

**Attachment B:
Methods for Assessing Access to the Current System of Care**

Approach	Population Access Exercise
Overview	PLWH-led process used to review the current system of care and identify access mechanisms and issues/barriers to care for specific groups of PLWH.
Expected Results	Information on the current system of care’s accessibility, from the perspectives of specific groups of PLWH who are out of care. Emphasis is on identifying any aspects of the current system of care that may make it hard for a particular group of PLWH to find or enter care.
Setting	Meeting, such as: <ul style="list-style-type: none"> ▪ A planning body meeting ▪ A joint meeting of a PLWH committee or caucus with planning body committee(s) responsible for the system of care, comprehensive planning, and/or needs assessment
Time Required	2 – 2½ hours
PLWH Roles	<ul style="list-style-type: none"> ▪ <i>Before the meeting:</i> leadership in planning the session ▪ <i>During the meeting:</i> facilitation by 1-2 PLWH; participation of all in sharing experiences with the system of care and perspectives of particular PLWH groups ▪ <i>After the meeting:</i> playing a lead role in reviewing findings, presenting them to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care
Participants	<p>A diverse group of PLWH, providers, and grantee personnel, which should include:</p> <ul style="list-style-type: none"> ▪ PLWH who are or have been consumers of Ryan White services in this State, EMA, or TGA and who are diverse in geographic place of residence within the service area, race/ethnicity, gender, sexual orientation, etc. ▪ Providers of Ryan White services, including core medical and support services ▪ Grantee personnel or other individuals who are familiar with intake procedures and points of entry into the system of care
Process	<ol style="list-style-type: none"> 1. A group of PLWH (typically PLWH members of the planning body or the formal PLWH committee or caucus) works with staff and/or an appropriate planning body committee, agree on about 8-12 important groups of PLWH who are believed to have high rates of unmet need. 2. Using that list of PLWH groups, the planning committee develops a set of brief descriptions of individual PLWH assumed to be out of

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	<p>care and in need of Ryan White services – using race/ethnicity, gender, place of residence, and other special characteristics to describe them. The planning group puts each of these PLWH descriptions onto a separate slip of paper. For example:</p> <ul style="list-style-type: none"> ◦ A young African American MSM who was recently diagnosed with HIV ◦ An undocumented Latino who works as a laborer, speaks limited English, and has just begun to have symptoms ◦ An African American woman with 2 small children who recently moved to from another State to an outlying county with very limited HIV-related services and has no car ◦ A 45-year old white MSM who recently moved to the service area from another state and lives in a suburban area ◦ An American Indian who recently moved to the city from a reservation and has previously received health care through the Indian Health Service ◦ A professional who lives in the city and recently lost his job and his health insurance because he became ill ◦ A recently incarcerated man who knew he was HIV-positive but whose status was not known while he was in prison, so he received no pre-discharge counseling ◦ An older white woman who is a widow and was recently diagnosed with HIV ◦ An African immigrant who has been unwilling to seek care because of concerns about confidentiality and stigma ◦ A PLWH with a long history of substance abuse and homelessness <p>5. At the meeting, the PLWH lead facilitator explains the purpose of the session:</p> <ul style="list-style-type: none"> ◦ To review the current system of care, with emphasis on how people find out about the availability of services, how they can enter care, and how they move within the system to obtain the services they need ◦ Then to explore probable access points and barriers for PLWH with a variety of different characteristics <p>6. The first 15-20 minutes are spent reviewing how PLWH can enter the system of care – points of entry, eligibility requirements, intake locations and methods, flexibility, etc.</p> <p>7. Then participants are divided into groups of 2-3 (depending on the number of people present), and each group receives one of the slips of paper. That group is responsible for exploring the following questions, which are listed in writing on a form the group’s “recorder” can use for summarizing their discussion:</p>

