NEEDS ASSESSMENT

SELF-ASSESSMENT MODULE

Ryan White CARE Act
Title I HIV Health Services Planning Councils
Title II HIV Care Consortia/Planning Bodies

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INTRODUCTION

The Self-Assessment Module Series, Second Edition

The Division of Service Systems (DSS) and the Office of Science and Epidemiology (OSE) of the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA) have developed a series of tools to help Titles I and II planning bodies assess their effectiveness in critical areas of responsibility defined by the Ryan White CARE Act. This second edition of the HRSA/HAB Self Assessment Module Series incorporates changes in the roles and responsibilities of CARE Act entities resulting from reauthorization of the Act in 2000. The topics covered in the Self-Assessment series are:

- Comprehensive HIV Services Planning.
- Continuum of Care.
- Developing and Pursuing the Mission.
- Needs Assessment.
- Priority Setting and Resource Allocation.
- Representation and Diversity.

Each topic is addressed in a separate Self-Assessment Module (SAM). Information is complementary across the modules and cross-referenced when appropriate. The modules can be used independently of each other or as a full series.

The modules are designed to facilitate self-assessment by planning bodies. Use of any and all modules in the series is completely voluntary. Planning bodies are free to determine which area(s) they want to assess, when to conduct the self-assessment, how extensive the scope of the assessment will be, and with whom they will share results.

DSS staff and the Technical Assistance Contractor (TAC) are available to introduce the modules or to respond to any concerns raised through the self-assessment process. Please contact your DSS project officer if you have any questions about the Self-Assessment Modules or would like assistance.

Purpose of the Needs Assessment SAM

Assessing the health and social service needs of people living with HIV disease and AIDS (PLWH) is an essential prerequisite to developing a responsive service delivery system. The CARE Act recognizes the critical role of needs assessment in assuring a comprehensive array of cost-effective services. Titles I and II planning bodies (referred to as "planning bodies" throughout this document) are required by the Act to assess service needs in order to develop a plan for organizing and delivering comprehensive HIV services. Planning bodies are also expected to participate in the development of a Statewide Coordinated Statement of Need (SCSN) led by the Title II grantee.

The primary purpose of this SAM is to help planning bodies assess the effectiveness of their needs assessment process and outcomes. It is designed to help planning bodies improve the quality of their needs assessments, looking at three primary areas:

- First, the module assesses the completeness of the components of a needs assessment.
- Second, it evaluates the process used to conduct a needs assessment.
- Third, it assesses the outcomes of the needs assessment and how these outcomes are used in planning and priority setting.

This SAM is targeted both to planning bodies that already have undertaken some components of a needs assessment and to those that are beginning to plan their needs assessment process. Using this SAM, planning bodies will gain knowledge about the specific components of a needs assessment. Going through the SAM process will provide planning bodies with insight into the methods used to collect and analyze data. This knowledge can be used to assess the adequacy of past activities and to help refine or expand future needs assessments.

What is Needs Assessment?

Needs assessment is 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 exist. This requires obtaining information from multiple sources about current conditions — including problems/service needs and the resources/approaches being used to address these needs. Findings should be used to develop a comprehensive plan, prioritize service needs, and develop strategies to address these needs, for both the overall population and for specific sub-populations.

There are various approaches to needs assessment. Several factors influence the type and scope of needs assessment activities, such as the size of the geographic area being assessed, impact of the epidemic, diversity of populations affected, resources available to conduct the assessment, and availability of prior needs assessments.

Needs assessments may vary in terms of the definition of need used, the components of the needs assessment, and the approaches used to measure need. These issues are discussed below.

Definitions of Need

Needs assessments may focus on one or more types of need.

- ***Met need*** refers to the needs that are currently being addressed through existing services. These services are available to, appropriate for, and accessible to the target population.
- ***Unmet need*** means the unmet need for primary health services among individuals who know their HIV status but are not receiving primary health care.

- ***Unmet need for health services*** refers to the need for HIV-related services by individuals with HIV disease who are aware of their HIV status, but are not receiving regular primary health care. Primary health care includes:
  - Medical evaluation and clinical care that is consistent with Public Health Service guidelines, including CD4 cell monitoring, viral load testing, antiretroviral therapy, prophylaxis and treatment of opportunistic infections, malignancies, and other related conditions;
  - Oral health care;
  - Outpatient mental health care;
  - Outpatient substance abuse treatment;
  - Nutritional services; and
  - Specialty medical care referrals.
- ***Severe need*** refers to the degree to which providing primary medical care to people with HIV disease in any given area is more complicated and costly than in other areas, based on a combination of the adverse health and socioeconomic circumstances of the populations to be served.

A needs assessment may address one or all of these types of needs, depending on the purpose of the assessment, availability of previous assessments or data, and the resources available. To understand how to improve services, it is most productive to assess multiple types of need simultaneously. For example, looking at the difference between objective need and perceived need points to areas where consumer and/or provider education might influence care-seeking behavior. Including a measure of demand can help identify which needs are priorities for consumers. Adding information about fulfilled need can distinguish services that are easier to obtain from those that are more difficult.

Components of a Needs Assessment

A comprehensive needs assessment includes several specific components. On an annual basis, specific components of the needs assessment should be expanded and/or updated, depending on trends and special issues facing the EMA. The major components of a comprehensive needs assessment are:

- ***An epidemiological*** profile is a document that describes the HIV/AIDS epidemic within various populations and identifies characteristics of both HIV-infected and HIV-negative persons in defined geographic areas. It includes information gathered to describe the effect of HIV/AIDS on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. The epidemiologic profile serves as the scientific basis from which HIV prevention and care needs are identified and prioritized for any given jurisdiction.
- ***An assessment of service needs*** among affected populations, including barriers that prevent PLWH from receiving needed services. This component involves gathering an array of information from multiple sources in order to identify trends and common themes. Data sources include PLWH and other community members, the health department, Medicaid agency, community-based providers and, where applicable, grantees funded by other CARE Act titles. Information must also be obtained from and about HIV-positive individuals who know their status and are not in care.

- ***A resource inventory*** that describes organizations and individuals providing services across the full continuum of HIV services accessible to PLWH in the area. The goal of the resource inventory is to develop a comprehensive picture of services, regardless of funding source. At a minimum, the resource inventory includes for each provider a description of the types of services provided, the number of clients served, and funding levels and sources.
- ***An assessment of provider capacity and capability*** which identifies the extent to which services identified in the resource inventory are accessible, available and appropriate for PLWH, including specific sub-populations. Estimates of capacity describe how much of which services a provider can provide. Assessments of capability describe the degree to which a provider is actually accessible and has the needed expertise to provide services. A careful assessment of barriers to PLWH receiving services is an important aspect of this component. Some needs assessments will also explore acceptability of services. However, assessment of client satisfaction is a complex effort that should be undertaken thoroughly in the planning body's quality improvement process.
- ***An assessment of gaps in services*** that brings together the quantitative and qualitative data on service needs, resources and barriers to help set priorities and allocate resources. This should include an estimate of unmet need or gap analyses for both PLWH in care and those not currently receiving primary health care or other HIV services.

Planning bodies take different approaches to completing the components of a needs assessment. Some planning bodies may decide to undertake a complete needs assessment at one time, and then repeat the process at periodic intervals (i.e., every three to five years). Others may begin with a less comprehensive approach designed to provide critical information on service gaps quickly, and then build a comprehensive assessment over time by conducting other components. For example, in its first year of operation, a new planning body may choose to assemble State surveillance data and conduct interviews and focus groups with key PLWH and provider groups to discern high priority needs. In subsequent years, it may expand its needs assessment efforts to design and conduct surveys of PLWH and providers.

Early in its operational life, though not necessarily at one time, a planning body should undertake all the components of a comprehensive needs assessment to provide a solid baseline for planning. From that base, specific components can be updated and augmented, according to available resources and the need for new information for planning and priority setting. Approximately every three to five years, a comprehensive reassessment of all components should be considered. Each planning body must determine when and how often each component of the needs assessment should be conducted.

Measuring Need

Needs assessments are conducted using a variety of methods and types of data. Typically, a needs assessment includes analysis of quantitative and qualitative data drawn from both primary and secondary data sources. In this module, these terms are defined as follows:

- ***Quantitative data*** are numbers that can be statistically analyzed and are used to describe what, who, when, how many, or how much in relation to a question or issue.
- ***Qualitative data*** are descriptive and usually presented in narrative form. Qualitative data can help illuminate what is happening, as well as describe how, and/or why something is occurring.
- ***Primary data*** are collected, compiled, and analyzed for the first time as part of the needs assessment process. Surveys, interviews, and focus groups are the main ways primary data are collected in needs assessments.
- ***Secondary data*** are existing data bases or reports prepared from previous studies or data collection efforts. AIDS surveillance data, hospital discharge data, vital statistics, seroprevalence studies, Medicaid or insurance claims data, and needs assessments conducted by other groups are secondary data sources.

Most needs assessments will use quantitative and qualitative data from primary and secondary sources to provide the most complete picture of needs.

Conducting the Self-Assessment

This section discusses how to conduct the self-assessment. It provides tips to make the self-assessment process efficient, productive, and positive. These recommendations are based on experience and feedback from the pilot tests of the modules. Each planning body should adapt these processes to fit local constraints and issues.

A. Who Should Use This Module?

This SAM is designed to assist planning bodies in both the pre-assessment design and the post-assessment evaluation of the needs assessment process:

- For planning bodies that have not yet conducted a needs assessment, this SAM can also be used as a development tool to design and plan future needs assessments. The questions in the module can serve as a checklist for items to include in the process.
- For planning bodies that have completed a needs assessment (or components of one), this SAM can be used to evaluate successes and identify areas for quality improvement in future needs assessments.

