions should also be used and are more general in nature to allow the group a chance to warm up and start talking. As the dialogue continues, questions should flow from general to more specific. Moderators will need to facilitate the conversation yet control the conversation enough to allow transitions into other areas. To gain further

insights on topics however, moderators can implement a number of probes. Examples of probes include: Explain. Go Further. Would you explain further? Would you say more? Is there anything else? Please describe what you mean. I don't understand. Can you give me an example?

Close the focus group session by thanking the participants and distributing the incentive for participating.

3. Analyzing the Results

A simple analysis would include a summary of the responses to each question. A more complex qualitative analysis is appropriate when experience and/or training in the analytic processes are available.

4. Make Recommendations/Disseminate Findings

The write-up following the focus group should include a description of the groups. Information collected from the data collection form should be utilized. Also to be included in the report is a summary of the content. In particular, report on agreements between members, variation or discord among group members about a subject matter and of distinct importance, any discoveries brought up by the group.

Conducting A Provider Survey

1. Define and Understand Your Objectives

One of the primary objectives of the provider survey is to ascertain service gaps for PLWH. Identifying provider perceived system wide assets and barriers that influence the delivery of timely and efficient care can be an important component of the gap analysis.

2. Identify the Survey Population

Depending on title requirements, areas may choose to survey providers who receive corresponding funding. However, in order to obtain a more comprehensive representation of providers, areas should identify all providers who provide HIV/AIDS specific services, despite funding source.

3. Conduct Survey

If time and budget allows, pilot testing the survey instrument is preferred. HRSA recommends that provider surveys be conducted via mail-in surveys. A study by Lensing, et al. (2000) found that when given a choice, physicians were more likely to request to be surveyed via fax. Either method would be acceptable. A good way to ensure high response rates is to keep the survey simple and short. In the case of low response rates however, reminders can be conducted via mail, fax or phone. If response rates still prove to be troublesome, areas may want to consider developing a short-form survey to use in its place. Whether using the long or short form, the minimum information to be collected for a resource inventory include: name, address funding amount, funding sources, program focus, services provided, geographic project area, target population and number of individuals served in a year.

4. Analyze Data

The resource inventory can be reported in tabular format as provided in the Appendix. Identification of common and unique barriers and provider perceived needs should also be reported.

5. Make Recommendations/Disseminate Findings

Audience specific reports can each be created for the state, EMA and survey respondents. In it, make recommendations for improvement as well as request technical assistance when necessary.

Conclusion

This guide to creating a needs assessment attempts to take into account the reporting requirements of the different CARE Act titles and lessons learned from area needs assessments conducted in Florida. Reporting guidelines along with other data collection recommendations can be found on the HRSA website and should be referred to for further clarification.

Appendix A. Epidemiological Tables

The following tables are for reference only. They should be modified to meet the needs of service areas.

Table X. AIDS Prevalence and Incidence				
	As of December 31 (previous year ex. 2002)		Previous two years (ex. 2000 – 2002)	
	AIDS Incidence n (%)	AIDS Prevalence n (%)	AIDS Incidence n (%)	AIDS Prevalence n (%)
Total Cases				
Race/Ethnicity				
Black (non-Hispanic)				
Hispanic				
White (non-Hispanic)				
Other				
Unknown				
Sex				
Male				
Female				
Age				
<13				
13 – 45				
46+				

Source:

Table X. AIDS Cases by Method of Exposure as of (December 31 previous year)								
	MSM	IDU	MSM & IDU	Heterosexual Contact	Mother at risk for HIV	Other Modes of Exposure	Risk not Reported	Total
Race/Ethnicity								
Black (non-Hispanic)								
Hispanic								
White (non-Hispanic)								
Other								
Unknown								
Sex								
Male								
Female								
Age								
<13								
13 - 45								
46+								

Source:

Table X. Sociodemographics of Service Area and State of Florida

	2000 Service Area (%) ¹	2000 Florida (%)	2001 Service Area (%)	2001 Florida (%)	2002 Service Area (%)	2002 Florida (%)
Total STDs						
Gonorrhea						
Syphilis						
Pulmonary TB						
Other STDs						
Total Population in Poverty						
Total population without insurance						

¹Represents percent increase or decrease from previous year; Source:

Appendix B. Consumer Survey (Long Form)

The following consumer survey was adapted from one that was used previously. The questions should be considered samples and not necessarily mandatory. In the cases where a substantial amount of questions are added to the following list, in order to reduce the amount of time being spent on this survey, conducting it in two parts to be distributed over the course of a year is advisable.

1. My gender is:

- (1) Male
- (2) Female
- (3) Transgender
- (4) Other

2. My main language is:

- (1) English
- (2) Spanish
- (3) Other (Please specify) _____

3. My age range is:

- (1) Under 13
- (2) 13-19 yrs.
- (3) 20-29 yrs.
- (4) 30-39 yrs.
- (5) 40-49 yrs.
- (6) 50-65 yrs.
- (7) Over 65 yrs.

4. My racial/ethnic background is:

- (1) White. Not Hispanic
- (2) Black. Not Hispanic
- (3) Hispanic
- (4) Asian/Pacific Islander
- (5) Native American
- (6) Other (Please specify) _____

5. My ZIP Code is _____

6. The County I live in is _____

7. The highest level of school that I finished is:

- (1) 0 to 8th grade
- (2) Some high school, but did not graduate
- (3) high school graduate
- (4) 1 - 4 years College
- (5) College graduate
- (6) Trade/technical school
- (7) Still in school

8. I am currently employed:

- (1) Full time
- (2) Part Time
- (3) I am not working for medical reasons
- (4) I am not working but am looking for work

9. My medical bills are paid mostly by:

- (1) Employer Insurance
- (2) Medicaid
- (3) Medicare
- (4) Private Health Insurance
- (5) Myself
- (6) Ryan White
- (7) Children's' Medical Services
- (8) Other. (Please specify) _____

10. My current monthly income is:

- (1) 0 - \$499
- (2) \$500-999
- (3) \$1,000-1,999
- (5) \$2,000-2,999
- (6) \$3,000-3,999
- (7) \$4,000 and over
- (8) No Income

11. I consider myself to be:

- (1) Heterosexual
- (2) Homosexual
- (3) Bisexual

12. Which of the following describes your current health status?

- (1) I have been diagnosed with HIV
- (2) I have been diagnosed with AIDS

13. I think I became HIV positive from:

- (1) Having sex with a woman
- (2) Having sex with a man
- (3) Using needles for drugs
- (4) Getting a blood transfusion
- (5) Don't Know
- (6) Maternal Transmissions
- (7) Other (Please specify) _____

14. Do you think you were under the influence of any of the following when you became infected?

- (1) Alcohol
- (2) Marijuana
- (3) Crack
- (4) Other Drugs
- (5) Don't Know
- (6) None

15. Please put a check next to the place where you go most of the time to see a doctor.

- (1) Private physician's office
- (2) Emergency room of a hospital. please specify which hospital
- (3) County health department, please specify which county
- (4) Children's Medical Services _____
- (5) Other, please specify _____

16. How many miles is this doctor from your home? _____

17. How long does it take you to get there? _____

18. How do you usually get to your doctor?

- (1) Walk
- (2) Own car
- (3) Public Bus
- (4) Taxi
- (5) Friend drives me
- (6) Handicapped Transport
- (7) Family drives me
- (8) Other (please specify) _____