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	<ul style="list-style-type: none"> ◦ How this PLWH would be likely to find out about the availability of Ryan White services ◦ Through what point of entry this PLWH might attempt to obtain care ◦ What barriers this PLWH might face ◦ Whether this PLWH would be able to navigate the system to obtain needed services <p>The slips are given out so that participants are responsible for doing this analysis for a PLWH who does <i>not</i> come from his/her background.</p> <ol style="list-style-type: none"> 6. The groups discuss the key questions for about 15-20 minutes, and take notes summarizing their discussion and conclusions. 7. Then the group comes back together. Each group presents its PLWH and summarizes its answers to the questions. Other participants add their ideas, and where possible some consensus is reached about how well the system is likely to provide access to this PLWH. 8. About 15 minutes are left at the end to summarize limitations or problems identified that relate specifically to the system of care. 9. Someone (generally staff) takes notes on the discussion, and also collects the notes taken by each group. These notes are summarized and provided to the PLWH committee. 10. The PLWH committee reviews the notes, identifies key aspects of the system of care that seem to negatively affect access for some or all groups of PLWH, and reports back to a committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction). 11. Based on the information provided, the PLWH committee, planning body, and grantee work together to develop plans to refine the system of care to help overcome identified access barriers.
Challenges	<p>It is important to have a diverse group of PLWH. If the planning body is limited in its diversity, the planners should invite other PLWH from the community to participate, and specifically invite PLWH with diverse backgrounds and experience.</p>

Approach	Community Meeting
Overview	Process that brings together representatives of various components of the system of care to review the current system of care and identify access mechanisms and issues/barriers to care, both for PLWH in general and for specific groups of PLWH.
Expected Results	Broad understanding of how well the current system of care is understood by those outside it and the extent to which it is accessible to specific categories of PLWH. Emphasis is on identifying facilitators of and barriers to care for groups of PLWH that are most likely to be out of care.
Setting	A community meeting or a series of meetings in several locations within the service area (State, EMA, or TGA)
Time Required	2 – 2½ hours
PLWH Roles	<p>PLWH help lead the discussion, provide critical input, and meet afterwards to review important findings</p> <ul style="list-style-type: none"> ▪ <i>Before the meeting:</i> leadership in planning the session ▪ <i>During the meeting:</i> key role in sharing their experiences with the system of care and learning about the experiences of other PLWH groups ▪ <i>After the meeting:</i> playing a lead role in reviewing findings, presenting them to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care for all PLWH
Participants	<p>A mix of individuals who together have in-depth knowledge about the current system of HIV/AIDS care in the service area and about PLWH, such as:</p> <ul style="list-style-type: none"> ▪ PLWH who are or have been consumers of Ryan White services in this State, EMA, or TGA and who are diverse in geographic place of residence within the service area, race/ethnicity, gender, sexual orientation, etc. ▪ Providers of Ryan White services, including core medical and support services ▪ Providers of HIV-related services that are not Ryan White funded ▪ Grantee representatives ▪ Other individuals knowledgeable about HIV prevention and points of entry into the system of care
Process	<ol style="list-style-type: none"> 1. A group of PLWH (usually the Ryan White program’s PLWH committee or caucus) works with staff and/or an appropriate committee to plan the meeting. 2. The group agrees on about 6-8 groups of PLWH (based on key

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	<p>characteristics) that are believed to have high levels of unmet need. The list might include, for example:</p> <ul style="list-style-type: none"> ◦ Women, especially African American women, with children ◦ African American MSM ◦ Recently incarcerated people ◦ PLWH who live in rural parts of the service area ◦ PLWH with co-morbidities such as substance use, mental health issues, or homelessness ◦ PLWH who recently moved into the service area from another State ◦ Older white MSM ◦ Immigrants who have limited English skills, including undocumented immigrants ◦ PLWH groups that have particular concerns about confidentiality and stigma, such as African refugees and immigrants <p>2. The PLWH committee works with staff and with other planning body members to invite a diverse group of people to the meeting, and to ensure the presence of PLWH that represent these various backgrounds, as well as providers and health and human service professionals with experience serving these varied populations.</p> <p>3. At the meeting, the facilitator explains the purpose of the meeting:</p> <ul style="list-style-type: none"> ◦ To review the current system of care, with emphasis on how PLWH are likely to find out about the availability of services, how they can enter care, and how they can move within the system to obtain the services they need ◦ Then to explore probable access points, issues, and barriers for various groups of PLWH (using the list developed before the meeting) <p>8. The first segment of the meeting involves a description of how PLWH can enter the system of care – points of entry, eligibility requirements, intake locations and methods, flexibility, etc. If there is a graphic describing the system of care and showing entry points and referrals within the system, it should be projected on an LCD projector and used to describe the system of care. This segment is especially important since some of the participants in the meeting may have only a general sense of the system of care.</p> <p>9. Then participants systematically consider each group of PLWH on the pre-determined list. Typically, the discussion addresses the following:</p> <ul style="list-style-type: none"> ◦ How likely this group of PLWH is to be familiar with Ryan White services, and how they would be likely to find out about the