The decision to use the SAM is often made by a planning body's standing committee, e.g., evaluation, planning, or executive committee or an ad hoc group convened to make recommendations about whether to use the module. This same group should also decide at the outset whether, how, and with whom the results of the assessment will be shared.

Use of this module is completely voluntary and should be decided upon solely by the planning body membership. Planning bodies are free to determine when to conduct the self-assessment and how comprehensive it will be.

B. Who Conducts the Self-Assessment?

A committee or workgroup should oversee the implementation of the self-assessment. This could be the same group that recommended the self-assessment or it

could be a newly convened group. A group of five to ten is suggested and should include PLWH and HIV medical and support service providers, as well as people with expertise in needs assessment methodology, health services planning, and evaluation. Attention to racial, ethnic, gender, diversity and geographic representation is critical. Some of the group should be drawn from existing planning body membership, but it may be useful to go outside the planning body for specific expertise. In general, it is desirable to include a grantee representative in order to promote a cooperative and collaborative relationship.

It is not advisable to have the person(s) directly responsible for the needs assessment lead this self-assessment effort because it may be difficult for that individual to be objective. On the other hand, their participation in the self-assessment will provide an important perspective and may help ensure that improvements are implemented in future assessments.

This and all other SAMs have been designed to be completed by groups of volunteers—members of planning bodies and others. However, planning body staff may be involved, depending on local circumstances and availability. For instance, staff may be needed to assist in the gathering of documents and to ensure effective communication among members. Consultants should not be used to conduct the self-assessment. They may, however, be helpful in modifying this module for the local environment, facilitating the self-assessment process, or developing plans for revising the needs assessment following the self-assessment. DSS staff is also available to assist in the application of the module.

C. What Activities should be Part of the Self-Assessment?

Six major activities must occur to complete the self-assessment.

1. Review and adapt the module to the local environment.
2. Collect information and documents needed to answer the questions in the module.
3. Conduct interviews.
4. Answer and score the questions in the module.
5. Develop an action plan to guide future activities.
6. Apply results of the self-assessment.

The five major activities of the self-assessment are described below.

1. ***Review and adapt the module.*** After the decision is made to proceed with the self-assessment, the first step is to review the module and adapt it as necessary to the local environment. Irrelevant questions should be eliminated and lists of stakeholders should be augmented or reduced as appropriate. Careful review of all the module's sections at the outset will facilitate its implementation and minimize frustration among workgroup members.

   The module should be distributed to all members of the self-assessment workgroup at least one week before the first workgroup meeting. The first meeting, to be held in person if possible, should be aimed at determining the scope, content and purpose of the self-assessment. The self-assessment workgroup should have and review the written charge from the planning body authorizing

the self-assessment. Participants should define the process and time line by which the self-assessment will be conducted, assign roles and responsibilities of workgroup members, and clarify specific questions for all members. If a chairperson has not been appointed, one should be elected at this meeting.

2. ***Collect information and documents.*** Once the workgroup has agreed on the scope of the self-assessment, members should collect and review related documents, instruments, and reports. This task may require more than one person and should include at least one person with expertise in needs assessment methodology. Documents that might be collected include:

    - The final needs assessment report.
    - Tools used to conduct the needs assessment, e.g., survey instruments, interview protocols, and focus group guides.
    - Minutes and attendance logs from meetings of committees or advisory boards that participated in the needs assessment.
    - Minutes from council and consortium meetings where the needs assessment was discussed.
    - Working papers and reports used in preparing the final needs assessment reports.
    - Request(s) for proposals and consultant reports (if any part of the needs assessment was conducted by consultants).

3. ***Conduct Interviews.*** Interviews could be conducted with members of the planning body's needs assessment committee; members of any advisory group formed to oversee the process; planning body staff who worked on the needs assessment; consultants who worked on the needs assessment; people at the grantee, council, or consortium level who used the needs assessment for planning or priority setting; and people representing affected populations or services covered in the needs assessment. This task will also require the involvement of more than one person to be completed in a timely way.

    The goal of the interviews is to gain understanding about how well the needs assessment was conducted and to identify areas for improvement in future needs assessments. The purpose is not to repeat the needs assessment itself. Questions may be taken directly from the SAM for use in the interview. It is advisable to identify in advance which questions you will discuss with each person being interviewed. For example, you may want to discuss methodology with a research consultant and the inclusiveness of the needs assessment process with affected populations.

4. ***Answer and score the questions.*** After collecting relevant information and conducting key interviews, the workgroup should convene to discuss the questions in the module. Depending on the number of questions being addressed, the discussion could take four to six hours. The discussion may occur in a single meeting, in a series of meetings, or by telephone conference calls. The questions have been subdivided into five sections to facilitate a segmented discussion. The sections correspond to the major components of the needs assessment process:

    A. Designing the Needs Assessment

    B. Conducting the Needs Assessment

    C. Outcome of the Needs Assessment

    D. Analysis and Results

    E. Dissemination and Use

Many questions will require significant discussion and coming to consensus. It is important to choose an individual who can focus and facilitate discussion.

There are two important things to consider in developing a response to each question.

- Of primary importance, the qualitative discussion of each question will help identify what the planning body did well and what it could do better.
- The assignment of a score, where scoring is indicated, will help .the planning body identify areas of strength and weakness. These scores also can provide a baseline for future self-assessments.

Many questions will require significant discussion and coming to concensus. It is important to choose an individual to lead the process who can focus and facilitate the discussion. Further discussion of the questions is provided at the beginning of the Questions Section of this SAM.

5. ***Develop action plans.*** The self-assessment will be most successful if it improves future needs assessment efforts by keeping what works well, modifying what doesn't, and adding important aspects that are missing. Each section of questions concludes with the development of an action plan for tasks related to that section. The action plans are intended to direct future needs assessment efforts. Particular attention should be paid to questions that were scored 0 to 1, because these may be problem areas. You also should note areas of strength to build into future needs assessment activities.

   Each section's action plan is formatted to list objectives, time line, resources needed, and lead person responsible for completing the objective. This may be modified to meet the needs of a particular planning body. Once the section-specific action plans are done, an overall plan with priorities should be developed.

6. ***Apply results.*** The results of the self-assessment, including answers to questions, scores, and action plans, belong only to the planning body. However, a planning body may decide to share part or all of its results with the grantee, with DSS, or with the community.

   The overarching purpose of conducting a self-assessment is to improve the planning body needs assessment activities so that the needs assessment meets legislative requirements and DSS guidelines, and provides reliable quantitative and qualitative information for planning and prioritizing services. There may be other reasons for conducting the self-assessment, such as responding to local questions or concerns, but the SAMs have been designed primarily as a tool to help planning bodies improve the quality of their operations. The action plan component of the module is intended to lead to such improvements.

   At the conclusion of the self-assessment, the planning body may want to develop a brief report summarizing the process. The report could address the charge to the workgroup or committee, workgroup membership, processes used to complete the module, and major findings.

D. How Much Time and Money are Required?

The self-assessment process has been designed to be very low cost. Time is the principal investment required of those who help complete the module.

Once a planning body has decided to proceed with the self-assessment, the process should take between eight and fourteen weeks, beginning with the first planning meeting and ending with an action plan.

Sample Time Line For The Self-Assessment

Deciding to Conduct the Self-assessment

Week 1:	Planning body decides to proceed with self-assessment, identifies ad hoc workgroup to conduct assessment, writes charge to the workgroup, distributes SAM to the workgroup, decides who will get results.

Preparatory Work

Weeks 2-3:	Workgroup meets, elects chair, reviews and modifies questions, assigns responsibilities.
Weeks 4-7:	Background documents obtained and reviewed, interviews conducted.

Answering Questions

Weeks 8-9:	Workgroup meets to discuss and to score questions, develops action plans for completed sections.
Week 10:	Workgroup meets to complete discussion of action plans.

Reporting and Implementing

Week 11:	Present results to planning body, report on process and final decision.
Weeks 12-14:	Decide on overall plan and implementation, request technical assistance, if needed.

SELF-ASSESSMENT QUESTION FORMAT

Question Types

The module contains four types of questions:

a. Questions that rank responses from 0 to 3, with 0 being the lowest score and 3 being the highest. Each planning council and consortium completing the module determines where to rank itself along this continuum.

b. Questions with a yes or no response. When the desired direction of response is known, these questions are also scored with "no" scoring 0 and "yes" scoring 3. For some yes/no questions where either answer may be equally good, depending on circumstances, no score is given.

c. Multi-part questions in which the sub-parts are not scored, but a summary question asks for an overall assessment scored from 0 to 3.

d. Open-ended questions that are not scored. These questions enable planning bodies to highlight aspects of complex questions they feel are particular strengths or weaknesses.

Discussion of Questions

To the right of each question is a set of Discussion of Questions to assist you in developing thorough answers. These "tips" may include a brief discussion of the question topic, a set of benchmarks to consider in your response to the question, or guidance on how to interpret your score and answers.

Scoring

The points in each section are added up and divided by the number of scored questions in the section. By dividing the total points by the number of scored questions, you will have a single score of 0 to 3 for each section. That score can be compared to the score in other sections. Combined with a qualitative assessment of strengths and weaknesses in each section, the scores can be helpful in highlighting areas where a planning body has done very well (high scores, e.g., 2 to 3), as well as areas in which changes or enhancements should be considered (low scores, e.g., 0 to 1).

As you work to assign scores, please remember that scoring is not the ultimate goal of the self-assessment. It is much more important that the group engage in substantive discussion of the questions.

If you get stuck on scoring, move on. All scores are confidential and are not compared across Titles I and II planning bodies or shared with DSS.