19. Do you have to take time off from work?

- (1) yes
- (2) no
- (3) Not Applicable

20. Are the hours your doctor is open convenient for you?

- (1) yes
- (2) no

21. Do you have to find childcare to make your appointments?

- (1) yes
- (2) no
- (3) Not Applicable

22. What is the biggest problem in getting treatment from your current provider?

23. What is the biggest advantage in getting treatment from your current provider?

24. How were you treated by provider and staff i.e. friendly, courteous, caring etc?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

25. Was your appointment promptly kept?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

26. How knowledgeable about HIV/AIDS are the staff and physicians?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

27. How well was your confidentiality protected?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

28. How well did staff and doctors listen to your concerns and answer your questions?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

29. How good were the services that you received?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

30. Do you currently have a case manager?

- (1) yes
- (2) no

31. How would you rate the services you receive from your case manager?

- (1) Excellent
- (2) Good
- (3) Satisfactory
- (4) Unsatisfactory

32. What would you like to see done to improve the services from your case manager?

33. Please indicate whether you have had a problem receiving care during the last six months because of any of the following, by selecting "yes" or "no".

- | | |
|-----------------------------------|----------------|
| Cost of medications | (1) yes (2) no |
| Long waiting list | (1) yes (2) no |
| Needed services not available | (1) yes (2) no |
| Inconvenient service location | (1) yes (2) no |
| Gender discrimination | (1) yes (2) no |
| Sexual orientation discrimination | (1) yes (2) no |
| Racism | (1) yes (2) no |
| Don't know where to go | (1) yes (2) no |
| Cost of services | (1) yes (2) no |
| Fear my HIV status would be known | (1) yes (2) no |
| Too much income to qualify | (1) yes (2) no |
| Transportation | (1) yes (2) no |
| Lack of childcare | (1) yes (2) no |
| Language barrier | (1) yes (2) no |
| Confidentiality issue | (1) yes (2) no |

34. Have you ever experienced discrimination or been mistreated because you are HIV positive?

- (1) yes
- (2) no

35. Have you ever been refused services because you are HIV positive?

- (1) Yes
- (2) no

36. Do you feel that you were adequately informed and educated about the disease and your local service providers by your local community?

- (1) yes
- (2) no

37.

	Received this service	Needed this service but couldn't get it	Did not need this service
Regular Medical Care	(1) 0	(2) 0	(3) 0
Specialty Care	(1) 0	(2) 0	(3) 0
Dental Care	(1) 0	(2) 0	(3) 0
Eye Care	(1) 0	(2) 0	(3) 0
Emergency Room Care	(1) 0	(2) 0	(3) 0
Hospital Care	(1) 0	(2) 0	(3) 0
Home Health Care	(1) 0	(2) 0	(3) 0
Nutritionist Services	(1) 0	(2) 0	(3) 0
Help with Housing	(1) 0	(2) 0	(3) 0
Mental Health Counseling	(1) 0	(2) 0	(3) 0
Substance Abuse Counseling	(1) 0	(2) 0	(3) 0
Detox Care	(1) 0	(2) 0	(3) 0
Medications	(1) 0	(2) 0	(3) 0
Food	(1) 0	(2) 0	(3) 0
Transportation	(1) 0	(2) 0	(3) 0
Child care	(1) 0	(2) 0	(3) 0
Homemaker Services	(1) 0	(2) 0	(3) 0
Financial Assistance	(1) 0	(2) 0	(3) 0
Adoption/Foster Care	(1) 0	(2) 0	(3) 0
Help Returning to Work	(1) 0	(2) 0	(3) 0
Domestic Violence Services	(1) 0	(2) 0	(3) 0
Buddy/Companion	(1) 0	(2) 0	(3) 0
Legal Assistance	(1) 0	(2) 0	(3) 0
Pastoral/Spiritual Care	(1) 0	(2) 0	(3) 0
Support Groups	(1) 0	(2) 0	(3) 0
Other (Please specify) _____	(1) 0	(2) 0	(3) 0

38. We would like to know the five services you need the most. From the list of services above, please write the service you need most next to number 1(Below), Write the next most needed service next to number 2 and continue through number 5.

- (1) (Most needed service) _____
- (2) (Next most needed service) _____
- (3) (Next most needed service) _____
- (4) (Next most needed service) _____
- (5) (Next most needed service) _____

Appendix C: Consumer Survey (Short Form)

1. My gender is:

- (1) Male
- (2) Female
- (3) Transgender
- (4) Other

2. My main language is:

- (4) English
- (5) Spanish
- (6) Other (Please specify) _____

3. My age range is:

- (5) Under 13
- (6) 13-19 yrs.
- (7) 20-29 yrs.
- (8) 30-39 yrs.
- (5) 40-49 yrs.
- (6) 50-65 yrs.
- (7) Over 65 yrs.

4. My racial/ethnic background is:

- (6) White. Not Hispanic
- (7) Black. Not Hispanic
- (8) Hispanic
- (9) Asian/Pacific Islander
- (10) Native American
- (6) Other (Please specify) _____

5. The highest level of school that I finished is:

- (8) 0 to 8th grade
- (9) Some high school, but did not graduate
- (10) high school graduate
- (11) 1 - 4 years College
- (12) College graduate
- (13) Trade/technical school
- (14) Still in school

6. I am currently employed:

- (9) Full time
- (10) Part Time
- (11) I am not working for medical reasons
- (12) I am not working but am looking
for work

7. My medical bills are paid mostly by:
- (9) Employer Insurance
 - (10) Medicaid
 - (11) Medicare
 - (12) Private Health Insurance
 - (13) Myself
 - (14) Ryan White
 - (15) Children's' Medical Services
 - (16) Other. (Please specify) _____
8. My current monthly income is:
- (1) 0 - \$499
 - (4) \$500-999
 - (5) \$1,000-1,999
 - (13) \$2,000-2,999
 - (14) \$3,000-3,999
 - (15) \$4,000 and over
 - (16) No Income
9. Which of the following describes your current health status?
- (3) I have been diagnosed with HIV
 - (4) I have been diagnosed with AIDS
10. I think I became HIV positive from:
- (8) Having sex with a woman
 - (9) Having sex with a man
 - (10) Using needles for drugs
 - (11) Getting a blood transfusion
 - (12) Don't Know
 - (13) Maternal Transmissions
 - (14) Other (Please specify) _____
11. Please put a check next to the place where you go most of the time to see a doctor.
- (1) Private physician's office
 - (2) Emergency room of a hospital. please specify which hospital
 - (3) County health department, please specify which county
 - (4) Children's Medical Services _____
 - (5) Other, please specify _____
12. How many miles is this doctor from your home? _____
13. Are the hours your doctor is open convenient for you?
- (3) yes
 - (4) no
14. Do you have to find childcare to make your appointments?
- (4) yes
 - (5) no
 - (6) Not Applicable
15. Do you currently have a case manager?
- (3) yes
 - (4) no

16. Please indicate whether you have had a problem receiving care during the last six months because of any of the following, by selecting “yes” or “no”.