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	<p>availability of these services</p> <ul style="list-style-type: none"> ◦ What points of entry this group is most likely to use in seeking care, and what role non-Ryan White providers are likely to play in this process ◦ What issues or barriers this group of PLWH might face in obtaining access to care ◦ What challenge this group of PLWH might face in navigating the system to obtain needed services <p>10. Key points of discussion are summarized on easel pad paper. This helps the group to see what has been written for the first few groups and agree on some issues and barriers that seem to apply to many groups of PLWH. Then the group can focus its discussion on the special issues or barriers specific to particular groups of PLWH.</p> <p>11. The facilitator spends about 15-20 minutes at the end of the meeting to summarize key limitations or problems identified within the current system of care.</p> <p>12. Staff takes notes on all three components of the discussion (overview, PLWH group-specific discussions, and sum-up). The notes are summarized and provided to the PLWH committee.</p> <p>13. The PLWH committee reviews the notes, identifies key aspects of the system of care that seem to negatively affect access for some or all groups of PLWH, and reports back to a committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction).</p> <p>14. Based on the information provided, the PLWH committee, planning body, and grantee develop plans to refine the system of care to help overcome some of the identified barriers.</p>
Challenges	<ul style="list-style-type: none"> ▪ It is important to have a diverse group of PLWH and providers in the room – people with knowledge of the system of care; issues facing residents of various parts of the State, EMA, or TGA; and the specific PLWH groups being discussed. It is equally important to have some non-Ryan White provider representatives who can speak as “outsiders” who may refer people to Ryan White providers, and to have PLWH who are not part of the planning body and may be less familiar with the system of care except for their own experiences and those of their friends. ▪ A large group works well – some very successful discussions have included 50 people or more – but it must be very well facilitated. The PLWH committee may want to ask for an outside facilitator rather than having a member of the planning body play that role.

Approach	PLWH-led Data Review
Overview	PLWH-led review of needs assessment, utilization, client satisfaction, and related data from consumers, providers, PLWH who are not in care, and PLWH who recently entered care, focusing on data addressing barriers and access to care for PLWH overall and for specific PLWH groups, in order to identify aspects of the system of care that facilitate or discourage entry to and/or retention in care.
Expected Results	Understanding of the current system of care and the extent to which PLWH in general and specific categories of PLWH are able to access and navigate that system, as well as the systemic barriers to care identified by PLWH who are or recently were out of care.
Setting	A review process that culminates in one or more work sessions including PLWH, especially consumers
Time Required	2-3 sessions lasting 2-3 hours each, preceded by considerable data review and preparation of user-friendly materials summarizing relevant data
PLWH Roles	<p>PLWH committee or caucus leads the planning, gets appropriate people to the sessions, carries out the review/discussion at the sessions, and meets afterwards to review important findings</p> <ul style="list-style-type: none"> ▪ <i>Planning the work sessions:</i> leadership in planning the data review, identifying the key questions to be addressed and the kinds of data needed ▪ <i>During the sessions:</i> review of the data and sharing of experiences that help in interpreting the data from the perspectives of different groups of PLWH ▪ <i>After the sessions:</i> playing a lead role in presenting observations and insights from the sessions to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care for all PLWH
Participants	<ul style="list-style-type: none"> ▪ PLWH who are members of the State, EMA, or TGA’s planning body ▪ Other members of PLWH committee or caucus (typically other Ryan White consumers) ▪ Staff and consultants involved in planning and implementing the needs assessment (especially the assessment of unmet need from PLWH who know their status but are not in care, or from PLWH who recently entered care after being out of care), doing consumer satisfaction surveys as part of clinical quality management, and analyzing utilization data – individuals who know the available data and are able to present it to the PLWH group in user-friendly formats and “mine” the data to answer questions from the PLWH group