NEEDS ASSESSMENT QUESTIONS

A. Designing the Needs Assessment

1a. Was an individual, committee, or workgroup assigned to design the needs assessment?

❑ **0 pts** *No*

❑ **3 pts** *Yes*

1b. Was an individual, committee, or workgroup assigned to conduct the needs assessment?

❑ **0 pts** *No*

❑ **3 pts** *Yes*

2. To what extent were people living with HIV/AIDS involved in designing the needs assessment?

❑ **0 pts** *No Involvement* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Significant Involvement*

3 To what extent were people with expertise in needs assessment methodology involved in designing the needs assessment?

❑ **0 pts** *No Involvement* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Significant Involvement*

4. Based on your experience, what perspectives and expertise are important to include when designing needs assessments?

_____

_____

_____

5. Was there a clear statement of the goals of the needs assessment prior to beginning the design process?

❑ **0 pts** *No statement of goals* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Clearly written goals*

6. Did the goals of the needs assessment, at a minimum, address legislative requirements?

❑ **0 pts** *Requirements not addressed* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Requirements fully addressed*

7. Were research questions or objectives clearly defined in the design of the needs assessment?

❑ **0 pts** *No questions or objectives defined* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *All questions or objectives clearly defined*

8. Were a time line and budget established, and were they reasonable to achieve the goals?

Time line

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No time line established			*Time line established*

Budget

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No budget established			*Viable budget established*

9. To what extent did the planning body consider information available from other local and State agencies or organizations?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No attempt to consider information from other organizations			*Information from existing organizations fully considered*

A list of organizations involved in assessing HIV-related needs follows. Not all communities have all of these organizations in place, and some communities may have other relevant resources. The activity involves identifying the potential data resources and considering whether they would be useful (Keep in mind that not all data resources will be useful. Data may be out-of-date, incomplete, or address issues outside the scope of the planning body assessment). The chart below is designed to help answer the question above.

Question 9	**External Data Sources**					
External Data Source	**Information Available?**		**Information Considered?**		**Information Useful?**	
	No	**Yes**	**No**	**Yes**	**No**	**Yes**
CDC HIV Prevention Community Planning Groups						
Statewide Coordinated Statement of Need (SCSN) working group						
Title III grantees						
Title IV grantees						
Another planning body with overlapping service area						
AIDS Education and Training Center (AETC) programs						
Special Projects of National Significance (SPNS)						
Substance Abuse and Mental Health Services Administration (SAMHSA) programs						
Housing Opportunity for People with AIDS (HOPWA) programs						
Federally-funded Migrant, Homeless, and Community Health Centers						
Maternal and Child Health programs						
TB programs						
STD programs						
Programs serving the mentally ill						
State Medicaid program						
Other Resources (list):						

10. What research methods/data sources were considered for use in the needs assessment, and which of those considered were actually used in conducting the needs assessment?

Needs assessments should use a combination of qualitative and quantitative methods. Specific methods used will depend on many factors, including the goals of the needs assessment, research questions to be addressed, and time and money available to conduct the needs assessment. This two-part question asks whether a range of methods was considered in designing the needs assessment and whether appropriate methods were used in conducting the assessment. The following chart includes several methods and data sources often used in HIV needs assessment and is designed to help answer questions 10a-d.

Question 10	**Methods Considered and/or Used in Conducting the Needs Assessment**			
Method/Source	**Considered?**		**Used?**	
	No	**Yes**	**No**	**Yes**
Secondary Data				
• Previous HIV-related needs assessment (e.g., CDC, AETC, Title III—See list in question 9)				
• HIV/AIDS surveillance data				
• Sero-prevalence studies				
• Data related to high-risk populations (e.g., homeless, IDUs and non-IDU users, migrant or seasonal farm workers, rural populations, runaway or street youth)				
• Data on co-morbidities (e.g., TB, STDs, adolescent pregnancy, substance abuse, etc.)				
• Insurance data: private insurers, Medicaid, Medicare				
• Hospital data				
• Provider records (e.g., waiting lists, case management referrals)				
• ADAP Data				
• Other (list):				
Primary Data: Surveys (mail, telephone, in-person)				
• PLWH				
• Providers				
• Community Leaders				
• Other (list):				
Primary Data: Interviews (telephone, in-person)				
• PLWH				
• Providers				
• Community Leaders				
• Grantee				
• Other (list):				
Primary Data: Focus Groups				
• PLWH				
• Providers				
• Community Leaders				
• Other (list):				
Primary Data: Public Forums/Hearings				
• Call-In Line				
• Informal Discussions				

10a. Was a range of methods and data sources considered in designing the needs assessment?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Very limited range considered			*Full range considered*

10b. To what extent were appropriate methods and data sources used in conducting the needs assessment?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Very few appropriate methods and data used			*Many appropriate methods and data used*

10c. Which methods and data sources were most useful in conducting the needs assessment and why? Which were least useful and why?

Most useful	*Why?*
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Least useful	*Why?*
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

10d. What methods should be considered for use in future needs assessments?

_____
_____
_____
_____
_____

11. To what extent was a plan for analyzing results developed during the design of the needs assessment?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Not at all			*The analysis plan was fully developed during the design*

SUMMARY: A. Designing the Needs Assessment

Scoring of Questions 1–11

To score, follow these steps:

STEP 1 Add up the points for questions 1 through 11 and enter that number in the **Total Points** box.

STEP 2 Add up the number of scored questions you answered and enter it in the **Total Number of Scored Questions** box.

STEP 3 Calculate and record your final score: **Total Points Divided by Total Number of Scored Questions Answered**.

Total Points _____

(Divided by) Number of Statements Answered _____

(Equals) Score _____

Maximum possible score is 3

**If your score equals more than 3, double-check your addition of points (Step 1) and re-count the number of scored questions (Step 2).*

Strengths And Weaknesses for Questions 1–11

What aspects of designing the needs assessment worked well and should be retained?

_____

_____

_____

_____

_____

_____

What should be added or improved?

_____

_____

_____

_____

_____

_____

_____

Action Steps for Questions 1–11

Based on your responses to questions 1 through 11, list the key areas where action is needed in designing future needs assessments. Action steps may address areas of strength that the planning body wants to retain in future needs assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments.

Objective: Resources:

Time line: Person Responsible:

Objective: Resources:

Time line: Person Responsible:

Objective: Resources:

Time line: Person Responsible:

Discussion of Questions 1–11

This section asks about who was involved in designing the needs assessment, whether the needs assessment started with clearly articulated goals, whether thought was given to the time and resources needed to carry out the needs assessment, whether the planning for the needs assessment involved organizations that could provide information for the assessment, and which methods and data sources were considered in designing the needs assessment.

Questions 1a and 1b award maximum points if a person or group was assigned specific responsibility for designing and conducting the needs assessment. Generally, a committee or workgroup is preferred to an individual in order to include diverse perspectives. It is not necessary that the same person or group oversee both the design and implementation of the needs assessment, but some continuity throughout the process may help ensure efficiency.

Questions 2-4 ask about who was involved in designing the needs assessment. It is advisable to include diverse perspectives at the outset. People living with HIV whose needs are being assessed, providers who will be asked to contribute information for the assessment, planning body members and funders who will use the results, and people with expertise in needs assessment methods can all make valuable contributions to designing the needs assessment.

Benchmark: Needs assessments must be as inclusive as possible. PLWH must participate in the needs assessment process. Grantees, community representatives, and service providers should also be included. Inclusion begins in the design phase.

Each community must select key people with diverse perspectives and expertise to involve in designing the needs assessment, while maintaining a reasonably sized planning group, e.g., five to ten people. Question 2 asks about involvement of PLWH in designing the needs assessment. PLWH can make important contributions by helping define key services or populations that should be the focus of study, suggesting effective ways of collecting data from PLWH, and describing how the PLWH community can use the results of the needs assessment. Give yourself maximum points for question 2 if you included a diverse group of PLWH in the design of the needs assessment and incorporated their suggestions into the design. Give yourself maximum points for question 3 if you included people with expertise in needs assessment methodology in designing your needs assessment. Needs assessments often obtain data through surveys, interviews, and focus groups, which may involve complex methods and analyses. People with research expertise are important to ensure that the needs assessment produces the best data possible given the resources available. Answer question 4 to highlight expertise and perspectives that should be included when you design future needs assessments.

Give yourself maximum points on question 5 if your planning group developed written goals for the assessment, and fewer points if goals were discussed but not written. Predefined needs assessment goals will direct the process and help assure that the results are useful in planning future needs assessments.

Question 6 specifically relates to HRSA requirements based on legislation and guidance. These are as follows:

Benchmark: Consortia must demonstrate that they have carried out an assessment of need in the geographic area to be served and have developed a plan to ensure delivery of services to meet identified needs.

Planning councils are required to develop or expand needs assessments processes that will determine the needs of individuals who know their HIV status and are not in care. The needs assessment must address disparities in access and services of underserved populations and affected subpopulations. The needs assessment must also identify any capacity development needs. Such needs results when disparities in the availability of HIV-related services are identified particularly in historically underserved communities. Priority setting and allocation of resources must reflect the results of the needs assessment process.

Question 7 asks whether specific research questions or objectives were defined during the design phase of the assessment. The more explicitly the questions are articulated in the design phase, the more likely the information collected will be useful. Ideally, a planning body will formulate clearly written and very specific questions during the design phase. This earns maximum points. More general objectives for the needs assessment or questions that cover only parts of the assessment should receive fewer points.

