

ORAL HEALTH & BEHAVIORAL HEALTH SERVICES ASSESSMENT:

*Improving Access &
Use of Services*

**Minnesota HIV Services Planning Council &
Hennepin County Human Services and Public Health -
The Ryan White Program**
June, 2008 – Final Report

Report prepared by
Bob Tracy Consulting

ORAL HEALTH AND BEHAVIORAL HEALTH SERVICES ASSESSMENT IMPROVING ACCESS AND USE OF SERVICES

June, 2008 TABLE OF CONTENTS

Section I	Executive Summary	2
	<i>Key Observations & Recommendations – Oral Health</i>	2
	<i>Key Observations & Recommendations – Mental Health</i>	4
	<i>Key Observations & Recommendations – Chemical Health</i>	6
	<i>Key Observations & Recommendations – Prevention with Positives</i>	7
Section II	Assessment Process	10
Section III	Oral Health Services Assessment	12
	<i>A. Standards for Care</i>	12
	<i>B. Challenges & Barriers/Discussion</i>	12
	<i>C. Ryan White Program as a Resource</i>	15
	<i>D. Key Observations and Options for Action</i>	16
Section IV	Mental Health Services Assessment	19
	<i>A. Standards for Care</i>	19
	<i>B. Challenges & Barriers/Discussion</i>	20
	<i>C. Ryan White Program as a Resource</i>	22
	<i>D. Key Observations and Options for Action</i>	23
Section V	Chemical Health Services Assessment	26
	<i>A. Standards for Care</i>	26
	<i>B. Challenges & Barriers/Discussion</i>	26
	<i>C. Ryan White Program as a Resource</i>	27
	<i>D. Key Observations and Options for Action</i>	28
Section VI	Prevention with Positives Services Assessment	30
	<i>A. Standards for Care</i>	30
	<i>B. Challenges & Barriers/Discussions</i>	31
	<i>C. Ryan White Program as a Resource</i>	33
	<i>D. Key Observations and Options for Action</i>	34
Section VII	Appendices	
	<i>A. Interview & Group Meeting Participants</i>	37
	<i>B. Schedule of Group Meetings</i>	39
	<i>C. Endnotes & Resources</i>	40

SECTION I: EXECUTIVE SUMMARY

Assessment Focus. This assessment explores barriers to access and use of oral health and behavior health services by people living with HIV in Minnesota. The focus is on barriers to services for lower income people living with HIV and supported with funding available through The Ryan White HIV/AIDS Treatment Modernization Act [the Ryan White Program]. Additionally, this assessment provides recommendations for addressing these barriers. The specific services constituting the focus for the assessment are (1) oral health, (2) mental health, (3) chemical health and (4) prevention with positives.

Purpose for Assessment. The Hennepin County Human Services and Public Health Department [HSPHD], in coordination with the Minnesota HIV Services Planning Council [the Planning Council] initiated and funded the assessment. The assessment's intent is to provide information to the Planning Council to help fulfill its priority-setting obligations related to The Ryan White HIV/AIDS Treatment Modernization Act [the Ryan White Program]. Specifically, to help the Planning Council (a) understand the need and utilization of services in these four areas, (b) establish priorities for allocating resources and (c) approve service area budget recommendations.

Additionally, the assessment is intended to help the Ryan White Program Part A and Part B grantees in Minnesota, namely HSPHD and Minnesota Department of Human Services] (a) develop Ryan White service area budget recommendations to present to the Planning Council and (b) develop requests for proposals to solicit providers who can deliver these services.

Summary of Process. The assessment process included review of existing reports, key informant interviews, and group discussions with people living with HIV, providers of services to people living with HIV and public program managers. Findings and recommendations were reviewed with the Planning Council and its Needs Assessment and Evaluation committee periodically through the assessment process. The assessment was conducted between June 2007 and May 2008 by Bob Tracy Consulting.

Key Observations & Recommendations. The following is a summary of key observations for each of the four services addressed by this assessment.

Oral Health

Oral Health – Key Observations:

- A. **Most – but not all – get the care they need.** Two-thirds of the people living with HIV interviewed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported they had a regular oral health care provider and 71 percent reported they visited that provider within the past year. These rates are comparable to national responses for the public as a whole regarding routine access and use of oral health care services. However, there are differences between Whites

who reported having a usual source of dental care compared to people of color, seemingly due to a difference in access to dental coverage through private insurance or an HMO.

- B. **Consumer knowledge about HIV and oral health needs improvement.** Consumers and HIV service providers perceive lower levels of knowledge among people living with HIV about the impact of oral health on HIV disease management, compared to other aspects of HIV care. 29 percent of the people living with HIV interviewed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported they thought oral health care was not necessary.
- C. **Medicaid reimbursement rates create a structural barrier to care.** The availability of oral health care providers willing and able to serve lower income individuals is severely compromised by low Medicare reimbursement rates. *This is a barrier to care for all lower income individuals and not just people living with HIV.*
- D. **Benefits vary.** Consumers and HIV service providers report challenges managing gaps in coverage resulting from differences in dental procedures that are paid for by the various oral health care programs available to lower income people and people living with HIV. Due to the multiple challenges to finding and paying for oral health services, consumers and HIV service providers report it is difficult to get timely oral health treatment, even in acute situations.
- E. **Finding an HIV-capable dentist is challenging.** Consumers and HIV service providers report significant challenges finding providers who are perceived to be welcoming to people living with HIV, well-informed about HIV and/or willing or able to accept patients who are unable to pay market rates for services. Consumers and HIV service providers express a desire for assistance to help them narrow their provider searches to those most willing and capable of providing HIV-responsive care. This is true in all parts of the state, but the challenge is even more pronounced in Greater Minnesota where there are fewer providers with HIV-specific knowledge or experience.

Oral Health – Options for Action – Key Recommendations:

1. **Sustain wrap-around assistance to fill gaps in benefits.** Dental assistance provided through DHS' HIV/AIDS Program's HH Program fills gaps in coverage due to limitations on benefits provided through publicly-funded dental insurance programs, as well as some private insurance. It assures that those living with HIV and particularly those who depend on public programs for dental coverage have access to a comprehensive array of dental services reflective of standards for oral health care in the context of HIV care. Recent staffing adjustments in the DHS HIV/AIDS Program designating a single staff person to help consumers, case managers and dental care providers access these funds and coordinate their use with other coverage will certainly not eliminate some of the administrative challenges, but should make them easier to navigate and less of a barrier. It would be appropriate to consider continuation of funding for this service as priority expenditure for any resources allocated oral health services.
2. **Improve information and referral support to help find HIV-capable oral health providers.** People living with HIV and those helping them find dental services need access to a narrowed list of reliable providers of oral health services for people living with HIV. They need to know which providers are (a) known to be knowledgeable about and experienced providing care consistent with standards of oral health care for people living with HIV, (b) sensitive to and

experienced working with populations affected by HIV, and (c) most familiar with and likely to accept and take advantage of publicly funded programs providing oral health coverage. There is a need for a well-research and periodically updated “insiders guide” to help locate that relatively small network of HIV-ready providers. This network needs to include providers both in the Twin Cities metropolitan area and in Greater Minnesota... In the interest of relieving a barrier and easing access to service, it is worth exploring the opportunity to leverage and build-upon the Ryan White Program’s investment in the AIDSLine infrastructure to make this service available to people living with HIV and those helping them find dental services. Initial development of this service might be an appropriate use of oral health capacity development resources, should they be available. However, sustaining the service might be achieved through a refocusing of currently funded information and referral services.

3. **Promote co-located services to help close the gap for those not getting the care they need.** Co-location of oral health services within the same complex and network of services as other HIV health care services has been demonstrated to be an effective model for increasing access and use of oral health services. Consumers are able to perceive the integral connection between oral health care and their HIV care when the services are organizationally linked. Clinicians are better able to facilitate and follow-up on referrals, as well. It is also easier to respond and manage emergency and acute care situations when the care can be coordinated within the same system.

If the Planning Council were to expand funding for oral health services to support this service model, it would want to consider some of the following special considerations. First, while a fee-for-service reimbursement structure is appropriate, a capacity-development contract is also necessary to support a specialty-focus service such as this. Second, the service needs to be open to clients who receive care outside of the affiliated HIV care clinic, at least for emergency or acute care or for early intervention services to those new to HIV care. Third, while the most affordable option would be to augment or improve the sustainability of existing clinic-affiliated oral health services, this also needs to be balanced with needs to address lower affiliations with a usual source of oral health care in communities of color. Finally, while supporting a well-dispersed network of dental care services that are co-located with HIV services would prove to be a steep financial challenge, partnerships between metro-based clinics and Greater Minnesota HIV care services should be explored to at least provide access to services and transportation assistance to address emergency situations.

Mental Health

Mental Health – Key Observations:

- A. **Coverage is available for many low income Minnesotans.** In 2006, 536 lower income people living with HIV, slightly over ten percent of those reported to be living with HIV in Minnesota, received mental health services through a health care assistance program administered by the Minnesota Department of Human Services. The total expenditure for mental health services for people living with HIV was \$685,590.
- B. **Navigating the mental health care system and finding an HIV-capable provider is challenging.** Numerous factors complicate finding a mental health services provider for people living with HIV. First, consumer knowledge about differences in types of mental health care and providers is limited [e.g. mental health care versus emotional support, or a counselor versus a

therapist]. This can limit their abilities to be self care advocates. Then there are challenges finding a provider they can trust, particularly someone who has experience and a good reputation that supports their ability to incorporate HIV into their mental health service and sensitivity to populations affected by HIV. Finally, the pool of HIV-ready providers to choose from is shallow. The push for peer-to-peer training of mental health professionals to improve incorporation of HIV into their care has stalled, an indicator that the already small HIV-ready provider network is not growing. Additionally, providers and consumers indicate they have experienced a wide range of professional capacity within programs providing group support or counseling specifically for people living with HIV.