- Cost of medications (1) yes (2) no
- Long waiting list (1) yes (2) no
- Needed services not available (1) yes (2) no
- Inconvenient service location (1) yes (2) no
- Gender discrimination (1) yes (2) no
- Sexual orientation discrimination (1) yes (2) no
- Racism (1) yes (2) no
- Don't know where to go (1) yes (2) no
- Cost of services (1) yes (2) no
- Fear my HIV status would be known (1) yes (2) no
- Too much income to qualify (1) yes (2) no
- Transportation (1) yes (2) no
- Lack of childcare (1) yes (2) no
- Language barrier (1) yes (2) no
- Confidentiality issue (1) yes (2) no

17.

	Received this service	Needed this service but couldn't get it	Did not need this service
Regular Medical Care	(1) 0	(2) 0	(3) 0
Specialty Care	(1) 0	(2) 0	(3) 0
Dental Care	(1) 0	(2) 0	(3) 0
Eye Care	(1) 0	(2) 0	(3) 0
Emergency Room Care	(1) 0	(2) 0	(3) 0
Hospital Care	(1) 0	(2) 0	(3) 0
Home Health Care	(1) 0	(2) 0	(3) 0
Nutritionist Services	(1) 0	(2) 0	(3) 0
Help with Housing	(1) 0	(2) 0	(3) 0
Mental Health Counseling	(1) 0	(2) 0	(3) 0
Substance Abuse Counseling	(1) 0	(2) 0	(3) 0
Detox Care	(1) 0	(2) 0	(3) 0
Medications	(1) 0	(2) 0	(3) 0
Food	(1) 0	(2) 0	(3) 0
Transportation	(1) 0	(2) 0	(3) 0
Child care	(1) 0	(2) 0	(3) 0
Homemaker Services	(1) 0	(2) 0	(3) 0
Financial Assistance	(1) 0	(2) 0	(3) 0
Adoption/Foster Care	(1) 0	(2) 0	(3) 0
Help Returning to Work	(1) 0	(2) 0	(3) 0
Domestic Violence Services	(1) 0	(2) 0	(3) 0
Buddy/Companion	(1) 0	(2) 0	(3) 0
Legal Assistance	(1) 0	(2) 0	(3) 0
Pastoral/Spiritual Care	(1) 0	(2) 0	(3) 0
Support Groups	(1) 0	(2) 0	(3) 0
Other (Please specify) _____	(1) 0	(2) 0	(3) 0

18. We would like to know the five services you need the most. From the list of services above, please write the service you need most next to number 1(Below), Write the next most needed service next to number 2 and continue through number 5.

- (1) (Most needed service) _____
- (2) (Next most needed service) _____
- (3) (Next most needed service) _____
- (4) (Next most needed service) _____
- (5) (Next most needed service) _____

Appendix D. Provider Survey (Long Form)

The following provider survey was adapted from one that was used previously. The questions should be considered samples and not necessarily mandatory.

Please check or short answer the following questions as appropriate.

Name of agency: _____

Address: _____

Telephone: _____ FAX: _____

Email: _____

Contact person and title: _____

1. In what zip codes are your service sites located?

2. Describe your agency: *(Check only one response.)*

- AIDS service organization
- Community-based organization (not AIDS-specific)
- Substance abuse/mental health treatment facility
- Other *(specify)* _____
- County Health Department
- Hospital-based clinic
- Health clinic

3. Identify the services your agency most often provides: *(Check no more than three.)*

- Benefits/financial assistance
- Childcare
- Complementary/alternative therapy
- Dental care
- Family services (e.g., guardianship, adoption)
- Food distribution/nutrition
- Housing
- Medical care
- Mental health counseling

- Non-mental health counseling
 - Optical care
 - Pastoral care
 - Respite care
 - Substance abuse treatment
 - Transportation
 - Other (*specify*) _____
-

4. What are the payer sources for client services? (*Check all that apply.*)

- Charity
- Medicaid
- Medicare
- Private insurance
- Ryan White
- Self-pay
- Other (*specify*) _____

5. Services/programs are currently funded through:

- | | |
|--|---|
| <input type="radio"/> Ryan White Title I | <input type="radio"/> Ryan White Title II |
| <input type="radio"/> HOPWA | <input type="radio"/> United Way |
| <input type="radio"/> Federal Government | <input type="radio"/> Local Government |
| <input type="radio"/> Local County Health Dept | <input type="radio"/> County |
| <input type="radio"/> Other (<i>specify</i>) _____ | |

6. What are your days and hours of operation? (*Check all that apply.*)

- | | |
|----------------------------------|--------------------------------------|
| <input type="radio"/> Weekdays | <input type="radio"/> Weekend days |
| <input type="radio"/> Weeknights | <input type="radio"/> Weekend nights |

7. Are you accepting new HIV-positive clients at this time?

- | | |
|---------------------------|--------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No |
|---------------------------|--------------------------|

8. Is there a waiting list for HIV-positive clients?

- | | |
|---|--------------------------|
| <input type="radio"/> Yes How long? _____ | <input type="radio"/> No |
|---|--------------------------|

9. Languages spoken by your staff: (*Check all that apply.*)

- | | |
|--------------------------------------|-------------------------------|
| <input type="radio"/> English | <input type="radio"/> Spanish |
| <input type="radio"/> Haitian-Creole | <input type="radio"/> Other |

10. Identify your target population:

- | | | |
|---|--|---|
| <input type="radio"/> Seniors (older than 65) | <input type="radio"/> Males | <input type="radio"/> Hispanics/Latinos |
| <input type="radio"/> Adults (ages 25-64) | <input type="radio"/> Females | <input type="radio"/> Whites |
| <input type="radio"/> Youth (ages 13-24) | <input type="radio"/> Injection drug users | <input type="radio"/> Other |
| <input type="radio"/> Children (ages 3-12) | <input type="radio"/> Homeless | |
| <input type="radio"/> Infants (ages 0-2) | <input type="radio"/> African-Americans | |

11. If available, which of the following services would help you to better serve your clients/patients living with HIV? (*Check all that apply.*)

- Training in working with people from other cultures
- Training to learn other languages
- Opportunities for networking among providers to share information and HIV/AIDS care and available resources
- Training to gain additional experience/knowledge about providing HIV care, such as antiretroviral treatments, dealing with opportunistic infections, and monitoring and explaining a patient's health status
- Providing services in a more convenient manner (such as better office hours, quicker appointments, less waiting, in a location that is easier to get to)
- Training on how to better advocate for clients/patients
- Other (*specify*) _____

12. Over the past year, please estimate:

- a. The total number of clients you served: _____
- b. The total number of HIV positive clients you served: _____
- c. The percentage of your HIV-positive clients who have not been diagnosed with AIDS: _____
- d. The percentage of your HIV-positive clients who have been diagnosed with AIDS: _____

13. Identify the top three barriers that your organization encounters in providing care to persons living with HIV/AIDS:

- a. _____
- b. _____
- c. _____

14. Based on your experience working with persons living with HIV/AIDS, list the three most important needs (met or unmet) of a person living with HIV/AIDS:

a. _____

b. _____

c. _____

15. Which of the following barriers do you think prevent your clients from accessing needed HIV-related services in an efficient and timely manner?

- Funding/staffing needs
- Space/capacity issues
- Cost to clients
- Transportation
- Language barriers
- Cultural differences
- Confidentiality issues
- Housing problems
- Drug/alcohol addiction
- Other health problems
- Clients' lack of knowledge about where or how to access services
- Providers' lack of knowledge about services or referral options
- Providers' lack of knowledge about HIV/AIDS treatment options
- Coordination of care/communication among agencies
- Duplication/fragmentation of service structure
- Lack of evening or weekend hours
- Lack of babysitting/respite care
- Application process too complicated or restrictive
- Other (specify) _____

16. What is the single most important change you would suggest to improve services for individuals or families infected with HIV?