Question 8 gives points if a budget and time line for the assessment were developed and followed. Budgets and time lines are important to assure that desired information is collected in a cost-effective and timely manner. You may give yourself maximum points even if the budget and time line were revised during the process. Similarly, if you developed budgets and time lines for specific components of the needs assessment, score maximum points.

Question 9 asks whether information available from several different groups was considered in designing the needs assessment. Needs assessments can be expensive and time-consuming to conduct. Planning bodies should strive to build their assessments on data and information that is already available. A chart is provided to help answer this question. The groups listed in the chart often conduct needs assessments or have data that are relevant to the planning body assessment. Since communities may not have all these organizations in place, the chart first asks whether a particular group exists in the community and then whether information from the organization was considered. Maximum points should be awarded if the planning body discussed and reviewed information available from groups in its area. Actually using the data as part of the needs assessment is not required to earn maximum points because some information may not be relevant or useful.

Benchmark: Needs assessments should be coordinated with other related efforts, e.g., CDC HIV Prevention Community Planning Groups, other CARE Act Titles, AETCs.

Benchmark: Titles I and II planning bodies are expected to participate in the development of the Statewide Coordinated Statement of Need working group led by the State.

Question 10 presents an extensive list of secondary data sources and primary data collection methods that may be used in a needs assessment. No planning body is expected to have used all these data sources and methods, but every planning body should assess a range of methods carefully and select those that are best suited to their goals, research questions, and available resources. Question 10a asks whether a range of methods was considered in designing the needs assessment. Question 10b asks the extent to which appropriate methods were used in the needs assessment. Questions 10c and 10d are open-ended and highlight which methods were most useful, which were less useful, and which methods should be considered in future needs assessments.

Needs assessments should use a combination of qualitative and quantitative methods to ensure the most complete picture of need. State surveillance data should be used in all needs assessments.

Benchmark: Titles I and II planning bodies should establish methods such as public meetings, focus groups, and ad hoc panels for obtaining input on community needs and priorities.

Benchmark: Epidemiological data should be part of the needs assessment. AIDS surveillance data and estimates of HIV disease incidence and prevalence should be used to describe trends in the epidemic since the outset and in the last two years. These trends should be forecast three to five years, as appropriate.

Benchmark: Both quantitative and qualitative data should be used in conducting the needs assessment.

Question 11 concludes the section. It asks whether an analysis plan was developed during the needs assessment design. The clearer you are at this stage about the data you will collect, how you will analyze the data, and how the data will achieve your research goals, the more effectively you will be able to carry out the needs assessment. Award maximum points if a detailed analysis plan was developed during the design phase.

B. Conducting the Needs Assessment

12. To what extent did key stakeholders participate in the needs assessment? (*Refer to Figure 1 for a list of stakeholders.*)

Many people and organizations have a stake in the needs assessment. First and foremost are the people whose needs are being assessed, people living with HIV disease. Other stakeholders include individuals and organizations providing services to affected populations; advocates, government officials, and leaders who are concerned with the well-being of the community; planning body members who will apply the results of the needs assessment; and agencies which provide funding or other resources for HIV services.

The CARE Act of 2000 requires planning councils to develop or expand needs assessments processes to determine the needs of those individuals who know their HIV status but are not in care. HIV positive individuals who know their status yet are not in care should be included in the needs assessment design and implementation. The needs assessment should explore reasons that they are not in care, including barriers to care.

The needs assessment process should be as inclusive as possible, in terms of who participates throughout the process. The following list is intended to help planning bodies think about who is included in their needs assessment.

Figure 1 Stakeholders in HIV/AIDS Needs Assessment

There are many ways to divide stakeholders into groupings, e.g., demographically, geographically, stage of illness, and type of service. The list of potential stakeholders is extensive, especially when combinations of categories are considered. This list is intended to help planning bodies think about who is included in their assessment, not to be exhaustive or prescribe a specific way of categorizing stakeholders. Stakeholders may be divided into five major groups: affected populations, providers, organizations, community leaders, and funders/collaborators.

Affected Populations

Affected populations may be categorized along numerous dimensions. Selection of categories of affected populations will depend on the epidemiology of the epidemic in the area being assessed, the goals and objectives of the needs assessment, and the availability of and/or ability to develop reliable data. Some ways consumers can be grouped include:

- Demographics: e.g., gender, race/ethnicity, age, income
- Transmission mode: e.g., men who have sex with men, IDU, blood product, heterosexual, perinatal
- Geography: e.g., rural/urban, political subdivisions within EMA or consortium area, census tracts, or zip codes
- Stage of illness: e.g., HIV versus AIDS
- Co-morbidities: e.g., mental illness, substance use, pregnancy, TB, STDs
- Social Factors: Homeless individuals, individuals who were recently released from prison, sex workers, non-English speaking individuals
- HIV status: individuals who know their HIV status yet are not in care, individuals who know their HIV status and are in care, individuals who are HIV positive but do not know their HIV status

Types of Individual Providers

Providers also may be categorized in a number of ways: by type of service, geographical location, credentials, etc. They may be included as individuals (e.g., physicians or home care nurses) and/or as organizations (e.g., hospitals or home care agencies).

- Primary care: e.g., pediatrics, adolescent medicine, internal medicine, obstetrics/gynecology, family practice; and/or MD, DO, PA, NP
- Medical specialties: e.g., infectious disease, dermatology,. oncology, ophthalmology, pulmonology, neurologists, psychiatrists
- Nurses
- Mental health: e.g., social workers, psychologists, nurses, psychiatrists
- Case managers (medical/RN, social model)
- Dentists and hygienists
- Substance abuse counselors
- Housing providers
- Prisons/Corrections staff
- Nutritionists
- Buddies
- Pastoral counselors
- Pharmacists

Types of organizations

These will vary by community, but types of organizations to consider are:

- Community and migrant health centers
- Group practices
- Health departments
- Hospitals
- Home care agencies
- AIDS service organizations
- Mental health centers
- Substance abuse treatment centers
- Homeless shelters
- Housing Services
- Prisons
- Meals on wheels and food pantries
- Hospice
- HIV Prevention Programs

Community Leaders and Advocates

These will vary by community, but types of people to consider are representative of:

- Religious communities
- Business communities
- Women's groups
- Gay/lesbian groups
- Racial/ethnic groups
- HIV activist groups
- Neighborhood/community coalitions
- PLWH groups
- Children's advocates

Funders/collaborators

These could be few or several, depending on the service area. A list of potential collaborators is included in the summary chart for Question 9. In addition, the Title I or II grantee and any other significant funders (e.g., foundations) should be included in the process.

There are many ways people may participate in the needs assessment: on committees, workgroups or advisory boards; as focus group participants, key informants in interviews, or survey respondents; in public hearings; as interviewers or focus group moderators; or by analyzing results. The chart below is designed to help answer questions 12a-g.

Question 12	Stakeholder Participation				
Check if stakeholder participation is satisfactory:	**PLWH**	**Providers**	**Leaders**	**Members**	**Funders**
On committees or workgroups					
On advisory boards					
As focus group participants					
As interview key informants					
As survey respondents					
In public hearings					
As interviewers or focus group moderators					
In the analysis					
As draft report reviewer and commenter					
Other:					

12a To what extent did PLWH participate in the needs assessment?

❑ **0 pts** *No participation*
❑ **1 pt**
❑ **2 pts**
❑ **3 pts** *Significant participation in many aspects of the needs assessement*

12b. To what extent did HIV service providers participate in the needs assessment?

❑ **0 pts** *No participation*
❑ **1 pt**
❑ **2 pts**
❑ **3 pts** *Significant participation in many aspects of the needs assessement*

12c. To what extent did community leaders and activists participate in the needs assessment?

❑ **0 pts** *No participation*
❑ **1 pt**
❑ **2 pts**
❑ **3 pts** *Significant participation in many aspects of the needs assessement*

12d. To what extent did planning body members participate in the needs assessment?

❑ **0 pts** *No participation*
❑ **1 pt**
❑ **2 pts**
❑ **3 pts** *Significant participation in many aspects of the needs assessement*

12e. To what extent did funders participate in the needs assessment?

❑ **0 pts** *No participation*
❑ **1 pt**
❑ **2 pts**
❑ **3 pts** *Significant participation in many aspects of the needs assessement*

12f. Were there any other stakeholders who made an important contribution to the needs assessment?

_____

_____

_____

_____

12g. List any groups that have not participated adequately in past needs assessments but should be included in the future.

_____

_____

_____

_____

13. For planning bodies that contracted some or all of the implementation of the needs assessment, how involved were planning body members in setting objectives, designing the needs assessment, and reviewing the consultant's work?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Not at all involved			*Involved in directing all aspects of the needs assessement*

14. What would you do differently to improve the performance of contractors or consultants?

_____

_____

_____

_____

15. For focus groups or interviews, was a discussion guide used to ensure that the desired questions were asked of each group or individual?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
No guides developed			*Guides developed and followed*

16. For focus groups or interviews, to what extent was training for facilitators/interviewers assured?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Used untrained facilitators/ interviewers			*All facilitators/ interviewers fully trained on process and content issues*

Figure 2	Conducting Surveys of PLWH
Questions 17-25 address the process by which surveys of PLWH were conducted. Many of these questions address issues of survey methodology and may best be answered by someone with expertise in methodology. Conducting surveys of PLWH presents particular challenges. Because the universe of people living with HIV disease is not known, it is impossible to conduct a survey based entirely on random or probability samples. Moreover, even when lists are available for some groups (e.g., those in the care of a particular provider), issues of confidentiality make standard survey implementation practices and follow-up difficult to administer. Despite these constraints, however, it is important to follow as many of the principles embedded in rigorous survey research as possible. These principles will help to achieve an accurate picture of the needs of PLWH in the area: 1. Try to reach all key population groups of interest, not just those that are most convenient to reach. Within each group it is also important to reflect the diversity present in the population in terms of geography, income, stage of illness, racial/ethnic identity, age, gender, family status, etc.	2. Have a systematic plan for approaching people to respond to the survey. Do not just include people who are most motivated to participate or who happen to be in a certain place at a certain time. 3. Assure that a large enough group of people responds to the survey(s) that you are confident the answers reliably reflect the group and not just a few individuals. 4. Compare the characteristics of people responding to the survey(s) to known characteristics of the HIV population in the community. Weight your analysis to adjust for differences. *Every survey will not be able to achieve all these principles. The following questions are intended to highlight key aspects of survey(s) with PLWH that will lead to the best information on which to base service decisions.* *If the needs assessment did not include surveys of PLWH, please skip to question 26.*

17. To what extent were target sub-populations identified in the survey(s) design?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
No target sub-populations identified			***target sub-populations fully identified***

18. Did the survey design(s) include specific strategies for collecting information from target sub-populations of people living with HIV disease, and were the strategies successful in reaching those sub-populations?