- C. **There are significant barriers to getting timely psychiatric care.** There is a shortage of psychiatric care providers in the Minnesota medical market. Consequently, psychiatric services are expensive. These factors combine to make it difficult for HIV clinics to include psychiatric service providers in their staff budgets. The consequence is that it makes it difficult to gain access to psychiatric services at the time when they are needed, and in some cases, it places HIV health care providers in the position of having to prescribe and manage both psychotropic medications and HIV-related medications without the desired level of consultation with a psychiatric or psychiatric nurse practitioner.
- D. **Providers' routine skills and experiences are put to a test when working with and negotiating the needs of clients with mental distress or disorder.** Providers perceive an increase in the numbers of clients in their care who experience more serious mental distress or disorder, or at the very least, are finding clients with these higher needs are requiring more time and skill. They also note the specialized nature of mental health screening and assessment processes, legal protections to guide care and treatment of those with mental illnesses, unique funding structures for reimbursing care and significant changes in how services are structured. In short, the mental health care system has unique features that are beyond the routine experiences of HIV medical case managers.
- E. **The Ryan White Program's current approach to addressing gaps in access to mental health services is under performing.** Administrative complications with providing mental health care subsidy payments through DHS centralize health care services have proven to be out of scale for the service. Despite efforts to resolve the problem, the service continues to be underutilized.

Mental Health – Key Recommendations:

1. **Ease access to psychiatric care.** HIV primary care providers need dedicated access to psychiatric care services, both those provided by a psychiatrist and qualified nurse practitioner. HIV care for clients who experience severe and persistent mental illness pose unique challenges for providers and to their own self care. Stabilizing HIV treatment and care, particularly if the prescription of drug treatments to address psychiatric distress or disorders is required, calls for timely collaboration between the HIV and the psychiatric care providers and coordinated care. HIV clinics, particularly those that see larger numbers of clients who present with severe and persistent mental illness, need assistance to purchase dedicated time and services of psychiatric care providers. While an expensive proposition, this is a critical gap in HIV-related mental health care for which there few other options and should be considered a priority should sufficient resources be available

through mental health services allocations. Such an arrangement should include a consultative relationship with HIV care providers providing services in Greater Minnesota.

2. **Improve information and referral support to help find HIV-capable mental health providers.** People living with HIV and those helping them find mental health services, particularly the services of a therapist or counselor, need access to a narrowed list of reliable providers of mental health services for people living with HIV. They need to know which providers are (a) known to be knowledgeable about and experienced working with populations affected by HIV, and also those who are (b) familiar with and likely to accept and take advantage of coverage provided through publicly funded programs. There is a need for a well-researched and periodically updated “insiders guide” to help locate that relatively small network of HIV-ready providers who are working both in the Twin Cities metropolitan area and in communities in Greater Minnesota. In the interest of relieving a barrier and easing access to service, it is worth exploring the opportunity to leverage and build-upon the Ryan White Program’s investment in the AIDSLine infrastructure to make this service available to people living with HIV who are looking for an HIV-ready therapist or counselor. Initial development of this service might be an appropriate use of mental health capacity development resources, should they be available. However, sustaining the service might be achieved through a refocusing of currently funded information and referral services.

Chemical Health

Chemical Health – Key Observations:

- A. **Chemical health issues complicate coordination of care for many.** HIV case managers surveyed as part of the Planning Council’s 2006 Minnesotans Living with HIV survey reported that 13 percent of their clients demonstrated problems adhering to their care plans because of alcohol or drug use. HIV service providers who participated in service assessment interviews agreed this was a problem and suggested that based on their experiences it was greater than reported.
- B. **Timely access to a Rule 25 assessment is a critical step in the path to receiving treatment.** HIV service providers consider funding for treatment services to be accessible in Minnesota. However, they cite timely access to individuals capable of conducting Rule 25 assessments required to establish eligibility for funding for treatment as a barrier to linking clients to chemical health services.
- C. **Funding system doesn’t assure access to HIV-capable service.** Consumers and HIV service providers report confidence in the system’s ability to provide access to treatment services, but a concern that local differences in the administration of treatment access programs can limit access to providers that have specialized capacity to address the needs of people living with HIV.
- D. **Providers need capacity development and support to explore alternative approaches to care.** HIV service providers and systems planners report the need to develop alternative approaches to providing HIV services, including case management, and chemical health services. Alternative approaches were considered to be needed to for after care or and for those for whom a service based in harm-reduction principles might be more relevant.

Chemical Health – Key Recommendations

1. **Provide funding for staff to be trained, certified and to provide Rule 25 assessments.** A priority use for any funds allocated for chemical health services should be provide access to certified Rule 25 assessors, particularly for the Ryan White Program’s primary care, early intervention services, medical case management and outreach services providers. Options for organizing such a service might include designating this as part of the responsibility of staff person within one of these programs, or by a group of providers coming together to purchase the service through an “on call” assessor. Additionally, capacity development resources should be available to support initial and ongoing training and certification for staff within these programs to qualify as Rule 25 assessors.
2. **Re-establish ongoing HIV education and networking support for HIV and chemical health service providers.** There a number of challenges within HIV and chemical health services systems that create barriers for people with HIV who need chemical health services. Among these are staff training and support to either work more sensitively with people living with HIV or to be more effective in working with clients who have chemical health issues, developing policies and procedures that can relieve unnecessary barriers to getting people into treatment, or developing alternatives to treatment programs for helping people living with HIV address chemical health issues. ASAP [the AIDS and Substance Abuse Partnership] was an effective professional network that identified and created solutions within existing systems and services to improve chemical health services for people living with HIV. A combination of substance abuse services capacity development and quality management resources through the Ryan White Program might provide enough leverage to attract additional resources [for example through the DHS Chemical Health Division, a supporter of ASAP’s initial development] to revive this valuable and effective professional network.

Prevention with Positives

Prevention with Positives – Key Observations:

- A. **Consumers view prevention to be an integral part HIV self-care and wellness.** Consumers report risk-reduction information to be most useful when it is part of a holistic approach to HIV wellness that combines information about HIV disease management, general health and wellness promotion and risk-reduction, along with peer-influenced learning and support. Consumers look for providers of emotional support, health education, outreach and information and referral services to be able to provide reliable information about risk reduction and opportunities to explore options and problem-solve challenges to sustaining risk reduction behaviors. Consumers express a preference for emotional support and health education services that have clearly-defined beginning and ending points and that are centered on discussions related to HIV wellness. They identified the value of being introduced to role-models [e.g. Hero’s Conference] and to access to anonymous or confidential, individual level services to help them start the process of learning HIV medical and emotional self-care and risk reduction behaviors [e.g. AIDSLine, confidential meetings with other individuals living with HIV].

- B. The funding structure poses barriers.** Difficulties associated with integrating federal funding for HIV prevention available through the CDC and HIV care available through HRSA make it difficult to develop and sustain prevention with positives service. This problem is further complicated by the multiple core and support service areas within the Ryan White Program structure that touch upon prevention-related activities. Currently, almost a half million dollars is allocated through the Ryan White Program in Minnesota in three distinct service areas that include prevention as a significant service element. An additional \$148,000 is allocated by the Minnesota Department of Health for prevention with positives services. The total amount of funding available for services that have an impact on prevention with positives is relatively significant. However, the dollars are not allocated in a coordinated manner that providers feel have a targeted or strategic impact. According to interviews with HIV service providers, because the resources are allocated through a variety of different service areas and in relatively small contracts across a range of providers, it is difficult for to develop and sustain services that replicate or adapt effective, research-based intervention models.
- C. Providers want to learn more about prevention with positives interventions.** Providers report a need for education and technical assistance to develop evidence-based prevention with positives services, particularly services incorporating group, community or multi-level interventions.
- D. Peer-based service is what consumers want.** Consumers report a desire to promote risk-reduction among peers. They also report a need for training and support for their efforts to provide services to peers. They identify individual, group and Web-based communication to all be effective approaches for providing peer-based learning and support. The role of peers in health education and prevention services added element of emotional support to these services.
- E. Clinic-based prevention services are not maximized.** HIV medical care providers report limits to the effectiveness of HIV prevention education in medical care settings to be of without other, community-based interventions to influence and sustain behavior change. A notable exception is prevention of mother-to-child transmission, an intervention that is based primarily on medical rather than behavior intervention. Clinicians have expressed an interest in receiving technical assistance to identify and integrate simple, but effective interventions that are appropriate and sustainable in the clinic setting. Additionally, they note people with HIV are open to making behavior changes to reducing transmission risk upon learning of an HIV positive diagnosis. HIV medical care providers report a need to engage peers when promoting HIV wellness and risk-reduction for those clients who are newly diagnosed or new to HIV care. However, they report challenges finding individuals living with HIV who are skilled and experienced at providing peer-based support to participate in this process in a timely manner.

Of Special Note - The Minnesota “epi” points to communities needing special attention. The large prevalence of HIV, a continuing trend in syphilis infections with notable occurrences among men who are co-infected with HIV and who are in older age groups and substance abuse support a sustained trend in new infections among white men who have sex with men. Social stigma creates closed social networks that are facilitating disproportionately high and increasing infection rates among African American men who have sex with men and Latino men who have sex with men. Almost all of the new infections among young men are among men who have sex with men. Social stigma and cultural norms continue to create higher risk for women of

color, particular women in African communities, who have heterosexual relationships. The barriers to dealing with risk among African American men who have sex with men contribute to disproportionate infection rates among African American women.

Prevention with Positives – Key Recommendations:

1. **Promote collaborative, integrated service delivery.** Budgeting, administration of the requests for proposal and contract management should encourage service providers to collaborate and deliver multi-level prevention intervention services for people living with HIV that integrate risk reduction and health education, psychosocial support, outreach and referral for health care and support services intended to aid self-care. A strong link with one or more primary care clinics is encouraged to be part of such collaborative efforts in order to promote referrals and coordination of efforts to promote and sustain primary and secondary prevention and wellness.
2. **Expand peer-based service capacity.** Capacity development services should be available to the network of people living with HIV who deliver services through the Ryan White Program. They should focus on developing professional skills and attributes to support delivery of services as peers, balancing professional and HIV self-care to promote retention, and developing skills to support quality management and improvement with an emphasis on including the perspectives of people living with HIV. While this effort should emphasize supporting development of peer-based service capacity in health education/risk reduction, psychosocial support, outreach and referral for health care and support services intended to aid self-care, there would be benefits to opening this opportunity to peer-based providers of other services. This should be a priority for any capacity development funds available to support health education/risk reduction, psychosocial support, outreach and referral for health care and support services.