17. Are you a Ryan White provider?

- Yes No Don't know

18. If you are a Ryan White provider, what problems, if any, have you encountered with the authorization for services process?

19. If you are **not** a Ryan White provider, what barrier(s) have prevented you from becoming a Ryan White service provider?

Appendix E: Provider Survey (Short Form)

Please check or short answer the following questions as appropriate.

Name of agency: _____

Address: _____

Telephone: _____ FAX: _____

Email: _____

Contact person and title: _____

1. In what zip codes are your service sites located?

2. Describe your agency: *(Check only one response.)*

- AIDS service organization
- Community-based organization (not AIDS-specific)
- Substance abuse/mental health treatment facility
- Other *(specify)* _____
- County Health Department
- Hospital-based clinic
- Health clinic

3. Identify the services your agency most often provides: *(Check no more than three.)*

- Benefits/financial assistance
- Childcare
- Complementary/alternative therapy
- Dental care
- Family services (e.g., guardianship, adoption)
- Food distribution/nutrition
- Housing
- Medical care
- Mental health counseling
- Non-mental health counseling
- Optical care
- Pastoral care
- Respite care

- Substance abuse treatment
- Transportation
- Other (*specify*) _____

4. Services/programs are currently funded through:

- | | |
|--|---|
| <input type="radio"/> Ryan White Title I | <input type="radio"/> Ryan White Title II |
| <input type="radio"/> HOPWA | <input type="radio"/> United Way |
| <input type="radio"/> Federal Government | <input type="radio"/> Local Government |
| <input type="radio"/> Local County Health Dept | <input type="radio"/> County |
| <input type="radio"/> Other (<i>specify</i>) _____ | |

5. Identify your target population:

- | | | |
|---|--|---|
| <input type="radio"/> Seniors (older than 65) | <input type="radio"/> Males | <input type="radio"/> Hispanics/Latinos |
| <input type="radio"/> Adults (ages 25-64) | <input type="radio"/> Females | <input type="radio"/> Whites |
| <input type="radio"/> Youth (ages 13-24) | <input type="radio"/> Injection drug users | <input type="radio"/> Other |
| <input type="radio"/> Children (ages 3-12) | <input type="radio"/> Homeless | |
| <input type="radio"/> Infants (ages 0-2) | <input type="radio"/> African-Americans | |

6. Over the past year, please estimate:

- a. The total number of clients you served: _____
- b. The total number of HIV positive clients you served: _____
- c. The percentage of your HIV-positive clients who have not been diagnosed with AIDS: _____
- d. The percentage of your HIV-positive clients who have been diagnosed with AIDS: _____

7. Identify the top three barriers that your organization encounters in providing care to persons living with HIV/AIDS:

- a. _____
- b. _____
- c. _____

8. Based on your experience working with persons living with HIV/AIDS, list the three most important needs (met or unmet) of a person living with HIV/AIDS:

- a. _____
- b. _____
- c. _____

9. Which of the following barriers do you think prevent your clients from accessing needed HIV-related services in an efficient and timely manner?

- Funding/staffing needs
- Space/capacity issues
- Cost to clients
- Transportation
- Language barriers
- Cultural differences
- Confidentiality issues
- Housing problems
- Drug/alcohol addiction
- Other health problems
- Clients' lack of knowledge about where or how to access services
- Providers' lack of knowledge about services or referral options
- Providers' lack of knowledge about HIV/AIDS treatment options
- Coordination of care/communication among agencies
- Duplication/fragmentation of service structure
- Lack of evening or weekend hours
- Lack of babysitting/respice care
- Application process too complicated or restrictive
- Other (specify) _____

10. Are you a Ryan White provider?

- Yes No Don't know

Appendix F

Ryan White CARE Act Needs Assessment Guide VI-65

FACILITATOR'S GUIDE

As participants arrive

Greet participants as they arrive. Ask them to take a seat and make themselves comfortable. (If there are refreshments, encourage them to help themselves).

Distribute profile questionnaire and ask participants to complete it while they wait for the focus group to begin. Explain that the questionnaire will provide us information about their background; and that this information will be used for descriptive purposes only. In other words their names will not be in the survey, and we will never use any identifying information such as their name or the name of the agency where they get services in any of our reports.

Also, distribute confidentiality agreement for participants to review.

INTRODUCTION

1. Introduction of facilitator and note taker

Welcome and thank you for coming today. My name is _____ and this is _____. We are both from Area Health Consulting Group (AHCG) in MetroCity, AnyState, an independent organization that is helping the *This County HIV/AIDS Advisory Board* to identify the service needs of women, children, and adolescents with HIV/AIDS and their families in the community. (We will use *Advisory Board* when referring to the agency during our discussion). AHCG is not affiliated with the *Advisory Board*, or with any of the HIV service providers in the area.

I will be leading today's discussion. My role, for the most part, is to make sure that we get through our agenda, keep to the time frame, and make sure that you all have a chance to talk. _____ will help me do these things, and s/he will also be taking notes. In addition we will be audio taping the session, which will ensure that we record the discussion accurately. The discussion session today will take about 1 1/2 hours.

2. Participant introductions

Now, let's go around the room and have each of you introduce yourselves; give your first name and any other information about yourself you want to share with the group.

3. Purpose of the focus group session

As I mentioned earlier, AHCG is helping the *Advisory Board* to identify the service needs of women, children, and adolescents living with HIV/AIDS and their families in ThisCounty.

We have asked you here to talk about your experiences in seeking and receiving service-both about the things you like and the kinds of problems you may have encountered in getting services. We are also interested in hearing about other services or help you may need that you are not currently receiving.

4. Confidentiality

All of the information we collect here today is confidential. We will not identify any of the participants. For example, we will not use your name, address, or any other identifying information in reports or other materials related to this study.

5. Consent forms and participant questionnaire

Before we begin the discussion, I would like you to sign the consent form given to you when you came in. The consent form will be our record that you agreed to participate in the focus group and that you agreed to the taping.

We would also like to collect the questionnaires that we asked you to complete when you arrived. As we explained before, the questionnaire will give us some information about your background. We will use this information for descriptive purposes only. In other words, we will never use any identifying information such as your name or the name of the agency where you get your services in any of our reports.

Please pass the signed consent form and completed questionnaire to _____.

[Recorder: Collect signed consent forms and completed questionnaires.]

6. Compensation

(Explain compensation arrangements.)

INSTRUCTIONS

Let me begin our discussion by reviewing a few things about how we will run the session.

During this discussion, we would like you to focus on topics that are of particular interest to us. We are interested in what everyone has to say about our discussion topics. If someone throws out an idea that you want to expand on, or if you have a different point of view, please feel free to speak up. Occasionally, I may have to interrupt the discussion in order to bring us back to a particular topic to make sure that we cover everything on our agenda.

There are several common-sense guidelines that we will follow during this session:

1. We want all of you to express your opinions about the discussion topics. We are interested in multiple points of view about them. There are no right or wrong answers, and we are not here to resolve any issues you may bring up.
2. Please do not hold side conversations. We want to be able to hear from everyone, and side conversations will disrupt the discussion. We want to make sure that we hear what everyone says. Because we are also recording the session, it would really help us if you could speak up so that everyone can hear you.