People living with HIV disease have different service needs and priorities based on many factors, such as their residence, income and insurance, gender, and other illnesses in addition to their HIV infection (co-morbidity factors). In surveying PLWH, it is important to define key subpopulations within the service area and to design specific strategies to reach each group. The goal is to reach enough people in each group so that conclusions about that group's needs can be made with confidence. The chart below is designed to help answer questions 17 and 18a-d.

Question 18	Strategies to reach target sub-populations			
	Considered specific strategies?		Reached people within this population?	
Sub-Population	No	Yes	Not at all	Significant participation
Pregnant women				
White/Anglo men who have sex with men				
Men of color who have sex with men				
Injecting drug users				
Non-injecting drug users				
Sex workers				
Homeless				
Adolescents				
Runaway or street youth				
Rural populations				
Migrant or seasonal farm workers				
Recently Released Prisoners				
Other (list):				

18a. To what extent were specific strategies considered to reach target sub-populations?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
No specific strategies considered			*Specific strategies fully considered for each target sub-population*

18b. To what extent were strategies successful in reaching target sub-populations?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Not at all successful			*Successful in reaching all target sub-populations*

18c. Were specific sub-populations targeted but not reached? What barriers were encountered in reaching these sub-populations?

Sub-population(s)	*Barrier(s)*
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

18d. List sub-populations to target in future surveys and list potential strategies to reach them

Sub-population(s)	*Strategy(ies)*
_____	_____
_____	_____
_____	_____
_____	_____

19. To what extent were systematic procedures for recruiting people to participate in the survey(s) developed and followed?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
No procedures			*Well defined procedures were followed*

20. How successful was the project in getting people who were approached to participate in the survey(s)?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
Less than 25% responded			*More than 75% responded*

21. Were different approaches used to encourage high response rates among groups being surveyed?

❑	❑	❑	❑
0 pts	**1 pt**	**2 pts**	**3 pts**
No approaches used			*Several approaches used*

The following chart lists approaches that may help achieve high response rates. Not all are appropriate for every situation and there may be other effective approaches to increase response rates.

Question 21	Approaches Used to Encourage Participation	
Approach	Approach Used?	
	No	Yes
Interviews scheduled at convenient times and locations		
Incentive for participation		
Translation of surveys and interviews for non-English-speaking respondents		
Opportunity to complete orally for people with difficulty reading written instruments		
Follow-up reminders for non-respondents		
Child care while participating		
Assistance with transportation		
Other (list):		

21a. What approaches should be used to achieve high response rates in future surveys? List both those that have worked well in the past and new approaches that could be helpful.

_____

_____

_____

_____

22. To what extent were comparisons made between the characteristics of people responding to the survey(s) and the most currently available epidemiological data for the community?

❑ **0 pts** *No comparison made* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Respondent characteristics fully compared to community data*

23. To what extent did analyses weight the characteristics of people responding to the survey(s) to correspond to the most currently available epidemiological data for the community?

❑ **0 pts** *No adjustments for differences* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Analysis statistically corrected for differences*

24. To what extent were all survey instruments, including translated instruments, pre-tested before implementation?

❑ **0 pts** *No instruments pretested* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *All instruments pretested, including pretests of translated instruments*

25. To what extent did the questions included in the survey(s) provide useful information about the needs of PLWH?

❑ **0 pts** *Nothing new learned* ❑ **1 pt** ❑ **2 pts** ❑ **3 pts** *Information provided extensive knowledge about PLWH needs*

SUMMARY: Conducting the Needs Assessment

Scoring of Questions 12–25

To score, follow these steps:

STEP 1 Add up the points for questions 12 through 25 and enter that number in the **Total Points** box.

STEP 2 Add up the number of scored questions you answered and enter it in the **Total Number of Scored Questions Answered** box.

STEP 3 Calculate and record your final score: **Total Points *Divided by* Total Number of Scored Questions Answered**.

Total Points _____

(Divided by) Number of Statements Answered _____

(Equals) Score _____

Maximum possible score is 3

**If your score equals more than 3, double-check your addition of points (Step 1) and re-count the number of scored questions (Step 2).*

Strengths And Weaknesses for Questions 12–25

What aspects of conducting the needs assessment worked well and should be retained?

_____

_____

_____

_____

_____

_____

_____

_____

What should be improved?

_____

_____

_____

_____

_____

_____

_____

_____

Action Steps for Questions 12–25

Based on your responses to questions 12 through 25, list the key areas where action is needed in designing future needs assessments. Action steps may address areas of strength that the planning body wants to retain in future needs assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments.

Objective:	Resources:
Time line:	Person Responsible:
Objective:	Resources:
Time line:	Person Responsible:
Objective:	Resources:
Time line:	Person Responsible:

Discussion of Questions 12–25

This section addresses how the needs assessment was conducted. It looks at who was targeted in the needs assessment and how information was collected from various target groups. It also asks several specific questions about how surveys of PLWH were conducted. Some of these questions are quite technical, so you may want to include a person with expertise in survey methodology and statistics in this aspect of the self-assessment.

Question 12 is a multi-part question and asks about the extent to which various stakeholders participated in the needs assessment. The question recognizes that many different people have a stake in an HIV services needs assessment. Most important are the people living with HIV disease who may gain or lose access to services, based on the results of the needs assessment. PLWH must have confidence in the needs assessment process, so that they will participate actively in providing information about their needs and use the results to set service priorities. The needs assessment process must recognize PLWH sub-populations and target high priority groups to ensure their inclusion in the process.

Other stakeholders include service providers who must provide information for the needs assessment and respond to results with services; advocates, officials, and leaders who are concerned with the well-being of the community; planning body members who will use the needs assessment in services planning and resource allocation; and agencies that provide funding or other resources for HIV services. Figure 1 includes a list of possible stakeholders in an HIV needs assessment. The figure is not intended to be all-inclusive, nor is every community expected to have all these stakeholders. The figure is provided to help you think about stakeholders in your community. The clear intent of conducting needs assessments is to be as inclusive as possible. Questions 12a-g are intended to assess whether and how well you included key stakeholders in the needs assessment. A chart, suggesting ways stakeholders might be involved in your needs assessment, is included to help answer the questions.

Questions 12a-e ask about the participation of specific groups: PLWH, service providers, community leaders and activists, planning body members, and funders. It is important to include stakeholders, particularly PLWH, in as many ways as possible, not only to ensure the relevance of information but also to encourage buy-in to the process and the use of needs assessment results in planning and priority setting. Maximum points are given for involving all stakeholders in as many ways as possible. Question 12f asks if any other stakeholders made an important contribution to the needs assessment. Question 12g concludes this important series of questions by asking you to identify other groups that should be included more effectively in future needs assessment activities.

The remaining questions in this section address how the needs assessment was conducted. Question 13 is intended for a planning body that contracted part or all of its needs assessment to an individual consultant or organization. It asks about the degree to which planning body members

provided oversight of consultants that helped with the needs assessment. While consultants can bring valuable expertise to a needs assessment process, ownership and control of the process should remain with the planning body. Maximum points are given when the planning body remains extensively involved with consultants' work. Question 14 is not scored but asks a planning body to highlight how it would improve its use of a consultant in the future.

Focus groups and key informant interviews are important and cost-effective ways to collect qualitative information about service needs from the full range of stakeholders. In order to provide reliable information, all focus groups and interviews should be conducted using written guides. These guides clearly define the questions to be asked and may define the order of questions. Interviews and focus groups should be implemented by interviewers/moderators who are carefully trained in the content and process of the interviews. Training can minimize interviewer bias and ensure that consistent information (if desired) is collected. Questions 15 and 16 award maximum points if guides are both developed and followed in the process of conducting interviews and focus groups, and if interviewers and moderators are trained to implement the guides.

Questions 17-25 relate specifically to surveys conducted with PLWH. Please refer to the discussion immediately preceding this section for an overview of the issues.

Question 17 asks whether specific sub-populations were identified during the design of the survey(s).

Question 18a explores the extent to which you considered specific strategies for reaching target sub-populations. Question 18b measures how successful you were in reaching these sub-populations. Maximum points are awarded for tackling the very difficult tasks involved in identifying and reaching diverse and often hard-to-reach sub-populations. This question lists the sub-populations that have been identified by DSS as priority populations. You should identify other important sub-populations for your community.

Questions 18c and 18d are open-ended questions that enable you to highlight sub-populations not reached and barriers encountered. Sub-populations you did not consider, were unsuccessful reaching, or would like additional information on may be targeted in future surveys. List sub-populations to target in the future and potential strategies for reaching them in question 18d.