Providers of Ryan White Program core services, particularly those providing primary care, early intervention and medical case management, indicate the need for peers to help their clients develop strategies for integrating primary and secondary prevention with general HIV self-care. They seek access to individuals living with HIV who have some training to provide peer support of consistent quality, can support introduction and navigation into the care system, and can be routinely accessed. Should short-term resources become available, it would be a worthy investment to develop this service on a pilot basis to assess its feasibility.

SECTION II: ASSESSMENT PROCESS

The assessment process included review of existing reports, key informant interviews, and group discussions with people living with HIV, providers of services to people living with HIV and public program managers. Findings and recommendations were reviewed with the Planning Council and its Needs Assessment and Evaluation committee periodically through the assessment process. The assessment was conducted between June 2007 and May 2008 by Bob Tracy Consulting.

Review of Existing Reports. The assessment design recognizes that both HSPHD and the Planning Council routinely collect, analyze and report about the needs of people living with HIV in Minnesota and access and use of services funded by the Ryan White Program. Rather than duplicate this process, the assessment was designed to draw attention to essential pieces of information members of the Planning Council could use to make decisions. The existing documents reviewed for this assessment include:

- 2006 – 2008 Minnesota HIV Services Planning Council Comprehensive Plan
- 2003 Needs Assessment of HIV Positive Minnesotans
- Planning Council’s 2006 Minnesotans Living with HIV survey
- Service Area Reviews and Summaries
- Minneapolis-St. Paul TGA Application for 2008 Ryan White HIV/AIDS Treatment Modernization Act Part A and Minority AIDS Initiative

Individual and Group Interviews. A series of individual and group interviews were conducted with key informants that included people living with HIV, providers of services to people living with HIV and managers of public programs. The interviews were provided qualitative perspective and expert knowledge to build upon information previously collected by HSPHD and the Planning Council and to develop recommendations for addressing access and service use barriers.

Thirty-four [34] individual interviews were conducted. Of those who were interviewed, 50 percent had primary experience as providers, 32 percent had primary experience as public program managers and 18 percent had primary experience as people living with HIV. The interviews were structured around open questions allowing for discussion about each of the four services comprising the focus for the assessment. Sixty-two [62] percent of the interviews were broad in scope and addressed all four of the services. Twelve [12] percent covered three of the four services. Twenty-six [26] percent of the interviews addressed only one or two of the services [e.g. chemical health and mental health, or just prevention with positives], reflecting the specific expertise or interest of the interviewee.

Eight group interviews were conducted. Five of the group interviews were with people living with HIV. These included a meeting with the Planning Council’s Community Voice Committee, and two community forums hosted by Minnesota AIDS Project’s Positive Link program, two community meetings hosted by Rural AIDS Action Network. A total of 21 individuals participated in these group interviews. In another group, seven HIV service providers were interviewed. A group of eleven individuals who manage public programs related to HIV or the four services that were the focus for the assessment was also assembled for a group interview. Finally, a group of four advisors who had both

service delivery and public program management experiences was assembled to provide technical consultation.

Preliminary findings from the assessment were shared with the Planning Council and its Needs Assessment and Evaluation committee periodically through the assessment process between June 2007 and May 2008. Four presentations were presented to the Planning Council in advance of the completion of this final report on the assessment. Similarly, nine presentations were made to the Planning Council's Needs Assessment and Evaluation Committee.

Concurrent with this service assessment, the consultant conducted a series of health education workshops and interviews for two television programs under contract with HSPHD's Ryan White Program. Information collected through both group discussion and individual interviews in these projects also supported this service assessment process.

Organization of Report. The structure of this report assigns a section to each of the four services that are the subjects of this services assessment:

- 1) oral health,
- 2) mental health,
- 3) chemical health and
- 4) prevention with positives.

Each section includes:

- A. a description of the standard for care for the service,
- B. a discussion of challenges and barriers identified through the service assessment research process, including an introduction that highlights what stands out as a primary challenge and barrier,
- C. a summary of how the Ryan White Program resources can be and are used to support the service, and
- D. key observations and options for action, with the options of actions including two or three *key recommendations* for emphasis, along with additional recommendations.

The report's appendices include a listing of those who participated in individual and group interviews, a schedule of the group meetings, acknowledgements and endnotes crediting sources for information presented in the report, other than that collected through the interview process.

SECTION III: ORAL HEALTH SERVICES ASSESSMENT

A. Standards for Care

Oral health care is an essential element of comprehensive HIV primary care. Poorly functioning dentition can adversely affect the quality of life, complicate the management of medical conditions and create or exacerbate nutritional and psychosocial problems.¹

Poorly functioning dentition can be an indicator of immune deterioration and has prognostic significance for diagnosis related to advanced HIV disease. For example, oral candidiasis may precede other indicators of immune deficiency. It can be a clinical indicator for initiating or continuing prophylactic treatment for pneumocystis carinii pneumonia [PCP]. Hairy leukoplakia or persistent and painful herpetic lesions and ulcers in the mouth might also be indicators of marked immune deficiency. HIV-infected individuals also risk occurrence of specific types of gingival periodontal disease.² Left untreated, infections associated with poor oral health conditions due to immune deficiency and complicate HIV-related treatment can have those conditions exacerbated.³

Some medications prescribed to treat HIV-related complications have side-effects that may manifest in the mouth causing problems with soft tissue [e.g. candidal growth or ulcers] or lead to increased, cavities or vulnerability of gums and other tissues to disease.⁴

Poor oral health conditions and related pain and discomfort, due to underlying immune deficiency or medication side-effects, have also been known to affect antiretroviral (ARV) treatment adherence. Additionally, they create or exacerbate nutritional and psychosocial problems.⁵ Poor nutrition, which is a common challenge in populations disproportionately affected by HIV, also creates risk for poor oral health.

At a minimum, HIV clinical care should include an oral examination as part of each medical visit. When an individual initiates HIV clinical care, he or she should be referred to a dentist for ongoing care. Such care should, at the very least, include semiannual examinations, prophylactic treatment and other appropriate preventive care.⁶ Treatment should be available to resolve poor oral health conditions that cause pain and discomfort, exacerbate nutritional and psychosocial problems, and complicate management of HIV-disease. People living with HIV should have a basic understanding of oral health and HIV so they can engage in self-care in a manner appropriate to supporting chronic disease management.

B. Challenges & Barriers / Discussion

The primary challenges to oral health care for people living with HIV are: (a) people living with HIV do not view oral health care as an essential part of their HIV or general health care, (b) insurance coverage, especially that provided through public programs for lower income individuals, does not meet provider reimbursement expectations, and (c) finding providers that are both capable of providing oral health care in a context of HIV-disease management is difficult and is made even more difficult if an individual relies on a public program to provide reimbursement for care.

(a) *Oral health is not viewed as a central part of HIV care.* When it comes to oral health care, the attitudes and behaviors of people living with HIV in Minnesota are not much different than the public as a whole. Socially, many people in the United States consider oral health care a discretionary activity, viewing oral health care as somehow not part of health care. This is mirrored in the way health care service is organized. Rarely are dental services included and co-located in multi-specialty care settings. It is evident in how insurance is provided. It is considered a bonus of sorts if dental coverage is included in an employer's benefits package. Most people, even those with dental insurance, tend to seek care only when they have a problem.

In a survey of HIV-positive Minnesotans conducted in 2006, about two-thirds [60%] of survey respondents had a dentist's office or clinic that they usually go to for care, a rate similar to that for HIV-infected adults in the U.S. Among respondents with a usual source of dental care, 71% had visited a dentist in the six months before the survey. Factors cited by respondents for *not* receiving dental care included that they did not think going to the dentist was necessary [29%] or that they thought it was necessary but they did not try to visit a dentist [11%]. 15% could not afford a dentist. 11% could not get an appointment. 5% could not find a dentist. 6% did not have a dentist that treats HIV in their community. 5% did not want anyone to know in their community they had HIV.⁷

The social norms for oral health care are problematic for people living with HIV since the consequences of poor monitoring and treatment that come from attitudes that disassociate oral health care from primary health care are more pronounced for those experiencing immune deficiency. Based upon interviews conducted as part of this assessment, people living with HIV and their service providers perceive a distinct lack of knowledge about oral health care as part of HIV chronic disease management and self-care. This is particularly true when comparing the opportunities people living with HIV have to learn about monitoring, treating and self-care practices related to the virus, whether available in clinical, social service, public health, self-care education or social networking environments.

Co-location of oral health services in the HIV clinical care setting, or at least the availability of routine preventative examinations and cleaning, has helped to increase awareness about the role of oral health in comprehensive HIV care. Providers increase and intensify the information they provide about oral health care because they are able to follow-up by assisting with a manageable referral, and people living with HIV both see and experience oral health as an integral part of their HIV care.

What does not seem to be as much of a factor in keeping people living with HIV from seeking oral health services is fear of mistreatment when seeking oral health services. During the early years of the HIV epidemic, oral health providers were known to be resistant to providing care to people living with HIV due to stigma and discrimination. In fact, one of the most noted anti-discrimination cases against a health care provider in Minnesota resulted in an adverse action against a dentist. However, based upon interviews conducted through this assessment, it seems that attitudes and willingness to serve people living with HIV in Minnesota have made a positive progression through the years of the epidemic.

The good news is that such a high percentage of people living with HIV have a designated oral health care provider and see that provider on a routine basis. However, for the significant number of those who do not, the bigger barrier keeping them from seeking care is simply not perceiving or understanding the importance of oral health care and the need for routine care.