Do you have any questions so far?

Respondent Questionnaire

Note: All of the information collected here will be kept strictly confidential. If you feel uncomfortable answering any questions, you can leave it blank.

1. Gender

- Female
- Male
- Transgender

2. Age

- 13 - 20 years
- 21 - 30 years
- 31 - 40 years
- 41 - 50 years
- Over 50 years

3. Race

- American-Indian or Alaska Native
- Asian
- Black, Non-Hispanic or African-American
- Native Hawaiian or other Pacific Islander
- Hispanic
- White, Non-Hispanic

4. Where are you living now?

- Rent/own house/apartment
- Live with family
- Staying with friends
- Halfway house or drug treatment program
- Shelter
- On the street - no home
- Other (Specify) _____

5. What is your zip code?

6. What is your sexual orientation?

- Heterosexual/straight
- Gay/lesbian
- Bisexual
- Other (specify) _____

7. Which languages do you speak? (Mark all that apply.)

- English
- Spanish
- French
- Haitian-Creole
- Other (specify) _____

8. Which of the above languages is your preferred language?

9. Highest level of education completed
- Some high school but didn't graduate
 - High school graduate or GED
 - Vocational certification
 - Associate degree
 - Some college
 - Graduated college
10. Current employment status
- Employed full-time
 - Employed part-time
 - Unemployed
 - Volunteer work
 - Other (specify) _____
11. How do you get (cover the cost of) your medications?
- Pay for them myself or get help from family or friends
 - Private insurance
 - Medicaid
 - Medigap policy
 - Clinical trials
 - AIDS Drug Assistance Program (ADAP)
 - Other (specify) _____
12. What type of health insurance do you have?
- Medicaid
 - Medicare
 - HMO
 - Private insurance (not an HMO)
 - Private insurance (HMO)
 - None
13. In general, how would you rate your overall health at this present time?
- Very good
 - Good
 - Fair
 - Poor
14. What was your last CD₄ count?
- Less than 200
 - 200 - 500
 - Over 500
 - Don't know
15. When was your last CD₄ count taken?
- Within the last 3 months
 - 3 - 6 months
 - More than 6 months ago

16. Measuring the amount of HIV in your blood is called a viral load test. Have you ever had a viral load test?

- Yes
- No

If yes, when was it taken?

- Within the last 3 months
- 3 - 6 months
- More than 6 months ago

17. Are you receiving services funded through the Ryan White CARE Act?

- Yes
- No
- Not sure

18. Do you have any children?

- Yes
- No

If yes, what are the ages of your children?

19. Are any of your children HIV-positive?

- Yes
- No

Appendix G: Focus Group Questions

Based on the results of the consumer surveys, individual service areas may identify questions or topics that need further clarification. Development of focus group questions should occur with these topics in mind. The following questions are examples that can be modified.

1. Which groups of people in this community are vulnerable for contracting HIV?
2. What are the beliefs that influence HIV risk for these groups?
3. What factors might increase or decrease the likelihood of changing risk behaviors in these groups?
4. What are the needs of this community and are they being met?
5. What are the barriers for those groups of people not accessing care?
6. Are there any services or programs that are not working or that should be changed?
7. What are the reasons why people choose not to utilize community resources?
8. What support services are working well?
9. What is the extent and availability of existing interventions, treatment and care?
10. What intervention strategies have not been implemented in this community?
11. What are the advantages and disadvantages of the existing interventions and services?
12. What is the sociocultural appropriateness of existing interventions and strategies?
13. Who is not being served?
14. What are the critical conditions in the community that makes people vulnerable to HIV infection.
15. Where should new interventions be located in the community?

Appendix H. Provider Inventory

Provider Name	Number of Providers	Location/Zip code	Type(s) of Services	Total Caseload Capacity	PLWH Caseload Capacity	Target Population(s)	Funding Sources & Amounts

Appendix I. Definition of Terms

It is apparent upon review of previous needs assessments that definitions of certain terms vary from service area to service area. This tool is taken directly from the HRSA guidelines to ensure uniformity. Particular attention should be paid to the definitions of “needs, unmet needs, met needs and service gaps.”

Ryan White CARE Act Needs Assessment Guide VI-3

AAR (*Annual Administrative Report*): The AAR is a provider-based report generating aggregate client, provider and service data for each State and EMA. Information is reported on all clients who receive at least one service during the reporting period. (For a complete list of AAR terms, please see Section VIII of the AAR manual.)

ADAP (*AIDS Drug Assistance Program*): A state-administered program authorized under Title II of the CARE Act that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid.

Administrative or Fiscal Agent: An organization, agent, or other entity (e.g., public health department or community-based organization) which assists a grantee in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing Requests for Proposals [RFPs], monitoring contracts). Not all grantees use a separate administrative or fiscal agent.

AETC (*AIDS Education and Training Center*): Regional centers providing education and training for primary care professionals and other AIDS-related personnel. AETCs are authorized under Part F of the CARE Act and administered by the HRSA, HIV/AIDS Bureau's Division of Training and Technical Assistance (DTTA).

Aggregate Data: Combined data, composed of multiple elements, often from multiple sources; for example, combining demographic data about clients from all primary care providers in a service area generates aggregate data about client characteristics.

AIDS (*Acquired Immunodeficiency Syndrome*): A disease caused by the human immunodeficiency virus.

ASO (*AIDS service organization*): An organization which provides medical or support services primarily or exclusively to populations infected with and affected by HIV disease.

Average: A way of describing the typical value or measuring the “central tendency” among a group of numbers, such as average age or average income. Technically, the average is the **mean** (numerical average), but two other measures, the **median** (middle) and **mode** (most), are often called averages (see each in the *Glossary*).

Bar Chart or Bar Graph: A visual way to show and compare scores or values for different categories of variables; for example, a bar chart might be used to show the number of reported AIDS cases from major racial/ethnic groups; the taller the bar, the larger the number of AIDS cases.

CARE Act (*Ryan White Comprehensive AIDS Resources Emergency Act*): The Federal legislation created to address the health care and service needs of people living with HIV/AIDS (PLWH) disease and their families in the United States and its territories. The CARE Act was enacted in 1990 (PUB. L 101-381) and reauthorized in 1996 as the Ryan White CARE Act Amendments of 1996.

CBO (*community-based organization*): An organization which provides services to locally-defined populations, which may or may not include populations infected with or affected by HIV disease.

CD4 or CD4t Cells: Also known as “helper” T-cells, these cells are responsible for coordinating much of the immune response. HIV’s preferred targets are cells that have a docking molecule called “cluster designation 4” (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4 levels appear to be the best indicator for developing opportunistic infections.

CD4 Cell Count: The number of T-helper lymphocytes per cubic millimeter of blood. The CD4 count is a good predictor of immunity. As CD4 cell count declines, the risk of developing opportunistic infections increases. The normal range for CD4 cell counts is 500 to 1500 per cubic millimeter of blood. CD4 counts should be rechecked at least every 6 to 12 months if CD4 counts are greater than 500/mm³. If the count is lower, testing every 3 months is advised. A CD4 count of 200 or less indicates AIDS.