Questions 19-21 address how well you applied survey research principles and techniques to get survey responses that were as unbiased as possible.

Question 19 asks about procedures to recruit people for participation in the survey. While true random selection of respondents may not be possible, every attempt should be made to avoid drawing respondents only from those who are most willing to answer the questions or are easiest to reach. For example, while you may choose to approach people at service delivery sites because you are trying to reach an infected population efficiently, you should approach people on a random basis. Maximum points should be scored on this question if you defined and followed systematic procedures for selecting people to answer survey questions.

Question 20 assesses the extent to which you were successful in getting people who were approached to complete the survey. Points are awarded based on response rates achieved.

Question 21 focuses on specific strategies you used to encourage high response rates and asks you to highlight particularly successful approaches.

In questions 22 and 23, points are awarded if a planning body examines the population that responded to the survey, compares it to the actual population in the community, and factors any differences into the analysis. While this can be a complicated undertaking, it is necessary to ensure that results do not paint a distorted picture. In many surveys, the people who respond may be different in important ways from the community at large. Sometimes this is due to intentional strategies to reach particular groups and other times it is due to difficulties in reaching certain sub-populations. Whatever the reason, it is important to consider these differences in the analysis.

Question 24 asks whether survey instruments have been pretested. Pretests reveal important information about how long it takes to complete the instrument, which questions are confusing, and whether the flow of questions is clear. When instruments have been translated, it is particularly important to pretest the translated version within the same language-speaking group that will complete it. The pretest need not be complicated, especially if the instrument has been used in other settings. For example, an instrument could be tried in a focus group with feedback provided at the time.

Question 25 is a general one about the usefulness of the survey questions. It is intended to reinforce the importance of asking questions that lead to useful information for planning and prioritizing service needs of PLWH. It also will help you think about which questions should be included in future survey efforts.

C. Analysis and Results

26. How adequately did the data analysis answer the study questions or objectives defined for the needs assessment?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No questions or objectives answered/met			*All questions or objectives answered/met*

27. How well did the data analysis integrate qualitative and quantitative data?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
The analysis did not attempt to link qualitative and quantitave data			*The analysis fully integrated qualitative and quantitative data in answering all questions (as appropriate)*

28. Were report(s) of the data analysis easy to understand?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Reports were very difficult to understand			*Reports were very easy to understand*

29. Did the report(s) identify gaps or weaknesses in the data or study design?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No gaps or weaknesses identified			*Full discussion of methods, including gaps and weaknesses in the data and implications for the analysis*

30. Did the results of the needs assessment address needs for each sub-population of interest?

Needs assessments should consider needs across the full continuum of care for all key sub-populations of PLWH. Defining primary care needs is a particular priority for CARE Act-funded planning bodies. Refer to the Attachment, HIV Continuum of Care, at the end of this module for a full discussion of the HIV continuum of care and a definition of primary care. The following chart is intended to help answer questions 30a-c.

Question 30	Addressed Service Needs			
	Addressed service needs in general for each sub-population		Addressed primary care needs for each sub-population	
Sub-Population	No	Yes	No	Yes
Women				
Pregnant women				
White men who have sex with men				
Men of color who have sex with men				
Injecting drug users				
Non-injecting drug users				
Sex workers				
Homeless				
Adolescents				
Runaway or street youth				
Migrant or seasonal farm workers				
Recently Released Prisoners				
Individuals who know their HIV status but are not in care				
Other (list):				

30a. To what extent did the needs assessment address service needs across the continuum of care for all sub-populations of interest?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
General needs not addressed for any sub-populations			*General needs fully addressed for all sub-populations*

30b. To what extent did the needs assessment address primary care needs for all sub-populations of interest?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Primary care needs not addressed for any sub-populations			*Primary care needs fully addressed for all sub-populations*

30c. List sub-populations whose needs have not been adequately assessed and that should be the focus of future needs assessments.

Sub-population(s)	*Strategy(ies)*
_____	_____
_____	_____
_____	_____

31. Did the needs assessment analyze co-morbidity factors that may indicate severe need and affect HIV service needs and/or costs (e.g., homelessness, substance abuse, TB, STDs, and severe mental illness)?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No analysis of co-morbidity factors or costs			*Full analysis of co-morbidity factors or costs*

32. Did the needs assessment quantify needs and gaps across all services included in the HIV continuum of care for each sub-population? (Refer to Attachment on Continuum of CARE at end of this Module.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No discussion of needs by type of service			*Full discussion of needs and gaps across all services*

33. To what extent did the needs assessment examine the following barriers to PLWH receiving services?

33a. Financial (e.g., no insurance coverage, inability to pay)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No consideration of this issue			*Full consideration*

33b. Logistical (e.g., travel distance or time, hours of operation, waiting lists for appointments, accessibility to transportation, handicapped accessibility, child care)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No consideration of this issue			*Full consideration*

33c. Cultural (e.g., language, provider attitudes, appropriate treatments)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No consideration of this issue			*Full consideration*

34. Did the needs assessment identify service resources available across the full continuum of care needed by PLWH in the community? (Refer to Attachment on Continuum of CARE in this Module and to the Continuum of Care module.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No inventory of resources			*Comprehensive inventory of resources*

35. Did the needs assessment quantify the capacity of providers to render services to PLWH in the system of care?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Provider capacity not quantified			*Provider capacity quantified*

35a. Did the needs assessment quantify the capacity of providers to render services to PLWH **not** in the system of care?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Provider capacity not quantified			*Provider capacity quantified*

36. What populations, services, or barriers were not adequately addressed in the needs assessment?

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37. Did the needs assessment use the epidemiologic profile for your jurisdiction to describe the current status of HIV/AIDS cases in the service area since the outset of the epidemic and over the last two years?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Did not use epidemiologic profile			*Used epidemiological profile to describe HIV/AIDS cases*

37a. Did the needs assessment use secondary source data from the epidemiologic profile to describe the status of HIV/AIDS cases in the service area?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Did not use secondary source data from the epidemiological profile			*Used secondary data from the epidemiological profile*

38. Did the needs assessment use the jurisdiction's epidemiologic profile to analyze AIDS incidence, prevalence, and trends?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Surveillance data not used			*Surveillance data used to describe incidence, prevalence, and trends in detail*

38a. From which source did the needs assessment committee obtain HIV prevalence data?

❑ 0 pts	❑ 1pt	❑ 2 pts	❑ 3pts
No HIV prevalence used	*CDC HIV prevalence estimates*	*CDC HIV prevalence case surveillance*	*Actual State reported HIV prevalence case surveillance*

39. To what extent did the assessment address the evolution of needs over time from the outset of the epidemic to the present, emphasizing the last two years?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No discussion of evolution of needs over time			*Full discussion of trends based on data*

40. To what extent did the assessment project needs three to five years into the future?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No future projections			*Detailed projections for the next 3-5 years*

41. To what extent did the needs assessment report address the issues listed below? (Use the box to help answer this question.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No report developed			*All issues fully addressed*

Question 41	Contents of Needs Assessment Report	
	Addressed service needs in general for each sub-population	
Report Included	No	Yes
Why assessment was conducted		
Goals/objectives/research questions		
Methods		
Results/findings (both overall and for sub-populations)		
Implications and recommendations for action		
Need for further study		

SUMMARY: Analysis and Results

Scoring of Questions 26–41

To score, follow these steps:

STEP 1 Add up the points for questions 26 through 41 and enter that number in the **Total Points** box.

STEP 2 Add up the number of scored questions you answered and enter it in the **Total Number of Scored Questions Answered** box.

STEP 3 Calculate and record your final score: **Total Points *Divided by* Total Number of Scored Questions Answered**.

Total Points _____

(Divided by) Total Number of Scored Questions _____

(Equals) Score _____

Maximum possible score is 3

**If your score equals more than 3, double-check your addition of points (Step 1) and re-count the number of scored questions (Step 2).*

Strengths And Weaknesses for Questions 26–41

What aspects of the analysis worked well and should be retained?

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What should be improved?

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Action Steps for Questions 26–41

Based on your responses to questions 26 through 41, list the key areas where action is needed in designing future needs assessments. Action steps may address areas of strength that the planning body wants to retain in future needs assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments.

Objective:	Resources:
Time line:	Person Responsible:
Objective:	Resources:
Time line:	Person Responsible:
Objective:	Resources:
Time line:	Person Responsible:

Discussion of Questions 26–41

This section asks about the results of the needs assessment and how the results were analyzed and reported. It explores the scope of the results for each component of a comprehensive needs assessment: epidemiological profile, assessment of service needs for each key sub-population, inventory of service resources, assessment of provider capacity and access barriers, and quantification of gaps in services. A planning body that has completed only some components of needs assessment may not answer all questions. The questions may still be helpful in identifying areas of focus for future needs assessment activities.

Question 26 provides an overview of how well the analysis addressed the study questions. A low score on this question should lead to specific objectives in the action plan to improve the analysis in future assessments.

Question 27 gives high points if the analysis integrates quantitative and qualitative data.

Question 28 emphasizes the importance of developing clear reports. This is critical to ensuring that reports can be used in the planning and priority-setting processes.

Question 29 awards high points if the analysis report(s) discusses gaps and weaknesses in the needs assessment, including implications for analysis. This information helps people interpret the results of the report(s); it is not a judgment of the assessment.

Question 30 asks whether the results of the needs assessment focused on needs across the continuum of care for key sub-populations. The sub-populations identified as high priority by DSS are listed in a chart, and each community should augment this list with sub-populations important to their community. Question 30a asks for an overall assessment of whether service needs were considered across the HIV continuum of care for all sub-populations identified as a priority in the service area. High points should be awarded if needs were identified across the continuum of care for sub-populations. Question 30b asks specifically about the assessment of need for primary care services, a priority of the CARE Act. Question 30c allows you to identify sub-populations and specific service needs that should be the focus of future needs assessments.