(b) *Public insurance coverage does not meet expectations for reimbursement.* Many oral health providers in Minnesota limit the amount of the service they provide to individuals who

depend upon public insurance coverage [e.g. Medical Assistance] to provide coverage for their care. For providers, the reimbursement rates tend to be 50% to 60% less than their usual and customary fees.⁸ People living with HIV and providers interviewed as part of this assessment described the experience of being told by a provider they were “no longer accepting Medical Assistance clients because they had reached their limit” as if it were a fairly routine experience. In the past, this response from a provider was sometimes interpreted as an expression of discrimination based on stigma or fear. However, those interviewed through this assessment do not perceive that to be the case any longer. Their perception is providers simply cannot accept too many clients for whom the reimbursement will be so much less than their usual or customary fees.

The practice of not accepting clients who depend upon public programs for oral health care coverage is widespread in Minnesota, and is in no way limited to those who may be living with HIV. It is a systemic problem that has its roots in state health care access policy. Minnesota’s health insurance laws are structured in such a way as to allow the state to have a considerable, regulatory influence over access, coverage and cost of care. However, coverage for oral health care is not governed by the same laws, which limits the state’s abilities to regulate access, coverage and cost of care. This has resulted in a long-standing policy dispute between public policy makers and oral health care providers. The dispute is evidenced by resistance on behalf of the state to accept providers’ usual and customary fee standards for establishing reimbursement rates for its programs. Conversely, providers are resistant to professional standards that might allow other oral health care staff to provide certain services that are delivered by dentists and at a lower cost. People living with HIV who rely on public programs for oral health coverage and, for that matter, all lower income or disabled Minnesotans who rely on these programs, experience the same difficulties in accessing care as a result of this policy impasse.

The problem of dealing with the cost of providing care to individuals with oral health care coverage through public programs is made more difficult because people who depend on this coverage also tend to experience a variety of barriers to efficiently using services and effectively following through on care. It is a population that seems to have a higher rate of “no shows” for appointments, which leave unproductive, costly gaps in provider’s schedules. It is also a population that tends to present with more difficult conditions and has trouble following through with self-care instructions, both of which lead to higher and future costs.

The Minnesota Department of Human Services [DHS] administers the Minnesota Health Care Programs [MHCP], which include public programs for oral health care coverage. DHS has taken steps to create incentives for more providers to offer services to people who have state funded coverage. Providers who are willing to accept a higher than usual percentage of Minnesota Health Care Programs clients, receive a slightly higher reimbursement rate. In some cases, insurance and health service providers are willing to operate with rate capitations for dental services. However, to manage cost and operate under this model, the provider has found it to be necessary to limit providers and services for MHCP clients to one clinic in the Twin Cities metropolitan area. DHS has also extended grants to nonprofit clinics to cover capital and equipment expenses as a way to subsidize the cost of providing services to low income individuals.

Further complicating oral health care for people living with HIV relying on MHCP dental coverage are limited benefits that do not provide coverage for services at a level that would meet oral health standards of care for people living with HIV. DHS’ HIV/AIDS Program helps close benefits gaps by offering assistance through its HH Program to pay for services that fall outside of the benefit sets established by MHCP dental coverage and at higher reimbursement rate than other MHCP programs. Additionally, the HH Program eases access to coverage by providing assistance with deductibles and co-payments that

might be required as part of MHCP or other dental insurance plans. Since funding for dental assistance provided through the HH Program comes from the Ryan White Program, eligibility requirements including income restrictions apply.

Utilization of HH Program dental assistance resources and information collected through this assessment's interview process suggest the program is generally effective in achieving the objective of closing benefit gaps and coverage affordability gaps. However, consumers and providers commented that matching the various coverage options and benefit sets to achieve full and affordable coverage was cumbersome and particularly difficult to manage when trying to respond to emergency or acute care situations. Also, HIV care providers noted they still encountered oral health service providers who were resistant to accepting clients who had HH Program coverage because they perceived the program to have the same limitations as other MHCP coverage or did not want to assume responsibility for additional administrative paperwork. DHS has taken steps to provide assistance to consumers, HIV service providers and oral health care providers make the process of matching coverage and benefits easier.

It should be noted that according to the Planning Council's 2006 Minnesotans Living with HIV survey, having *private* insurance or HMO enrollment was positively and statistically significant in association with having a usual source of dental care. Additionally, almost two-thirds (66%) of Whites reported a usual source of dental care, compared to 55% of Black Africans/African Americans and 52% of other racial/ethnic groups.⁹

(c) *Finding an HIV-capable provider is difficult.* Both people living with HIV and their providers indicated it they had difficulties locating oral health providers who were perceived to be knowledgeable about standards of oral health care for people living with HIV, sensitive and experienced in working with HIV *and* willing to accept coverage offered through publicly-funded program. This situation is only made worse when a client is facing an emergency or acute care need.

DHS offers referrals to providers that accept MHCP coverage. However, the agency's is limited by state law in its ability to tailor and narrow the referrals in a way that people living with HIV and their providers find to be most helpful. Essentially, they are looking for an "insider's guide" that will help them narrow their search for a provider who meets the tests of having current knowledge about standards of oral health care for people living with HIV, demonstrated sensitivity and experience working with populations affected by HIV and likely to accept coverage offered through publicly-funded programs. They feel that what DHS is able to provide them is a rather a large, unwieldy list that in its lack of focus can be as much of a barrier as an aid. This is particularly true in situations where there is some degree of urgency.

While help narrowing the search for a provider seems to be desired by people living with HIV and providers in all parts of the state, it is especially true for those in Greater Minnesota where there are even fewer options from which to choose.

C. The Ryan White Program as a Resource

Oral health care is a HRSA-designated core medical service. Ryan White Program resources can support oral health care that includes "diagnostic, preventative and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries and other trained primary care providers."¹⁰

The Minnesota HIV Services Planning Council has approved allocations for oral health services that have increased from \$71,000 in 2006-07 to \$138,600 in 2007-08. Funds have been used to close gaps in benefits and to ease access by reducing the burden of co-payments. The service is administered by DHS's HIV/AIDS Program as part of the HH Program, and 272 individuals used the service in 2006.¹¹

Additional resources from the Ryan White Program are also available to assist with dental care for people living with HIV in Minnesota. Westside Community Health Services/LaClinica allocates a portion of its Part D allocation to provide dental care to its clients through the agency's dental clinic. Hennepin County Medical Center's [HCMC] Positive Care Center uses a combination of funds received through Part C and Part F of the Ryan White Program to fill gaps in coverage, primarily for clients of its clinic, with provide services through HCMC dental providers.

D. Key Observations and Options for Action

Oral Health – Key Observations:

- A. **Most – but not all – get the care they need.** Two-thirds of the people living with HIV interviewed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported they had a regular oral health care provider and 71 percent reported they visited that provider within the past year. These rates are comparable to national responses for the public as a whole regarding routine access and use of oral health care services. However, there are differences between Whites who reported having a usual source of dental care compared to people of color, seemingly due to a difference in access to dental coverage through private insurance or an HMO.
- B. **Consumer knowledge about HIV and oral health needs improvement.** Consumers and HIV service providers perceive lower levels of knowledge among people living with HIV about the impact of oral health on HIV disease management, compared to other aspects of HIV care. 29 percent of the people living with HIV interviewed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported they thought oral health care was not necessary.
- C. **Medicaid reimbursement rates create a structural barrier to care.** The availability of oral health care providers willing and able to serve lower income individuals is severely compromised by low Medicare reimbursement rates. *This is a barrier to care for all lower income individuals and not just people living with HIV.*
- D. **Benefits vary.** Consumers and HIV service providers report challenges managing gaps in coverage resulting from differences in dental procedures that are paid for by the various oral health care programs available to lower income people and people living with HIV. Due to the multiple challenges to finding and paying for oral health services, consumers and HIV service providers report it is difficult to get timely oral health treatment, even in acute situations.
- E. **Finding an HIV-capable dentist is challenging.** Consumers and HIV service providers report significant challenges finding providers who are perceived to be welcoming to people living with HIV, well-informed about HIV and/or willing or able to accept patients who are unable to pay market rates for services. Consumers and HIV service providers express a desire for assistance to help them narrow their provider searches to those most willing and capable of providing HIV-

responsive care. This is true in all parts of the state, but the challenge is even more pronounced in Greater Minnesota where there are fewer providers with HIV-specific knowledge or experience.

Oral Health – Options for Action – Key Recommendations:

- 1. Sustain wrap-around assistance to fill gaps in benefits.** Dental assistance provided through DHS' HIV/AIDS Program's HH Program fills gaps in coverage due to limitations on benefits provided through publicly-funded dental insurance programs, as well as some private insurance. It assures that those living with HIV, and particularly those who depend on public programs for dental coverage have access to a comprehensive array of dental services reflective of standards for oral health care in the context of HIV care. Recent staffing adjustments in the DHS HIV/AIDS Program designating a single staff person to help consumers, case managers and dental care providers access these funds and coordinate their use with other coverage will certainly not eliminate some of the administrative challenges, but should make them easier to navigate and less of a barrier.
- 2. Improve information and referral support to help find HIV-capable oral health care providers.** People living with HIV and those helping them find dental services need access to a narrowed list of reliable providers of oral health services for people living with HIV. They need to know which providers are (a) known to be knowledgeable about and experienced providing care consistent with standards of oral health care for people living with HIV, (b) sensitive to and experienced working with populations affected by HIV, and (c) most familiar with and likely to accept and take advantage of publicly funded programs providing oral health coverage. There is a need for a well-research and periodically updated "insiders guide" to help locate that relatively small network of HIV-ready providers. This network needs to include providers both in the Twin Cities metropolitan area and in Greater Minnesota.. In the interest of relieving a barrier and easing access to service, it is worth exploring the opportunity to leverage and build-upon the Ryan White Program's investment in the AIDSLine infrastructure to make this service available to people living with HIV and those helping them find dental services.
- 3. Promote co-located services to help close the gap for those not getting the care they need.** Co-location of oral health services within the same complex and network of services as other HIV health care services has been demonstrated to be an effective model for increasing access and use of oral health services. Consumers are able to perceive the integral connection between oral health care and their HIV care when the services are organizationally linked. Clinicians are better able to facilitate and follow-up on referrals, as well. It is also easier to respond and manage emergency and acute care situations when the care can be coordinated within the same system.