CDC (*Centers for Disease Control and Prevention*): The DHHS agency that administers HIV/AIDS prevention programs, including the HIV Prevention Community Planning process, among other programs. The CDC is responsible for monitoring and reporting infectious diseases, administers AIDS surveillance grants and publishes epidemiologic reports such as the *HIV/AIDS Surveillance Report*.

Chief Elected Official (CEO): The official recipient of Title I CARE Act funds within the EMA, usually a city mayor, county executive, or chair of the county board of supervisors. The CEO is ultimately responsible for administering all aspects of the CARE Act in the EMA and ensuring that all legal requirements are met. In EMAs with more than one political jurisdiction, the recipient of Title I CARE Act funds is the CEO of the city or urban county that administers the public health agency that provides outpatient and ambulatory services to the greatest number of people with AIDS in the EMA.

Closed-Ended Questions: Questions in an interview or survey format that provide a limited set of predefined alternative responses; for example, a survey might ask PLWH respondents if they are receiving case management services, and if they say yes, ask “About how often have you been in contact with your case manager for services during the past six months, either in person or by telephone?” and provide the following response options: Once a week or more, 2-3 times a month, about once a month, 3-5 times, 1-2 times, not at all.

Co-morbidity: A disease or condition, such as mental illness or substance abuse, co-existing with HIV disease.

Coding: The process of “translating” data from one format to another, usually so the information can be entered into a computer to be tabulated and analyzed; often, coding involves assigning numbers to all the possible responses to a question, such as Yes = 1, No = 2, Not Sure = 3, No Response = 0.

Community Forum or Public Meeting: A small-group method of collecting information from community members in which a community meeting is used to provide a directed but highly interactive discussion. Similar to but less formal than a focus group, it usually includes a larger group; participants are often self-selected (*i.e.*, not randomly selected to attend).

Comprehensive Planning: The process of determining the organization and delivery of HIV services. This strategy is used by planning bodies to improve decision-making about services and maintain a continuum of care for PLWH.

Consortium/HIV Care Consortium: A regional or statewide planning entity established by many State grantees under Title II of the CARE Act to plan and sometimes administer Title II services. An association of health care and support service providers that develop and delivers services for PLWH under Title II of the CARE Act.

Continuum of Care: An approach that helps communities plan for and provide a full range of emergency and long-term service resources to address the various needs of PLWH.

Cultural Competence: The knowledge, understanding, and skills to work effectively with individuals from differing cultural backgrounds.

DCBP (*Division of Community Based Programs*): The division within HRSA's HIV/AIDS Bureau that is responsible for administering Title III, Title IV, and the HIV/AIDS Dental Reimbursement Program.

Data Analysis: Careful, rigorous study of data; usually involves studying various elements of information and their relationships.

Decimal Places: Number of digits to the right of the decimal point, which separates numbers with a value greater than one from numbers with a value of less than one; the more numbers or decimal places used, the more precise the number; for example, 34.03 has two decimal places.

DSS (*Division of Service Systems*): The division within HRSA's HIV/AIDS Bureau that is responsible for administering Title I and Title II (including the AIDS Drug Assistance Program, ADAP).

DTTA (*Division of Training and Technical Assistance*): The division within HRSA's HIV/AIDS Bureau that is responsible for administering the AIDS Education and Training Centers (AETC) Program and technical assistance and training activities of the HIV/AIDS Bureau.

Early Intervention: see **HIV Early Intervention Services/Primary Care**.

Eligible Metropolitan Area (EMA): The geographic area eligible to receive Title I CARE Act funds. The boundaries of the eligible metropolitan area are defined by the Census Bureau. Eligibility is determined by AIDS cases reported to the Centers for Disease Control and Prevention (CDC). Some EMAs include just one city and others are composed of several cities and/or counties. Some EMAs extend over more than one State.

Epidemic: A disease that occurs clearly in excess of normal expectation and spreads rapidly through a demographic segment of the human population. Epidemic diseases can be spread from person to person or from a contaminated source such as food or water.

Epidemiologic Profile: A description of the current status, distribution, and impact of an infectious disease or other health-related condition in a specified geographic area.

Epidemiology: The branch of medical science that studies the incidence, distribution, and control of disease in a population.

Exposure Category: In describing HIV/AIDS cases, same as **transmission categories**; how an individual may have been exposed to HIV, such as injecting drug use, male-to-male sexual contact, and heterosexual contact.

Family Centered Care: A model in which systems of care under Ryan White Title IV are designed to address the needs of PLWH and affected family members as a unit, providing or arranging for a full range of services. The family structures may range from the traditional, biological family unit to non-traditional family units with partners, significant others, and unrelated

caregivers.

Financial Status Report (Form 269): A report that is required to be submitted within 90 days after the end of the budget period that serves as documentation of the financial status of grants according to the official accounting records of the grantee organization.

Focus Group: A method of information collection involving a carefully planned discussion among a small group led by a trained moderator.

Forced-Choice Question: Type of question often used in a survey questionnaire in which the person responding is expected to choose from a list of pre-determined responses.

Frequency Distribution: A tally of the number of times each score or response occurs in a group of scores or responses; for example, if 20 women with HIV provided information about how they were infected with the virus, the frequency distribution might be 8 = injection drug use, 5 = heterosexual contact with an injection drug user, 3 = other heterosexual contact, 1 = blood transfusion, and 3 = don't know.

Generalizability: The extent to which findings or conclusions from a sample can be assumed to be true of the entire population from which the sample was drawn; findings can be generalized only when the sampling procedure and the data meet certain methodological standards.

Grantee: The recipient of CARE Act funds responsible for administering the funds. (For a full listing of definitions of grants management terms, see the PHS Grants Policy Statement, which can be accessed at (www.nih.gov/grants/policy/gps)).

HCFA (Health Care Financing Administration): The DHHS agency that is responsible for administering the Medicaid, Medicare, and Child Health Insurance Programs.

Health Insurance Continuity Program (HICP): A program authorized and primarily funded under Title II of the CARE Act that makes premium payments, co-payments, deductibles, or risk pool payments on behalf of a client to maintain his or her health insurance coverage.

HIV Disease: Any signs, symptoms, or other adverse health affects due to the human immunodeficiency virus.

HIV/AIDS Bureau (HAB): The bureau within the Health Resources and Services Administration (HRSA) of the DHHS that is responsible for administering the Ryan White CARE Act. Within HAB, the Division of Service Systems administers Title I, Title II, and the AIDS Drug Assistance Program; the Division of Community Based Programs administers Title III, Title IV, and the HIV/AIDS Dental Reimbursement Program; and the Division of Training and Technical Assistance administers the AIDS Education and Training Centers Program. The Bureau's Office of Science and Epidemiology administers the Special Projects of National Significance (SPNS) Program.

HIV/AIDS Dental Reimbursement Program: The program within HRSA's HIV/AIDS Bureau's Division of Community Based Programs that assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV positive patients.

HIV Early Intervention Services/Primary Care (HIV/EIS): Applied in the outpatient setting, HIV/EIS assures a continuum of care which includes: 1) identifying persons at-risk for HIV infection and offering them counseling, testing, and referral services; and 2) providing lifelong comprehensive primary care for those living with HIV/AIDS.

Home and Community Based Care: A category of eligible services that States may fund under Title II of the CARE Act.

HOPWA (*Housing Opportunities for People With AIDS*): A program administered by the U.S. Department of Housing and Urban Development (HUD) which provides funding to support housing for PLWH and their families.