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Process	<ol style="list-style-type: none"> 1. A group of PLWH (often the leaders of the Ryan White program’s PLWH committee or caucus and any PLWH who serve on committees responsible for Needs Assessment or involved in reviewing clinical quality management data) works with staff and/or consultants to agree on key questions to be answered, explore available data that can help answer these questions, and plan work sessions to review the data. 2. Staff and/or consultants review the available data from various sources and prepare user-friendly formats for ordering and summarizing it. Data typically include: <ul style="list-style-type: none"> ◦ Available information on the characteristics (profile) of people who are out of care in the State, EMA, or TGA, summarized to identify categories of PLWH that are especially likely to be out of care ◦ Client utilization data by service category for the most recent full year, focusing on what populations of PLWH are well represented and which are underrepresented – with emphasis on HIV-related primary medical care ◦ Needs assessment data from PLWH currently or recently out of care (from the needs assessment), particularly identification of barriers that address systemic issues (e.g., didn’t know where to go for care, trouble accessing the system due to language or other barriers) ◦ Needs assessment data from providers identifying what they perceived to be systemic barriers to care ◦ Client satisfaction survey data that identify perceived barriers to care or problems in navigating the service system 3. The PLWH committee leadership reviews these data with staff/consultants and agrees on formats for presenting the data to the PLWH group and a process for data review and discussion during work sessions. 4. The PLWH committee invites diverse PLWH to the work session, as well as providers and grantee personnel. 5. At the first work session, the relevant data are presented and broadly discussed. Any data gaps are identified, and efforts are made to fill them if possible. 6. At the second and any subsequent sessions, PLWH focus on analyzing and interpreting data with regard to specific aspects of the system of care, and adding and using their own experiences as consumers to provide context and improved understanding of the data. Individuals with special expertise in various aspects of the system of care also attend these sessions to provide information and clarification. The group might, over several sessions, address the

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	<p>following:</p> <ul style="list-style-type: none"> ◦ The extent to which PLWH out of care are aware of Ryan White services and their availability at no cost to those who can't pay ◦ Finding a point of entry into care ◦ Providing required documents and establishing eligibility ◦ Availability of culturally and linguistically appropriate service providers ◦ Accessibility related to geographic location or service days and hours ◦ Navigating the system to get the needed mix of services <p>The intent of the sessions is to understand the available data, add relevant personal experiences, and try to pinpoint system-based factors that are encouraging or limiting access to care. They review the data to consider both overall PLWH experiences and issues of concern for particular groups of PLWH.</p> <ol style="list-style-type: none"> 7. The facilitator (who may be a PLWH leader or an external person who knows the topic and is effective at coordinating group discussions of this type) moves the agenda, helping to ensure that conclusions are reached wherever possible. Key points are put onto easel pad paper to support the discussion. The facilitator summarizes key points and areas of consensus and non-consensus at the end of each session. 8. After the sessions, staff/consultants summarize the discussion and conclusions and provide this information to the PLWH leadership group. 9. The PLWH leadership group reviews the notes, identifies key aspects of the system of care that seem to need attention, and reports back to an appropriate committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction). 7. Based on the information provided, the PLWH committee, planning body, and grantee develop plans to refine the system of care to help overcome some of the identified barriers.
Challenges	<ul style="list-style-type: none"> ▪ Some Ryan White programs have not yet carried out successful assessments of unmet need, so they may have limited data from people out of care. This often indicates a need to revamp the needs assessment to specifically target PLWH not in care, and/or to identify individuals who recently entered care and ask them about barriers to care and how they overcame them. ▪ Some Ryan White programs do not typically bring together utilization data broken down by geographic area and demographic characteristics – data needed to identify PLWH groups that appear to be underrepresented, or explore whether certain categories of PLWH

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	<p>are especially likely to drop out of care or be loosely connected to care. The new client-level data systems should facilitate such analyses, and programs need to be prepared to make use of such data when available.</p> <ul style="list-style-type: none"> <li data-bbox="493 394 1417 646">▪ Client satisfaction surveys are sometimes carried out by the grantee as part of clinical quality management, and sometimes planned and implemented by individual providers. In such cases, the grantee may want to encourage the PLWH group to work with the appropriate committee to identify questions that need answering in order to conduct a thorough analysis of the system of care, so that needed questions are consistently asked.