If the Planning Council were to expand funding for oral health services to support this service model, it would want to consider some of the following special considerations. First, while a fee-for-service reimbursement structure is appropriate, a capacity-development contract is also necessary to support a specialty-focus service such as this. Second, the service needs to be open to clients who receive care outside of the affiliated HIV care clinic, at least for emergency or acute care or for early intervention services to those new to HIV care. Third, while the most affordable option would be to augment or improve the sustainability of existing clinic-affiliated oral health services, this also needs to be balanced with needs to address lower affiliations with a usual source of oral health care in communities of color.

Oral Health – Options for Action – Additional Recommendations:

4. **Support capacity development for HIV-capable providers.** Support the ability to continue to provide services to HIV positive clients, and particularly those who depend on publicly funded coverage by making capacity development grants to a small network of HIV-ready providers. The grants could be used to support staff and service development to better meet the needs of people living with HIV, and to establish and maintain networking relationships with other HIV core and support services to improve referral and coordination of care. This group of providers might also be encouraged to provide training to support quality improvement efforts related to oral health care among other Ryan White Program providers [see #5 below] and to provide training within their professional organizations. In practical terms, the grants might provide have the effect of providing both an incentive and subsidy to continue to provide specialized care for people living with HIV. While applicable for providers in the Twin Cities metropolitan area, it might be particularly appropriate for providers in Greater Minnesota.
5. **Provide training and quality improvement to promote awareness and integration of oral health care into HIV care.** Challenge primary care, medical case management and health education/risk reduction providers supported through the Ryan White Program to incorporate promoting awareness and increasing knowledge of oral health care and HIV care into their screening, monitoring and educational activities. Provide resources and training support to encourage and sustain these quality improvement efforts.
6. **Advocate for changes in state funded oral health care that will relieve barriers to care.** The larger systemic problem growing from unmet expectations for reimbursement for oral health care services through publicly funded programs is beyond the Ryan White Program's capacity to solve. But the ability to assure the impact that this public policy impasse has on people living with HIV does not go unnoticed is not. The Minnesota HIV Services Planning Council and the Ryan White Program can pursue advocacy strategies, both through their government agencies and through community agencies to assure that policy makers are aware of the impact this problem is having on the quality of health care for people living with HIV in Minnesota.

SECTION IV: MENTALHEALTH SERVICES ASSESSMENT

A. Standards for Care

HIV disease is a “chronic stressor. The entire experience with HIV disease presents conditions that can trigger episodic or persistent psychological distress or psychiatric disorders. This includes (a) the risk assessment, testing and diagnosis experience, (b) initiating and adapting to changes in HIV-related health and care [e.g. introduction of medication, occurrence of any physical illness, signs of disease progression including an advanced stage “AIDS” diagnosis changes in care such as hospitalization or initiating intensive medical case management], (c) cognitive disorders associated with HIV (d) social challenges such as disclosure of status to family, friends and community, life changes such as job loss or ending a relationship, or experiencing others’ deteriorating health or loss of life, and (e) facing end-of-life and permanency planning decisions.¹²

Unaddressed mental health distress or disorders has an impact on adherence with HAART and other treatment and care,¹³ transmission risk or risk for sexual victimization and risk for substance abuse.¹⁴

Depending upon the persistence or seriousness of a condition, different types of mental health interventions might be appropriate. This could range from emotional support provided individually or through groups, individual or group counseling, psychotherapy or various types of psychiatric care. Again, depending upon persistence or seriousness, these services may require a psychiatrist or nurse practitioner, a clinical psychologist, licensed social worker or counselor, or simply a social worker, counselor, trained peer or pastoral care provider. The range of need is wide, as are the appropriate options for care.

The stressors of living with HIV are even more challenging for individuals with a history of persistent mental illness, and particularly those who have a range of severe and persistent mental illness or those who experience both mental illness and chemical abuse.¹⁵

At a minimum, people living with HIV should know their primary care provider will conduct a routine assessment of risk for mental illness; a more complete assessment upon initiating care and at least an annual assessment thereafter, appropriate to the stage of HIV infection and the severity of distress or disorder. They should expect the their provider is capable of recognizing and addressing serious distress or disorders commonly associated with HIV and factors that trigger them. And, importantly, that the provider is prepared to work in a collaborative fashion with the patient, mental health clinicians [e.g. psychiatrists, psychologists, nurse practitioners social workers and other mental or chemical health professionals] case managers and community support and HIV risk reduction programs. In cases of severe and persistent mental illnesses, a referral and collaborative relationship with a psychiatrist to support diagnosis, prescription of medication and referral, if necessary, to other mental health professionals or services should be available. This is particular important when prescription of medication needs to be coordinated with ART and medications to treat HIV-related conditions.¹⁶

Capacity to assess and recognize the stressors of living with HIV and basic indicators of distress or disorder are necessary skills, to varying degrees, for providers of other HIV services, for example, medical case management, emotional support or information and referral providers.

B. Challenges & Barriers / Discussion

(a) Individuals who have dual conditions of HIV and serious and persistent illness pose unique challenges for HIV care management and prevention.

(b) Routine and timely access to the services of psychiatric care providers is a significant challenge to effectively treating individuals with co-diagnosis of HIV infection and mental illness.

(c) Matching consumer-defined mental health needs with service has been a persistent problem.

Discussion –

(a) Individuals who have dual conditions of HIV and serious and persistent mental illness pose unique challenges for HIV care management and prevention. Coordination of care for people with HIV and serious or persistent mental illness can be difficult. The consequences can be missed appointments or poor treatment adherence¹⁷ or high risk for HIV infection or risk behaviors that might lead to infection of others.¹⁸ Providers surveyed through this service assessment noted they experienced challenges when working to meet the needs of clients who were experiencing emotional or mental health difficulties, and particularly when working with those who had chronic or persistent mental health conditions. Some of what they expressed was as need for ongoing training and support to maintain their skills to help clients through difficult emotional situations or to manage their HIV care along with their mental health care. But concerns were also expressed about negotiating the complex and changing nature of the mental health service system. Understanding legal protections for those with serious and persistent mental illness, gaining access to specialized treatment services and facilities, and the varied public payment and coverage options tend to go beyond the routine for many HIV case managers. There was a lack of confidence in being able to both negotiate effective referrals, and to match clients with appropriate services. They expressed a need for additional training and the support of other professional peers who they could call upon for advice in difficult or unusual situations to help navigate the mental health services system.

According to the Planning Council's 2006 Minnesotans Living with HIV survey, a substantial portion, 96 percent of those living with HIV in the state who were surveyed, have some form of health coverage.¹⁹ That's significant. An assessment of mental health services for people living with HIV completed by the Planning Council in 1999 offered the observation that the relatively low level of demand for mental health services funded through the Ryan White Program reflected the scope of both private and public insurance available to Minnesotans living with HIV.²⁰

Still, the Planning Council's 2006 Minnesotans Living with HIV survey revealed ten [10] percent of the people living with HIV responding to a survey conducted as part of the study of needs and gaps in health care services reported they had psychiatric, psychological or mental health counseling needs that went unmet. Of note, 28 percent of the ten [10] percent who said they did not get the care they needed reported they could not afford it and 19 percent said they could not find a provider they liked or trusted. Other reported barriers included not knowing how to find help, feelings of stigma, transportation problems, unable to get an appointment or being denied service, not having the time to get help, and in some cases, not able to find someone who speaks the same language.²¹

Providers interviewed as part of this assessment suggested some of the challenges rested with not being able to negotiate administrative procedures to secure coverage for services. Some of this is not being familiar with how to take advantage of all public resources available to cover mental health services [see discussion above regarding lack of familiarity with mental health services system]. However, most of the concern was regarding the shift made in 2005 by the Department of Human Services in how funding for mental health services supported by the Ryan White Program was administered. The administrative system for pre-authorization, reimbursement and finding a provider was too cumbersome, both for consumers and mental health providers. This seems to be particularly true for the relatively small network of providers both experienced and well-known in the HIV community, who also tended to be smaller providers with limited administrative capacities. The impact of the barriers have been seen in steady underutilization of funds budgeted for the service.

In summary, providers of HIV services, and particularly case managers, feel they are facing clients with mental health needs that continue to challenge their skills and experiences, and would welcome ongoing training. They also find it can sometimes be difficult to connect clients with services and a way to pay for the services, particularly when it requires reaching outside of the conventional HIV service system and navigating the public mental health care system. They would like training and the opportunity to draw upon the occasional support of more experienced peers to help them work through unusual and difficult situations. Finally, integration of the Ryan White Program's service to help pay for mental health services when clients face coverage gaps into DHS's larger system for managing public health care access programs has not worked. It has made unmanageable and unworkable what should be a "niche service" designed to distribute a relatively small amount of funding to link a particular group of consumers with a specialized network of providers.

(b) Routine and timely access to the services of psychiatric care providers is a significant challenge to effectively treating individuals with co-diagnosis of HIV infection and mental illness. Clinic staff, HIV case managers and consumers interviewed as part of this assessment process cited connecting clients to psychiatric care providers in a timely manner as an emerging problem. This observation was reinforced by the group of public program managers and technical advisors interviewed through this assessment.

The problem has a combination of elements. First, is the need to carefully coordinate and manage HIV drug treatment and use of psychotropic medications to manage serious chronic and persistent mental illnesses. The second is a shortage of psychiatrists in the Minnesota medical care market, and consequently, the high cost for services. This makes it difficult to both find and to hire psychiatric care staff to be part of an HIV clinic. The result is delayed access to psychiatric services for diagnosis, to initiate treatment and to coordinate ongoing treatment and care between the HIV care provider and the psychiatric care provider.

The seriousness of the consequences that can result from delayed and poorly coordinated treatment, combined with an anecdotally noted increase in the number of clients who present with chronic and persistent mental health conditions requiring psychiatric screening and/or treatment, suggest a service gap of unique concern in the context of HIV care.