HRSA (*Health Resources and Services Administration*): The DHHS agency that is responsible for administering the CARE Act.

HUD (*Department of Housing and Urban Development*): The federal agency responsible for administering community development, affordable housing, and other programs including Housing Opportunities for Persons with HIV/AIDS (HOPWA).

IDU (*Injecting Drug User*)

IGA (*Intergovernmental Agreement*): A written agreement between a governmental agency and an outside agency that provides HIV services.

Incidence: The number of new cases of a disease or condition that occurs in a specified population during a specified time period.

Incidence Rate: The number of new cases of a disease or condition that occur in a defined population during a specified time period, often expressed per 100,000 population. AIDS rates are often expressed in this way.

Key Informant Interview: A non-survey information collection method involving in-depth interviews with a small number of individuals carefully selected because of their experiences and/or knowledge related to the topic of interest. An interview guide or checklist is used to guide the discussion. Also called a key person interview.

Lead Agency: The agency responsible for contract administration; also called a fiscal agent (an incorporated consortium sometimes serves as the lead agency).

Mean: Arithmetic average, calculated by adding up all the values or the responses to a particular question and dividing by the number of cases; for example, to determine the mean age of 12 children in a pediatric AIDS program, add up their individual ages and divide by 12.

Median: A type of “average” or measure of central tendency that calculates the central value, the one that falls in the middle of all the values when they are listed in order from highest to lowest; for example, if the annual incomes of seven families were \$37,231, \$35,554, \$30,896, \$27,432, \$24,334, \$19,766, and \$18,564, the median would be \$27,432. To determine the median of an even number of values, average the two central values (that is, add them together and divide by two).

Mode: A type of “average” or measure of central tendency that identifies the most frequently occurring value; for example, suppose a prevention project included 13 youth of the following ages: 16, 16, 15, 14, 14, 14, 14, 13, 13, 12, 12, 11, 10; the mode would be 14, which occurs four times.

Needs Assessment: A process of collecting information about the needs of persons living with HIV (PLWH) (both those receiving care and those not in care), identifying current resources (CARE Act and other) available to meet those needs, and determining what gaps in care exists.

OMB (*Office of Management and Budget*): The office within the executive branch of the Federal government which prepares the President’s annual budget, develops the Federal government’s fiscal program, oversees administration of the budget, and reviews government regulations.

Open - Ended Questions: Questions in an interview or survey format that allow those responding to answer as in a narrative and unrestricted context in contrast to close-ended questions that require selection from a limited set of predefined alternative responses.

Opportunistic Infection: (OI). An infection or cancer that occurs in persons with weak immune systems due to AIDS, cancer, or immunosuppressive drugs such as corticosteroids or chemotherapy. Kaposi's sarcoma, pneumocystitis pneumonia (PCP), toxoplasmosis, and cytomegalovirus are all examples of opportunistic infections.

OSE (Office of Science and Epidemiology): The office within HRSA's HIV/AIDS Bureau that administers the SPNS Program, HIV/AIDS evaluation studies, and the Annual Administrative Report (AAR).

Overrepresentation/Underrepresentation: Terms often used to indicate that a particular subpopulation makes up a larger proportion-or a smaller proportion-of a particular group than would be expected, given its representation in the total population; for example, African Americans are overrepresented among national AIDS cases, compared to their percentage in the U.S. population, while Asians and Pacific Islanders are underrepresented.

Oversampling: A procedure in stratified random sampling in which a larger number of individuals from a particular group (or **stratum**) are selected than would be expected given their representation in the total population being sampled; this is done in order to have enough subjects to permit separate tabulation and analysis of that group; for example, minorities are often oversampled to permit separate analysis of data by racial/ethnic group as well as comparisons among racial/ethnic groups.

Part F: The part of the CARE Act that includes the AETC Program, the SPNS Program, and the HIV/AIDS Dental Reimbursement Program.

Percent: Literally, per hundred; a proportion of the whole, where the whole is 100. Percent is calculated by dividing the part of interest by the whole, and then multiplying by 100; for example, if you want to know what percent of recently reported AIDS cases are women, take the number of women AIDS cases (the part of interest), divide by the number of total AIDS cases (the whole), and multiply by 100; if your community has a total of 70 recently reported AIDS cases and 14 are women, divide 14 by 70 (=0.2) and multiply by 100, and you get 20%.

Percentage Point: One one-hundredth; term used to describe numerical differences between two percents without comparing relative size; for example, if 16% of AIDS cases are Hispanic and 32% are African American, the difference is 16 percentage points (32 minus 16).

PHS (Public Health Service): An administrative entity of the DHHS. HRSA is an agency of the PHS.

PLWH (Person[s] Living with HIV Disease)

Planning Council: A planning body appointed or established by the Chief Elected Official of an EMA whose basic function is to establish a plan for the delivery of HIV care services in the EMA and establish priorities for the use of Title I CARE Act funds.

Planning Process: Steps taken and methods used to collect information, analyze and interpret it, set priorities, and prepare a plan for rational decision making.

Population Count: Data describing an entire population that were obtained from that entire population without sampling; the U.S. Census conducted every ten years is a population count since it attempts to obtain information from everyone living in the United States.

Prevalence: The total number of persons living with a specific disease or condition in a defined population at a given time (compared to the incidence, which refers to the number of new cases).

Prevalence Rate: The proportion of a population living at a given time with a condition or disease. (In contrast the incidence rate refers to new cases.)

Prevention Services: Interventions, strategies, programs, and structures designed to change behavior that may lead to HIV infection or other disease. Examples of HIV prevention services include street outreach, educational sessions, condom distribution, and mentoring and counseling programs.

Primary Source Data: original data that you collect and analyze yourself.

Priority Setting: The process used by a planning council or consortium to establish numerical priorities among service categories, to ensure consistency with locally identified needs, and to address how best to meet each priority.

Probability: The likelihood that a particular event or relationship will occur.

Probability Value: The probability that a statistical result—an observed difference or relationship—would have occurred by chance alone, rather than reflecting a real difference or relationship; statistical results are often considered to be significant if the probability or **p value** is less than 05, which means that there is less than a 5% chance—5 out of 100—that the result would have occurred by chance alone.

Profile of Provider Capability/Capability: A description of the extent to which the various services offered by a network of providers in the service area are available, accessible, and appropriate for PLWH, including particular populations.

Prophylaxis: Treatment to prevent the onset of a particular disease (primary prophylaxis) or recurrence of symptoms in an existing infection that has been brought under control (secondary prophylaxis).

Proportion: A number smaller than the total, which is calculated by dividing the number of subjects having a certain characteristic by the total number of subjects; for example, if 35 new AIDS cases have been reported in the community in the past year and 7 of them are women, the proportion of female AIDS cases is 7 divided by 35 or 1/5 (.2).

Public Health Surveillance: The ongoing, systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practice; closely integrated with the timely dissemination of these data to those responsible for prevention and control.

Public Hearing: A non-survey method of collecting information involving a structured open meeting at which residents may make formal presentations and sometimes engage in discussion with a decision-making or fact-finding body.

Random Sample: A sample in which every member of the population being sampled has an equal probability of being included. In order to be able to generalize findings from a sample, it is essential to use a probability (random) sampling method.