Benchmark: A needs assessment should address all population groups affected by HIV disease. Key groups must be addressed, including: pregnant women; women who are not pregnant; adolescents; white men who have sex with men; men of color who have sex with men; injecting drug users; non-injecting drug users;, homeless populations; runaway and street youth; farm and seasonal workers; recently released prisoners; and individuals who know their HIV status but are not in care. Other groups should be considered if they are affected differentially in an area.

In addition to looking at needs for specific sub-populations, needs assessments should look at co-morbidity factors that may affect HIV service needs. Question 31 assesses the extent to

which this was done. It is often difficult for a planning body to get specific information on co-morbidity factors and their implications for service. High points should be given if both qualitative and quantitative information on co-morbidity factors was obtained and included in analyses of results.

Benchmark: Planning bodies should document severe need, based on the presence of co-morbidity factors, such as TB, STDs, substance abuse, and severe mental illness, as well as on homelessness and/or new or growing sub-populations with HIV disease, using quantitative data where available.

Question 32 asks whether the needs assessment quantified gaps in service. This is the end result of a comprehensive needs assessment, and planning bodies that score high on this item should be able to focus on fine-tuning and updating their needs assessment.

Questions 33a-c address barriers to service, although they barely scratch the surface of this important issue. PLWH may face many barriers to receiving services, and it is critical to isolate and identify specific barriers in order to facilitate access best. High scores should be given if the needs assessment results discussed specific barriers in each category listed (financial, logistical, cultural) or other categories identified by the planning body. The questions are not intended to provide a comprehensive list of possible barriers but should lead a planning body to identify specific barriers in its community that should be addressed in the needs assessment.

Question 34 asks whether a resource inventory has been completed as part of the needs assessment. A high score should be given if the inventory covers the full range of services identified in the community's continuum of care.

Question 35 builds on this and asks whether the capacity of providers to render services to those in care and not in care has been quantified. Capacity development is defined by HAB as activities that increase core competencies that substantially contribute to an organization's ability to deliver effective HIV/AIDS primary medical care and health-related services. The needs assessment process for any given jurisdiction should consider access and service disparities among all populations that are highly impacted by HIV disease, especially among those who know they are HIV positive but are not receiving appropriate treatment. Jurisdictions must determine the number and characteristics of subpopulations experiencing disparities in access and services.

Question 36 synthesizes the answers for questions 30-35 and highlights the populations, services, or barriers that have not been adequately addressed. This open-ended question should lead directly into the action plan for this section.

An analysis of epidemiological data, both to define the current prevalence of HIV and AIDS among specific sub-populations in a community and to discern trends in the epidemic, is an essential part of any needs assessment.

Question 37 asks about use of the epidemiologic profile, and question 37a asks about use of the secondary source data from the epidemiologic profile, to describe the status of HIV/AIDS in the service area. Secondary source data provided

primarily by the State and/or local health department and the CDC, perhaps supplemented by special studies conducted in your service area, are often used in developing epidemiologic profiles. One advantage of using secondary source data is that such information is already available, although you have little control over the completeness and/or accuracy of the data.

> The HIV/AIDS epidemiologic profile should describe the HIV/AIDS epidemic within various populations and identify characteristics of both HIV-infected and HIV-negative persons in defined geographic areas. Its main components are:
>
> - *AIDS data, presenting data on people who are living with AIDS and those who have died from AIDS-related illnesses.*
> - *HIV data, presenting data (reported or estimated) on HIV-infected persons who have not developed AIDS.*
> - *Trends, analyzing changes in the epidemic over time.*
>
> Because all HIV/AIDS data are not "created equal," a profile also should discuss the strengths and limitations of different types and sources of information.

Question 38 asks specifically about AIDS incidence, prevalence and trends based on the epidemiologic profile. Question 38a asks specifically about HIV prevalence in the State obtained from the epidemiologic profile. HIV prevalence data can either be based on CDC estimates (for those States not yet collecting HIV case data), HIV prevalence reported to the CDC by the State (that may lag behind actual cases reported at the local level), or the actual cases of HIV reported by the State.

Questions 39 and 40 address the extent to which the needs assessment discusses the evolution of service needs and projects those needs three to five years into the future. Looking backward at trends helps to understand how the epidemic is evolving. Looking forward is necessary to plan effectively to meet service needs. In places where the epidemic is evolving quickly, it may be difficult to project some trends more than one to two years into the future. Further, rapid treatment advances make predicting future service needs challenging. Still, projecting service needs is an important basis for planning. High scores should be given for discussing trends and projecting future needs.

Question 41 highlights issues that should be addressed in a publicly available report on the needs assessment. The report should describe why the needs assessment was conducted; its goals, objectives, and research questions; the methods used to conduct the assessment, including a description of any weaknesses or gaps in the methods; results and findings, both overall and for each category of stakeholder and each sub-population within categories; implications of the findings and recommendations for action; and areas for further study. Award maximum points if these issues were covered comprehensively in the report and zero points if no report was developed.

D. Dissemination and Use of the Needs Assessment

42. Were results of the needs assessment distributed to all key stakeholder groups? (Refer to Figure 1, page 21, for list of stakeholders.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Needs assessment results were not distributed			*Results distributed widely to all key stakeholders*

43. Were discussions of results held in public forums?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
No public discussions			*Results discussed in several public forums with all key stakeholders*

44. To what extent was the needs assessment used in defining or refining the continuum of care for people with HIV disease in the area covered? (Refer to Attachment, HIV Continuum of Care, as well as Continuum of Care module.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Not a factor in defining the continuum of care			*Assessment used directly and substantially in defining or refining the continuum of care*

45 To what extent was the needs assessment used for developing or refining a comprehensive plan for services? (Refer to Comprehensive HIV Services Planning module.)

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Not a factor in developing a comprehensive plan			*Assessment used directly and substantially in developing or refining a comprehensive plan*

46 To what extent were the needs assessment results used in CARE Act-related priority setting and resource allocation? (Refer to Priority Setting and Resource Allocation module.)

Priority Setting

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Not used at all			*Priorities drawn directly from the needs assessment*

Resource Allocation

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Not used at all			*Resource allocation directly related to needs assessment*

47 To what extent was the needs assessment used in other planning activities?

❑ 0 pts	❑ 1 pt	❑ 2 pts	❑ 3 pts
Not used in any other planning activities			*Used as a model for other planning efforts*

SUMMARY: Dissemination and Use

Scoring of Questions 42–47

To score, follow these steps:

STEP 1 Add up the points for questions 42 through 47 and enter that number in the **Total Points** box.

STEP 2 Add up the number of scored questions you answered and enter it in the **Total Number of Scored Questions Answered** box.

STEP 3 Calculate and record your final score: **Total Points *Divided by* Total Number of Scored Questions Answered**.

Total Points _____

(Divided by) Number of Scored Questions _____

(Equals) Score _____

Maximum possible score is 3

**If your score equals more than 3, double-check your addition of points (Step 1) and re-count the number of scored questions (Step 2).*

Strengths And Weaknesses for Questions 42–47

What aspects of disseminating and using the needs assessment worked well and should be retained?

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What should be improved?

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Action Steps for Questions 42–47

Based on your responses to questions 42 through 47, list the key areas where action is needed in designing future needs assessments. Action steps may address areas of strength that the planning body wants to retain in future needs assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments.

Objective:

Resources:

Time line:

Person Responsible:

Objective:

Resources:

Time line:

Person Responsible:

Objective:

Resources:

Time line:

Person Responsible:

Discussion of Questions 42–47:

This section is brief but asks critical questions about how the needs assessment was distributed, and, even more importantly, how it was used to make decisions.

Question 42 asks whether results were widely distributed to key stakeholders. This is important for many reasons: to recognize people for their participation and to encourage involvement in future assessments; to encourage broad-based buy-in; and to enable results to be used in planning throughout the community. High points should be given if the results were widely disseminated.

Question 43 asks whether results were discussed in a public forum, encouraging greater buy-in and wider use of assessment results. Also, such discussion often leads to constructive ideas for future assessment activities. Needs assessments are not ends in themselves. They are worth the time and expense only if they help ensure that accessible and appropriate services are made available to people living with HIV disease.

The final series of questions in this module asks about how the results of the needs assessment were used in defining or refining the continuum of care for PLWH (question 44); developing the comprehensive plan (question 45); setting priorities and allocating resources (question 46); and other planning activities (question 47). High points are given when the needs assessment is used to make decisions in each of these areas.

Benchmark: Service priorities and resource allocation should be based on the documented needs and priorities of the infected population.

ATTACHMENT A: HIV CONTINUUM OF CARE

Continuum of care is a term encompassing the comprehensive range of services required by individuals or families with HIV infection in order to meet their health care and psychosocial service needs throughout the course of their illness. The concept of a continuum suggests that services must be organized to respond to the individual or family's changing needs in a holistic, coordinated, timely, and uninterrupted manner, reducing fragmentation of care. The continuum must also include strategies for linking services, so that from the perspective of people living with HIV disease, there exists a "seamless" service delivery system.

The continuum of care must be defined by and for each community. The defined continuum of care should be the ideal set of services and set of mechanisms for linking services that would be available to PLWH if the community had unlimited resources to allocate to HIV care. From this "wish list," the community should define its "core" continuum of care. The core continuum of care is the set of services and mechanisms to link services that a planning body has decided should be available to PLWH in their community. Neither the ideal continuum of care nor the core continuum of care is defined only by the resources directly available to the planning body. The planning body's funded continuum of care should represent a subset of the core continuum of care.