(c) Matching consumer-defined mental health needs with service has been a persistent problem. According to the Planning Council's 2003 needs assessment, nearly half of the people living with HIV interviewed reported seeking emotional support or mental health services since their

diagnosis. One-quarter said their HIV diagnosis was the primary reason for seeking services. One half felt their therapist was knowledgeable about HIV [conversely, half did not].²²

These findings were echoed in the interviews with consumers and their providers conducted as part of this service assessment. Consumers expressed a strong preference for working with a counselor or therapist who was knowledgeable about HIV and had experience working with patients from communities affected by HIV. They also expressed difficulties finding HIV-competent providers. Some indicated they were able to find providers based on referrals from peers in emotional support or health education groups. Others express confidence in providers who have a relationship with their clinic or social service provider [i.e. the service is offered as part of the clinic or agency or is co-located in the clinic or agency]. Finally, for those who are in case management, they rely on the assistance of their case manager. Both consumers and case managers expressed a strong interest in having access to information and referral support that can offer “cut to the chase” referrals to mental health providers who are HIV-competent and experienced and are likely to accept variety of public or private coverage plans.

Consumers also underscored the importance of emotional support in their mental health. They described emotional support, provided through support group, health education or social networking activities, as a core part of their ongoing, chronic care. They expressed several frustrations about current services, including the difficulty finding support groups due to dwindling offerings, a lack of commitment to providing these services, and varying quality and capability in programs and staff. While recognizing the value for emotional support services, providers noted difficulties developing and sustaining the services due to restrictions on public resources and low levels of private donor support. The Planning Council’s needs assessment reported that 73 percent of the survey respondents anticipated a need for emotional support services [and 65 percent anticipated a need for mental health services].²³ Additionally, the Planning Council’s outcome assessments have shown a correlation between use of emotional support and mental health services and fewer missed medical appointments and improved medication adherence.²⁴

C. The Ryan White Program as a Resource

Mental health services are a HRSA core medical service. Ryan White Program resources can support mental health services including “psychological and psychiatric treatment and counseling services offered 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.”²⁵

The Minnesota HIV Services Planning Council allocated approximately \$35,000 for mental health services in 2007, but only 26% of the allocated funds were utilized with services reach five individuals. While \$43,000 was allocated for the service in 2008, a mid-year reallocation was made to reduce the initial allocation by 43% to reflect anticipated underutilization of the service.²⁶

Currently, the Ryan White Program provides mental health services funding through the DHS HIV/AIDS Program to pay expenses for mental health services that eligible individuals encounter once their insurance coverage has been exhausted for the year or for co-payments.

Funding for mental health services has gone through an extended period of flux. The adjustment to the current service structure administered by the DHS HIV/AIDS Program was made during 2005 and

initiated during the 2007 allocation year. Part of the rationale for making this adjustment was to expand the range of service providers program participants could use to include any Medical Assistance-eligible provider. Prior to 2005, mental health services supported by the Ryan White Program were provided under contract through five different providers with 77 individuals using the service during the last year when it was available. Prior to 2005, mental health and emotional health services were combined as a Ryan White Program service area with 17 different providers and 463 individuals using the services during the last year when they were combined. Subsequently, allocation for emotional support services has been approached in combination with health education and risk reduction services and also as a separate service area.²⁷

D. Key Observations and Options for Action

Mental Health – Key Observations:

- A. **Coverage is available for many low income Minnesotans.** In 2006, 536 lower income people living with HIV, slightly over ten percent of those reported to be living with HIV in Minnesota, received mental health services through a health care assistance program administered by the Minnesota Department of Human Services. The total expenditure for mental health services for people living with HIV was \$685,590.²⁸
- B. **Navigating the mental health care system and finding an HIV-capable provider is challenging.** Numerous factors complicate finding a mental health services provider for people living with HIV. First, consumer knowledge about differences in types of mental health care and providers is limited [e.g. mental health care versus emotional support, or a counselor versus a therapist]. This can limit their abilities to be self care advocates. Then there are challenges finding a provider they can trust, particularly someone who has experience and a good reputation that supports their ability to incorporate HIV into their mental health service and sensitivity to populations affected by HIV. Finally, the pool of HIV-ready providers to choose from is shallow. The push for peer-to-peer training of mental health professionals to improve incorporation of HIV into their care has stalled, an indicator that the already small HIV-ready provider network is not growing. Additionally, providers and consumers indicate they have experienced a wide range of professional capacity within programs providing group support or counseling specifically for people living with HIV.
- C. **There are significant barriers to getting timely psychiatric care.** There is a shortage of psychiatric care providers in the Minnesota medical market. Consequently, psychiatric services are expensive. These factors combine to make it difficult for HIV clinics to include psychiatric service providers in their staff budgets. The consequence is that it makes it difficult to gain access to psychiatric services at the time when they are needed, and in some cases, it places HIV health care providers in the position of having to prescribe and manage both psychotropic medications and HIV-related medications without the desired level of consultation with a psychiatric or psychiatric nurse practitioner.
- D. **Providers' routine skills and experiences are put to a test when working with and negotiating the needs of clients with mental distress or disorder.** Providers perceive an increase in the numbers of clients in their care who experience more serious mental distress or disorder, or at the very least, are finding clients with these higher needs are requiring more time and

skill. They also note the specialized nature of mental health screening and assessment processes, legal protections to guide care and treatment of those with mental illnesses, unique funding structures for reimbursing care and significant changes in how services are structured. In short, the mental health care system has unique features that are beyond the routine experiences of HIV medical case managers.

- E. **The Ryan White Program’s current approach to addressing gaps in access to mental health services is under performing.** Administrative complications with providing mental health care subsidy payments through DHS centralize health care services have proven to be out of scale for the service. Despite efforts to resolve the problem, the service continues to be underutilized.

Mental Health – Options for Action – Key Recommendations:

1. **Ease access to psychiatric care.** HIV primary care providers need dedicated access to psychiatric care services, both those provided by a psychiatrist and qualified nurse practitioner. HIV care for clients who experience severe and persistent mental illness pose unique challenges for providers and to their own self care. Stabilizing HIV treatment and care, particularly if the prescription of drug treatments to address psychiatric distress or disorders is required, calls for timely collaboration between the HIV and the psychiatric care providers and coordinated care. HIV clinics, particularly those that see larger numbers of clients who present with severe and persistent mental illness, need assistance to purchase dedicated time and services of psychiatric care providers. While an expensive proposition, this is a critical gap in HIV-related mental health care for which there few other options and should be considered a priority should sufficient resources be available through mental health services allocations. Such an arrangement should include a consultative relationship with HIV care providers providing services in Greater Minnesota.
2. **Improve information and referral support to help find providers.** People living with HIV and those helping them find mental health services, particularly the services of a therapist or counselor, need access to a narrowed list of reliable providers of mental health services for people living with HIV. They need to know which providers are (a) known to be knowledgeable about and experienced working with populations affected by HIV, and also those who are (b) familiar with and likely to accept and take advantage of coverage provided through publicly funded programs. There is a need for a well-research and periodically updated “insiders guide” to help locate that relatively small network of HIV-ready providers who are working both in the Twin Cities metropolitan area and in communities in Greater Minnesota. In the interest of relieving a barrier and easing access to service, it is worth exploring the opportunity to leverage and build-upon the Ryan White Program’s investment in the AIDSLine infrastructure to make this service available to people living with HIV who are looking for an HIV-ready therapist or counselor. Initial development of this service might be an appropriate use of mental health capacity development resources, should they be available. However, sustaining the service might be achieved through a refocusing of currently funded information and referral services.

Mental Health – Options for Action – Additional Recommendations:

4. **Offer capacity development and support to providers.** Providers, particularly those who deliver medical case management services, need ongoing training and technical support related to

mental health. Specifically they seek help to improve and sustain capacity to serve clients with clients experience mental distress or disorders, and particularly those with serious and persistent mental illness or who experience both mental illness and chemical abuse, and to navigate the mental health services and funding system. This is a need that could be met through a specialty team to be comprised of capable staff from existing Ryan White Program providers. Should resources be available, this might be an appropriate priority for medical case management capacity development funding.

SECTION V: CHEMICAL HEALTH SERVICES ASSESSMENT

A. Standards for Care

Identifying those living with HIV who meet standards for drug or alcohol dependency so they can be referred to treatment is a key component of HIV primary care. Assessment and counseling for those who might be risky drinkers – those who consume above daily, weekly or per-occasion amounts, can help reduce alcohol consumption and should also be part of primary care. Screening that reveals a pattern of heavy smoking can also provide a marker of substance and alcohol dependency. Clinicians who provide and social workers who support primary care should include drug or alcohol screening upon initiating service to establish a baseline for risk assessment and care planning, and should repeat the screening annually even if no problem becomes evident as part of the baseline screening.²⁹

Those who provide or support HIV primary care need to be familiar with the range of substance use treatment options that are available to address drug or alcohol dependency and to be capable of facilitating referrals.³⁰ For those in their care who are in recovery, they should be prepared to provide positive feedback to support recovery and to recognize and respond considering the high risk for relapse.³¹

In addition to reducing risks abusive drug use, alcohol use and smoking pose for an HIV-compromised immune system, counseling to reduce use or treatment to address harmful dependency resolves problems for both the person living with HIV and the provider engaged with primary HIV care. Addressing these problems can reduce problems with treatment and care adherence and adopt risk reduction behaviors to reduce the effects of primary and secondary infection.³²

B. Challenges & Barriers / Discussion

(a) While assistance for those who lack a method to pay for chemical health treatment is generally available in Minnesota, a key step in qualifying for assistance is an assessment by an individual certified by a county to conduct “Rule 25” assessments. Convenient and routine access to a Rule 25 assessor is a key challenge to providing timely access to chemical health services for people living with HIV.

(b) Additionally, ongoing training for both HIV service providers and chemical health services providers to effectively address the needs of people who cope with dual HIV and chemical health conditions makes providing effective services a challenge.

Discussion –

(a) Assistance for chemical health treatment is generally available in Minnesota.