Ratio: A combination of two numbers that shows their relative size; the ratio of one number to another is simply the first number divided by the other, with the relation between the two numbers expressed as a fraction (X/Y) or decimal (X.Y/1), or simply the two numbers separated by a colon (X:Y); for example, the ratio of minority to white pediatric AIDS cases in a community with 75 total cases, 45 among Hispanic and Black children and 30 among white children, would be 45/30 (45:30), 3/2 (3:2), or 1.5:1.

Raw Data: Data in their original form, as collected, that have not been coded or analyzed; for example, if a woman participating in an HIV nutrition workshop is tested to determine her knowledge of nutrition needs and gets a score of 11, that is her raw score; if the score represented 11 correct answers out of 20, then the score could be converted to 11 divided by 20 times 100 or 55%, which is no longer a raw score.

Reliability: The consistency of a measure or question in obtaining very similar or identical results when used repeatedly; for example, if you repeated a blood test three times on the same blood sample, it would be reliable if it generated the same results each time.

Representative: Term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

RFP (*Request for Proposals*): An open and competitive process for selecting providers of services (sometimes called *RFA* or *Request for Application*).

Resource Allocation: The legislatively mandated responsibility of planning councils to assign CARE Act amounts or percentages to established priorities across specific service categories, geographic areas, populations, or subpopulations.

Risk Factor or Risk Behavior: Behavior or other factor that places a person at risk for disease; for HIV/AIDS, this includes such factors as male-to-male sexual contact, injection drug use, and commercial sex work.

Rounding: Presenting numbers in more convenient units; rounding is usually done so that all numbers being compared have the same level of precision (one decimal place, for example); usually numbers under 5 are rounded down while 5 and over are rounded up; for example, you would round 3.08 to 3.1 and 4.14 to 4.1.

SAMHSA (*Substance Abuse and Mental Health Services Administration*): The DHHS agency that administers programs in alcohol abuse, substance abuse, and mental health.

SCSN (*Statewide Coordinated Statement of Need*): A written statement of need for the entire State developed through a process designed to collaboratively identify significant HIV issues and maximize CARE Act program coordination. The SCSN is legislatively mandated and the process is convened by the Title II grantee, with equal responsibility and input by all programs. Representatives must include all CARE Act Titles and Part F managers, providers, PLWH, and public health agency(s).

Sample: A group of subjects selected from a total population or universe with the expectation that studying the group will provide important information about the total population.

Secondary Source Data: Existing information that was collected by someone else but which you can analyze or re-analyze and use. Such data may be in "r a w" (unanalyzed) or analyzed form.

Secondary Analysis: Re-analysis of data or other information collected by someone else; for example, you might obtain data on AIDS cases in your metro area from the Centers for Disease Control and Prevention, and carry out some additional analysis of those data.

Self-Administered Survey: A survey that is mailed or given to an individual to be completed independently by the individual and then returned, rather than having an interviewer ask the questions and record the answers.

Serology: The study of blood serum and its component parts; blood serum is the fluid that separates from clotted or blood plasma that is allowed to stand. HIV testing is conducted using

blood serum from the person being tested.

Seroprevalence: The number of persons in a defined population who test HIV-positive based on HIV testing of blood specimens. Seroprevalence is often presented as a percent of the total specimens tested or as a rate (per 100,000 persons tested.)

Seroprevalence Reports: Reports that provide information about the percent or rate of people in specific testing groups and populations who have tested positive for HIV.

SPNS (*Special Projects of National Significance*): A health services demonstration, research, and evaluation program funded under Part F of the CARE Act. SPNS projects are awarded competitively.

Statistical Significance: A measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone; statistical results are often considered to be significant if there is less than a 5% chance-5 out of 100-that they would have occurred by chance alone.

Statistics: Information presented in numerical terms (quantitative data); often refers to numerical summaries of data obtained through surveys or analysis.

Stratified Random Sample: A random sample drawn after dividing the population being studied into several subgroups or strata based on specific characteristics; subsamples are then drawn separately from each of the strata; for example, the population of a community might be stratified by race/ethnicity before random sampling.

Surrogate Measures: Substitute measures, used to help understand a situation where adequate direct measures are not available; for example, it may be difficult to obtain good HIV surveillance data on teenagers, but incidence rates of sexually transmitted diseases (STDs) among teenagers can be used as surrogate measures of high-risk sexual behavior, since HIV is an STD and people get STDs when they engage in unprotected sex.

Surveillance Reports: A report providing information on the number of reported cases of a disease such as AIDS, nationally and for specific subpopulations.

Survey: Data collection method in which a number of individuals (often a probability sample) are asked the same set of questions, which are usually largely multiple choice or short-answer, and their responses are tabulated, analyzed, and compared to provide quantitative data about the population surveyed.

Survey Research: Research in which a sample of subjects is drawn from a population and then interviewed or otherwise studied to gain information about the total population from which the sample was drawn.

Tabulation of Data: Ordering and counting of data to determine the frequency of responses, usually the first step in data analysis; often involves entering data into a computer for manipulation through some form of data analysis program.

Target Populations: A population to be reached through some action or intervention; may refer to groups with specific demographic or geographic characteristics.

Technical Assistance (TA): Training and individualized assistance that provides knowledge and skill development to enable people to do their work better.

Title I: The part of the CARE Act that provides emergency assistance to localities (EMAs) disproportionately affected by the HIV epidemic.

Title II: The part of the CARE Act that enables States and territories to improve the quality, availability, and organization of health care and support services to individuals with HIV and their families.

Title III: The part of the CARE Act that supports outpatient primary medical care and early intervention services to people living with HIV disease through grants to public and private non-profit organizations.

Title IV: The part of the CARE Act that supports coordinated services and access to research for children, youth, and women with HIV disease and their families.

Transmission Category: A grouping of disease exposure and infection routes; in relation to HIV disease, exposure groupings include injection drug use, men who have sex with men, heterosexual contact, perinatal transmission, etc.

Trend: Movement in a particular direction in the value of variables over time.

Trend Charts: Line charts which show changes or movement in the values of a particular variable over time; usually, values are recorded periodically as points on a graph, and then connected to show how the values are changing; often used to provide comparisons, such as separate lines showing reported AIDS cases among different population groups over time.

Universe: The total population from which a sample is drawn.

Unmet Need: Service needs of those individuals not currently in care as well as those in care whose needs are only partially met or not being met. Needs might be unmet because available services are either inappropriate for or inaccessible to the target population.

Validity: The extent to which a survey question or other measurement instrument actually measures what it is supposed to measure; for example, a question which asks men who have sex with men whether they are using condoms is valid if it accurately measures the actual extent to which they are using condoms; it is not valid if the men are not giving honest answers, and the question is really measuring the extent to which they realize that they should be using condoms.

Value: Individual response or score; for example, if people responding to a survey are asked to state their age, each age is a value.

Variable: A characteristic or finding that can change or vary among different people or in the same person over time; for example, race/ethnicity varies among individuals, and income varies for the same individual over time.

Weighting: A statistical procedure for adjusting the values of data by assigning more or less weight to some groups than others so that their distributions in the sample correspond more closely to their distributions in the population as a whole. For example, suppose for your needs assessment you stratified the community population by race/ethnicity and oversampled minorities so you could compare findings for each group. In order to combine your findings to describe the entire population, you would weight the data from each racial/ethnic group to reflect the percentage of the whole population that comes from that group.