The following categories of services should be considered for inclusion in the continuum of care:

1. *Ambulatory/outpatient medical care* is the provision of professional diagnostic and therapeutic services rendered by a physician, physician assistant, clinical nurse specialist or nurse practitioner in an outpatient setting. This includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). Primary medical care for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's Health Service guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.

2. *Mental health services* are psychological and psychiatric treatment and counseling services, to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.

3. *Oral health care* includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.

4. *Substance abuse services-outpatient* is the provision of medical treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) provided in an outpatient setting rendered by a physician or under the supervision of a physician.

5. *Substance abuse services-residential* is the provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) provided in an inpatient health service setting (short-term).

6. *Rehabilitation services* include services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.

7. *Home health: para-professional care* is the provision of services by a homemaker, home health aide, personal caretaker, or attendant caretaker. This definition also includes non-medical, non-nursing assistance with cooking and cleaning activities to help disabled clients remain in their homes.

8. *Home health: professional care* is the provision of services in the home by licensed health care workers such as nurses.

9. *Home health: specialized care* is the provision of services that include intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other high-tech therapies.

10. *Case management services* is a range of client-centered services that links clients with health care, psychosocial and other services. Ensures timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Also includes inpatient case management services that prevent unnecessary hospitalization or that expedite discharge from an inpatient facility. Key activities include: (1) initial assessment of service needs, (2) development of a comprehensive, individualized service plan, (3) coordination of services required to implement the plan and client monitoring to assess the efficacy of the plan, and (4) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services.

11. *Buddy/companion service* is an activity provided by volunteers/peers to assist the client in performing household or personal tasks and providing mental and social support to combat the negative effects of loneliness and isolation.

12. *Child care services* is the provision of care for the children of clients who are HIV positive while the clients are attending medical or other appointments or attending Title-related meetings, groups, or training. NOTE: This does not include daycare while client is at work.

13. *Child welfare services* is the provision of family preservation/unification, foster care, parenting education, and other child welfare services. Services are designed to prevent the break-up of a family and to reunite family members. Foster care assistance to place children under the age of 21 years, whose parents are unable to care for them, in temporary or permanent homes and to sponsor programs for foster families. Other services related to juvenile court proceedings, liaison to child protective services, involvement with child abuse and neglect investigations and proceedings, or actions to terminate parents' rights. Presentation or distribution of information to biological, foster, and adoptive parents, future parents, and/or caretakers of HIV-positive children about risks and complications, care giving needs, and developmental and emotional needs of children.

14. *Client advocacy is* the provision of advice and assistance obtaining medical, social, community, legal, financial, and other needed services. Advocacy does not involve coordination and follow-up on medical treatments, as case management does.

15. *Day or respite care for adults* is the provision of community or home-based, non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of an adult client.

16. D*evelopmental assessment/early intervention services* is the provision of professional early intervention by physicians, developmental psychologists, educators, and others in the psychosocial and intellectual development of infants and children. Assessment of an infant's or child's developmental status and needs in relation to the involvement with the education system, including assessment of educational early intervention services. Includes comprehensive assessment of infants and children taking into account the effects of chronic conditions associated with HIV, drug exposure, and other factors. Provision of information about access to Head Start services, appropriate educational setting for HIV-affected clients, and education/assistance to schools.

17. *Early intervention services for Titles I and II* are a combination of services that include outreach, HIV counseling and testing, referral, and the provision of outpatient medical care and supportive services designed and coordinated to bring individuals with HIV disease into the local HIV continuum of care.

18. *Emergency financial assistance* is the provision of short-term payment for essential utilities and for medication assistance when other resources are not available.

19. *Food Bank/home-delivered meals* is the provision of actual food, meals, or nutritional supplements. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item.

20. *Health education/risk reduction* is the provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information, including information dissemination about medical and psychosocial support services and counseling, to help clients with HIV improve their health status.

21. *Housing services* is the provision of short-term assistance to support temporary or transitional housing to enable an individual or family to gain or maintain medical care. Related housing services may be housing in medical treatment programs for chronically ill clients (e.g., assisted living facilities), specialized short-term housing, transitional housing, and non-specialized housing for clients who are HIV affected. Category includes access to short-term emergency housing for homeless people. This also includes assessment, search, placement and the fees associated with them. NOTE: If housing services include other service categories (e.g., meals, case management, etc.) these services should also be reported in the appropriate service categories.

22. *Legal services* is the provision of services to individuals with respect to powers of attorney, do not resuscitate orders, wills, trusts, bankruptcy proceedings, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under CARE Act. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.

23. *Nutritional counseling* is provided by a licensed registered dietitian outside of a primary care visit. Nutritional counseling provided by other than a licensed/registered dietitian should be recorded under "Psychosocial support services."

24. *Outreach services* include programs which have as their principal purpose identifying people with HIV disease so that they may become aware of and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that HIV-infected individuals will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.

25. Permanency planning is the provision of services to help clients or families make decisions about placement and care of minor children after the parents/caregivers are deceased or are no longer able to care for them.

26. *Psychosocial support services* is the provision of support and counseling activities, including alternative services (e.g., visualization, massage, art, music, and play), child abuse and neglect counseling, HIV support groups, pastoral care, recreational outings, caregiver support, and bereavement counseling. Includes other services not included in mental health, substance abuse or nutritional counseling that are provided to clients, family and household members, and/or other caregivers and focused on HIV-related problems.

27. *Referral for health care/supportive services* is the act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made formally from one clinical provider to another, within the case management system by professional case managers, informally through support staff, or as part of an outreach program.

28. *Residential or in-home hospice care* means room, board, nursing care, counseling, physician services, and palliative therapeutics provided to patients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal patients.

29. *Transportation services* include conveyance services provided, directly or through voucher, to a client so that he or she may access health care or support services.

30. *Treatment adherence services* is the provision of counseling or special programs to ensure readiness for and adherence to complex HIV/AIDS treatments.

31. *Other services* are other services not listed above.

ATTACHMENT B: RESOURCES

Below is a list of legislative, HRSA documents, articles, and books related to needs assessment.

Legislation

- Ryan White CARE Act of 1990 as amended by the Ryan White CARE Act Amendments of 1996 and amended by the Ryan White CARE Act Amendments of 2000.

HRSA Documents

- Title I and II Manuals, chapters on Needs Assessment (updated 2002)
- Needs Assessment Guide (updated 2002)
- Integrated Guidelines for Developing Epidemiological Profiles: HIV Prevention and Ryan White CARE Act Community Planning (2002)
- FY 2002 Title I Grant Application Guidance.
- FY 2002Title II Application Guidance.
- Letter to Title I Colleagues (March 6, 1996) with enclosure entitled "Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas."
- Needs Assessment: Technical Assistance Conference Call, Report by MOSAICA, The Center for Nonprofit Development and Pluralism, Washington, D.C., June, 1996
- Activities of Ryan White CARE Consortia, FY 1993, Conviser, R. October, 1994.
- First Year Experience of Title I Eligible Metropolitan Areas with Standard Protocol for Baseline Data Collection, Division of Service Systems.

Abstracts, Articles, and Reports

- University of California, San Francisco Project: Measuring Unmet Need for Care for HIV (2002)
- Fairchild, P., Block, J., Despard, M., Mangione, T., and Sachs, S. Assessing HIV Service Needs in Hard to Reach Populations. XI International Conference on AIDS abstract, 1996.
- Farel, A., Margolis, L., Lofy, L. The Relationship between Needs Assessments and State Strategies for Meeting Healthy People 2000 Objectives: Lessons from the Maternal and Child Health Services Block Grant. Journal of Public Health Policy 15.2 (1994): 173.
- JSI Research and Training Institute. Moving Forward: An Assessment of Needs and Services for the Evolving Epidemic of HIV in Massachusetts 1995-1999. 1995.
- Maine Community AIDS Partnership. Maine: A Report on HIV/AIDS Needs. 1994.
- Newark EMA HIV Health Services Planning Council. A Community Based Needs Assessment of People Living With and Affected by HIV/AIDS. 1994.
- Penner, S. Problems with Planning for the HIV Epidemic. AIDS and Public Policy Journal 7.2 (1993): 121.
- United Way of America. COMPASS: Practical Advice for Community Decision-Makers on Assessing and Addressing Community Needs. 1988.
- "State Efforts to Assess Met and Unmet Needs for HIV/AIDS Care Programs A Review of FY 1999 Ryan White CARE Act Title II Applications." National Alliance of State and Territorial AIDS Directors, September 2000.

Books

- Aday, L.A. At Risk in America: The Health and Health Care Needs of Vulnerable Populations in the United States. San Francisco: Jossey-Bass Publishers, 1993.
- Converse, J.M., and Presser, S. Survey Questions: Handcrafting the Standardized Questionnaire. Newbury Park, CA: Sage, 1976.
- Fink, A., and Kosecoff, J. How to Conduct Surveys: A Step by Step Guide. Newbury Park, CA: Sage, 1985.
- Fowler, F., and Mangione, T. Standardized Survey Interviewing: Minimizing Interviewer-Related Error. Newbury Park, CA: Sage, 1990.
- Hatry, H.P., and others. How Effective Are Your Community Services? Washington, D.C.: The Urban Institute and International City/County Management Association, 1992.
- Kish, L. Survey Sampling. New York: John Wiley, 1965.
- Mangione, T. Mail Surveys: Improving the Quality. Thousand Oaks, CA: Sage, 1995.
- Sudman, S., and Bradbum, N.M. Asking Questions: A Practical Guide to Questionnaire Design. San Francisco: Jossey-Bass Publishers, 1992.