Five[5] percent of the respondents to the Planning Council’s 2006 Minnesotans Living with HIV survey reported they needed drug or alcohol treatment, but for some reason were not able to get the service.³³ However, interviews with providers and public systems managers conducted as part of this assessment suggest that key to closing this gap is providing better access to “Rule 25 Assessments,” the assessment counties conduct to determine service need and eligibility for county payment for treatment services.

Based on the experiences described by these HIV service providers and public systems managers, funding is substantially available for anyone who needs treatment and has used the services responsibly. The greatest barrier they experience connecting people to treatment is making sure a person who is qualified to conduct a Rule 25 assessment is available in a timely manner; when the client is open to treatment and is ready to participate in the assessment.

(b) Ongoing training is needed for both HIV services providers and chemical health services providers. Nearly two-thirds of the people living with HIV who responded to the Planning Council's 2003 needs assessment indicated that alcohol or drug use was a factor in their infection.³⁴ HIV case managers who were surveyed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported that 13 percent of their clients demonstrated problems adhering to their care plans because of alcohol or drug use.³⁵ HIV service providers interviewed as part of this assessment agreed this was a problem and suggested that based on their experiences, it was greater than reported. They expressed a strong interest in developing their capacities to better respond to the needs presented by clients who are HIV positive and are abusing drugs or alcohol, are in recovery, or are trying to reduce the harm their drug or alcohol use might present to their health. This approach was supported by public systems managers who were interviewed through this service assessment and strongly encouraged the development of new approaches to helping people manage, reduce or eliminate their substance abuse. Among the alternatives suggested was a combined social case management/CD treatment counselor service, a suggestion that in some respects reflects the interest HIV services providers expressed in learning more about working more directly with their clients on alcohol and drug abuse issues.

An additional concern expressed by both providers and consumers is access to "the right" treatment program, one that is both HIV-capable and culturally relevant. Because public assistance for treatment programs is administered at the county level, the choice of what type of program and facility is available for services can be more dependent on where a person lives rather than what kind of care he or she may need. This is particularly a problem for people living with HIV, both from the perspectives of quality of care [i.e. will the service capably address the interaction of personal issues that create risk for HIV and may underlie drug or alcohol abuse] and cultural appropriateness. While Minnesota requires all chemical dependency programs in the state to provide training to assure HIV-capability, assessments conducted by the Minnesota AIDS Project in 2001 and 2004 suggest compliance and consistency in training quality are severely lacking. While achieving HIV-capable service in all programs throughout the state is not a realistic expectation, both providers and public systems managers reflected favorably on the impact of past efforts in Minnesota, namely the work of ASAP [AIDS and Substance Abuse Partnership] to improve upon the number and quality of facilities ready to service people living with HIV.³⁶

C. The Ryan White Program as a Resource

Substance abuse services are a HRSA-designated core medical service. Ryan White Program resources can support substance abuse services that include "the provision of medical or other treatment and/or counseling to address substance abuse problems [i.e. alcohol and/or legal and illegal drugs] in an outpatient setting, rendered by a physician or under the supervision of a physician, or by other qualified personnel."³⁷

The Minnesota HIV Services Planning Council has not authorized funding through the Ryan White Program for substance abuse services since 2005. Currently, no funds are allocated through the Ryan

White Program for substance abuse. Prior to 2005, Ryan White Program funding was authorized over a period of four years to support systems advocacy services intended to promote access to HIV-responsive chemical health services. Funding was also provided to support counseling and Rule 25 assessments provided in the conjunction with outreach and case management services to help people with HIV who were drug or alcohol dependent get connected with harm reduction or treatment services.

As part of the Service Area Review completed in 2006 for substance abuse services, the Planning Council's Needs Assessment and Evaluation Committee expressed a "hope that a focused systems assessment (and/or reviewing past assessments by systems advocates, when those positions were funded) would help identify any unmet needs and ways to target resources to needs."³⁸

D. Key Observations and Options for Action

Chemical Health – Key Observations:

- A. Chemical health issues complicate coordination of care for many.** HIV case managers surveyed as part of the Planning Council's 2006 Minnesotans Living with HIV survey reported that 13 percent of their clients demonstrated problems adhering to their care plans because of alcohol or drug use. HIV service providers who participated in service assessment interviews agreed this was a problem and suggested that based on their experiences it was greater than reported.
- B. Timely access to a Rule 25 assessment is a critical step in the path to receiving treatment.** HIV service providers consider funding for treatment services to be accessible in Minnesota. However, they cite timely access to individuals capable of conducting Rule 25 assessments required to establish eligibility for funding for treatment as a barrier to linking clients to chemical health services.
- C. Funding system doesn't assure access to HIV-capable service.** Consumers and HIV service providers report confidence in the system's ability to provide access to treatment services, but a concern that local differences in the administration of treatment access programs can limit access to providers that have specialized capacity to address the needs of people living with HIV.
- D. Providers need capacity development and support to explore alternative approaches to care.** HIV service providers and systems planners report the need to develop alternative approaches to providing HIV services, including case management, and chemical health services. Alternative approaches were considered to be needed to for after care or and for those for whom a service based in harm-reduction principles might be more relevant.

Chemical Health – Options for Action – Key Recommendations:

- 1. Provide funding for staff to be trained, certified and to provide Rule 25 assessments.** A priority use for any funds allocated for chemical health services should be provide access to certified Rule 25 assessors, particularly for the Ryan White Program's primary care, early intervention services, medical case management and outreach services providers. Options for organizing such a service might include designating this as part of the responsibility of staff person within one of these programs, or by a group of providers coming together to purchase the service through an "on call" assessor. Additionally, capacity development resources should be

available to support initial and ongoing training and certification for staff within these programs to qualify as Rule 25 assessors.

2. **Re-establish ongoing HIV education and networking support for HIV and chemical health service providers.** There a number of challenges within HIV and chemical health services systems that create barriers for people with HIV who need chemical health services. Among these are staff training and support to either work more sensitively with people living with HIV or to be more effective in working with clients who have chemical health issues, developing policies and procedures that can relieve unnecessary barriers to getting people into treatment, or developing alternatives to treatment programs for helping people living with HIV address chemical health issues. ASAP [the AIDS and Substance Abuse Partnership] was an effective professional network that identified and created solutions within existing systems and services to improve chemical health services for people living with HIV. A combination of substance abuse services capacity development and quality management resources through the Ryan White Program might provide enough leverage to attract additional resources [for example through the DHS Chemical Health Division, a supporter of ASAP's initial development] to revive this valuable and effective professional network.

SECTION VI: PREVENTION WITH POSITIVES SERVICES ASSESSMENT

A. Standards for Care

Three approaches to establishing a framework for standards of care for prevention with positives are shared below to illustrate the lack of consensus about what constitutes standards of care for prevention with positives.

The Centers for Disease Control and Prevention, in its 2004 Advancing HIV Prevention initiative promoted a strategy of preventing primary HIV infections through a four-prong strategy that included (1) making it easier for people infected with HIV to learn their status making screening and testing a part of routine medical care, (2) also making it easier for people infected with HIV to learn their status by expanding screening and testing into field based settings and increasing use of rapid testing, (3) providing education and counseling for persons diagnosed with HIV and their partners with an emphasis on incorporating HIV prevention into medical care, intensive behavior change counseling and support through prevention case management and partner notification and co-testing, and (4) full integration of screening and testing into prenatal care.³⁹

The CDC's initiative was received with resistance and resentment by many leading HIV prevention advocacy groups. Most notably, the National Association of People with AIDS found the initiative to be in substantial conflict with its 14-point Prevention with Positive Principles.⁴⁰ Among the more notable NAPWA standards the initiative failed to satisfy were (a) requiring a central role for HIV-positive people in developing and delivering prevention strategies and services, (b) the recognition that knowledge of serostatus is important, but not enough – it's a first step, but still requires support and skills, (c) recognizing that just like every other population, people living with HIV need a variety of interventions delivered in a variety of settings, (d) that the responsibility for changing behavior is a shared one and not just an obligation of those who are HIV-infected, and (e) that efforts need to both support the process of creating and sustaining behavior change while also supporting the human right to a fulfilling sexual life.

From NAPWA's perspective and that of other HIV prevention advocates, the 2004 CDC initiative ended and abruptly reversed a course that had been established through its PHIPP [Prevention for HIV-Infected Persons Project] of the previous five years that was focused on developing the framework for a national prevention with positives strategy that was more in line with the NAPWA principles.⁴¹

In an effort to establish quality measurement standards for clinical HIV care, the National Committee for Quality Assurance [NQCA] convened representatives from a range of public and private sector organizations that shared an interest in establishing quality standards for HIV clinical care.⁴² Of the six measures accepted by the American Medical Association's Physician Consortium for Performance Improvement for recognition as standards for measuring quality clinical care were:

- Screening for high risk injection drug use, and
- Screening for high risk sexual behaviors.

Of note, the NQCA's expert panel rejected suggestions to incorporate into the quality measurement standards counseling or education or referral to community based HIV risk reduction services into the quality measurement standards.

B. Challenges & Barriers / Discussion

(a) The primary challenges to prevention with positives are structural and are rooted in the lack of consensus and leadership to advance a robust and effective prevention with positives strategy.

(b) They also stem from a diminished role afforded to people living with HIV in shaping, delivering and assessing prevention with positives services.

Summary of Key Findings from Interviews –

Discussion –

(a) Funding structures for HIV prevention and care pose barriers. Federal laws and regulations make it difficult to integrate HIV prevention and care. It is difficult to overcome these restrictions on how federal resources for HIV prevention administered through the CDC and those for HIV care administered through HRSA can be used in order to create well-integrated, prevention with positives services. This problem is further complicated by the multiple core and support service areas within the Ryan White Program structure that touch upon prevention-related activities.

Currently, almost a half million dollars is allocated through the Ryan White Program in Minnesota in three distinct service areas that include prevention as a significant service element. These include health education/risk reduction, emotional support and outreach.⁴³ Additionally, the Minnesota Department of Health [MDH] is required by the CDC to recognize people living with HIV as the top ranked target population in guideline allocation of federal funds for HIV prevention. Currently, MDH allocates approximately \$148,000 annually for services to support individual behavior change interventions including partner notification and counseling and prevention case management.⁴⁴

The total amount of funding available for services that have an impact on prevention with positives is relatively significant. However, the dollars are not allocated in a coordinated manner that providers feel have a targeted or strategic impact. According to interviews with HIV service providers, because the resources are allocated through a variety of different service areas and in relatively small contracts across a range of providers, it is difficult for to develop and sustain services that replicate or adapt effective, research-based intervention models.

Additionally, this approach to funding tends to support small-scaled services, typically with one or fewer full time equivalent staff. Working in relative isolation, prevention with positives program staff do not experience the benefits that come from being able to share tasks with a co-worker and to develop skill and capacity through peer learning. The programs they support suffer in capacity and scale from this relative lack of organizational integration.

(b) People living with HIV seek a more integrated approach to prevention with positives services, and feel they have a role to play. The CDC's Advancing HIV Prevention initiative narrowed the national agenda to focus on prevention as a medical treatment and an individual

behavior change strategy. This focus of significant federal resources on clinic-based or individual behavior change interventions limit efforts to create multi-level range of well-developed and research-supported strategies. When the CDC launched the Advancing HIV Prevention initiative, the agency noted the relatively limited number of prevention with positives models that were research-based and found to be effective in supporting behavior changes, and could not support its own recommendations for clinic-based prevention services or prevention case management with solid research to support their effectiveness.⁴⁵ Notably, HIV service organizations throughout the country, including the National Association of People with AIDS [NAPWA],⁴⁶ raised strong objections to the change in course in providing prevention with positives services the CDC took with the Advancing HIV Prevention initiative. From their perspective, the CDC did not include people living with HIV in a substantive and formative way in developing the initiative and its focus. The approach proposed in the Advancing HIV prevention initiative was not viewed as consistent with a basic premise NAPWA cites in its principles for prevention with positives – which is that people living with HIV should be involved with creating and delivering prevention with positives services.

The interviews conducted as part of this assessment revealed local experiences and opinions to support the concerns expressed by NAPWA and others when the CDC launched Advancing HIV Prevention in 2003. Clinical providers expressed frustration about their efforts to incorporate prevention into the clinic setting. Even those who led efforts to provide training to clinical providers on how to approach HIV prevention in the clinic setting noted that the initial enthusiasm for the effort could not be translated into sustained implementation. The most notable barrier was the many demands that come with addressing primary medical care and the time limitations imposed on clinics to accomplish even accomplish that task. While their experiences suggested there is a role for clinicians to help their patients become aware of prevention issues, an particularly for those who are new to HIV or new to care, and are opportunities to reinforce awareness about prevention and risk-reduction strategies, more was needed. Clinicians cited the need for individual, group and community services outside of the clinic to help their patients learn about risk reduction, incorporate it into their self-care and get peer support to make and sustain changes. That said, those working in the clinic setting did not seem to be familiar enough with prevention with positives services, with either their existence or their quality and reliability to make routine referrals.

Stories from consumers were quite different through the interviews. There were a number of people living with HIV who were engaged in prevention and wellness education and support, both as part of organizations and on their own. They were doing peer counseling, organizing health education activities – formal and informal, using the Web and internet to reach individuals, create communities and share information, and creating social networks to promote and support behavior changes. They were also being called in by clinic staff and other providers to offer information and support as a peer, though typically on an informal basis. People with HIV expressed a strong desire for these peer-based services, but like clinic staff and other providers, also noted that the services were sometimes hard to find and that the quality varied significantly from provider to provider.

A forceful message that came from consumers through the interview process was the need to connect risk-reduction with HIV self-care. In terms of meeting their needs, risk reduction education and skill-development, HIV self-care education and treatment adherence, addressing psychosocial needs and emotional support were all connected. They wanted “prevention with positives” to be a seamless, integrated experience; one that was integral to general, HIV self-care. Additionally, they did not want to feel a sense of competition between the network of providers they relied upon [and that the funding structure tended to create] to provide the many pieces their “prevention with positives care.” They wanted to be able to move comfortably between providers to get their varied needs met.

Finally, prevention with positives brings together two professions and systems – the public health profession that primarily focuses on target populations to establish priorities for how to best use resources, and the health and social services professions that primarily focus on individuals and services [i.e. in the Ryan White “world,” that would be “service areas.” Managing the integration of these two professional systems is challenging, as has been noted above. However, drawing from both public health and the health and social services [or care] systems, it is important to be aware of what *populations* in Minnesota are most in need of prevention with positives *services*:

The need for a different approach to prevention with positives services is evident in how the epidemic is growing in disproportionately affected communities. The large prevalence of HIV, a continuing trend in syphilis infections with notable occurrences among men who are co-infected with HIV and who are in older age groups and substance abuse support a sustained trend in new infections among white men who have sex with men. Social stigma creates closed social networks that are facilitating disproportionately high and increasing infection rates among African American men who have sex with men and Latino men who have sex with men. Almost all of the new infections among young men are among men who have sex with men. Social stigma and cultural norms continue to create higher risk for women of color, particular women in African communities, who have heterosexual relationships.

C. The Ryan White Program as a Resource

Prevention with positives is not a HRSA-designated service activity. But prevention is a significant element of service delivery in health education/risk reduction [HERR], psychosocial support services and outreach services. Each of these services is HRSA-designated support service activities.

HERR includes “provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of 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.” It also includes health education and wellness support provided in a culturally appropriate manner,” as well as “all day special events for consumers focused on health education issues such as, education on HIV and management of the disease including transmission, progression, treatment options, clinical trials, side effects, etc. Also, education focused on remaining healthy and promoting self-care; i.e. how to lead a healthier lifestyle, reduce stress, stop smoking, reduce harm, promote sexual health and reduce risk, and have healthy nutrition.”⁴⁷

Psychosocial support services includes emotional support that offers “support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. It also includes nutrition counseling provided by a non-registered dietitian but excludes the provision of nutritional supplements.” It also includes “emotional support provided in a culturally appropriate manner.”⁴⁸

Outreach services specifically do not include HIV prevention education, but are to be planned and delivered in coordination with local HIV prevention outreach programs and are intended to accomplish case finding to help people living with HIV get into care and treatment, which is inclusive of HERR and psychosocial support services. The services include “programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status 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. These services may target high-risk communities or individuals. Outreach program must be planned and delivered in coordination with local HIV

prevention outreach program 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 individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.”⁴⁹

The Minnesota HIV Services Planning Council approved allocations of \$176,000 for psychosocial support and \$176,000 for health education/risk reduction in 2007 for a total of \$352,000. An additional \$217,000 was allocated for outreach. This suggests an annual investment ranging from \$352,000 to \$569,000 [if outreach is included] for services that incorporate or are closely related to prevention with positives.⁵⁰

Additionally, the Minnesota Department of Health is authorized to allocate \$152,000 annually for prevention with positives services, including \$67,000 for prevention case management targeting HIV-positive men who have sex with men and \$85,000 for partner notification and counseling targeting HIV-positive high risk heterosexuals [primarily African-born women and couples].⁵¹

D. Key Observations and Options for Action

Prevention with Positives – Key Observations:

A. Consumers view prevention to be an integral part HIV self-care and wellness.

Consumers report risk-reduction information to be most useful when it is part of a holistic approach to HIV wellness that combines information about HIV disease management, general health and wellness promotion and risk-reduction, along with peer-influenced learning and support. Consumers look for providers of emotional support, health education, outreach and information and referral services to be able to provide reliable information about risk reduction and opportunities to explore options and problem-solve challenges to sustaining risk reduction behaviors. Consumers express a preference for emotional support and health education services that have clearly-defined beginning and ending points and that are centered on discussions related to HIV wellness. They identified the value of being introduced to role-models [e.g. Hero’s Conference] and to access to anonymous or confidential, individual level services to help them start the process of learning HIV medical and emotional self-care and risk reduction behaviors [e.g. AIDSLine, confidential meetings with other individuals living with HIV].

B. The funding structure poses barriers. Difficulties associated with integrating federal funding for HIV prevention available through the CDC and HIV care available through HRSA make it difficult to develop and sustain prevention with positives service. This problem is further complicated by the multiple core and support service areas within the Ryan White Program structure that touch upon prevention-related activities. Currently, almost a half million dollars is allocated through the Ryan White Program in Minnesota in three distinct service areas that include prevention as a significant service element. An additional \$152,000 is authorized for allocation by the Minnesota Department of Health for prevention with positives services. The total amount of funding available for services that have an impact on prevention with positives is relatively significant. However, the dollars are not allocated in a coordinated manner that providers feel have a targeted or strategic impact. According to interviews with HIV service providers, because the resources are allocated through a variety of different service areas and in relatively small contracts across a range of providers, it is difficult for to develop and sustain services that replicate or adapt effective, research-based intervention models.

- C. **Providers want to learn more about prevention with positives interventions.** Providers report a need for education and technical assistance to develop evidence-based prevention with positives services, particularly services incorporating group, community or multi-level interventions.
- D. **Peer-based service is what consumers want.** Consumers report a desire to promote risk-reduction among peers. They also report a need for training and support for their efforts to provide services to peers. They identify individual, group and Web-based communication to all be effective approaches for providing peer-based learning and support. The role of peers in health education and prevention services added element of emotional support to these services.
- E. **Clinic-based prevention services are not maximized.** HIV medical care providers report limits to the effectiveness of HIV prevention education in medical care settings to be of without other, community-based interventions to influence and sustain behavior change. A notable exception is prevention of mother-to-child transmission, an intervention that is based primarily on medical rather than behavior intervention. Clinicians have expressed an interest in receiving technical assistance to identify and integrate simple, but effective interventions that are appropriate and sustainable in the clinic setting. Additionally, they note people with HIV are open to making behavior changes to reducing transmission risk upon learning of an HIV positive diagnosis. HIV medical care providers report a need to engage peers when promoting HIV wellness and risk-reduction for those clients who are newly diagnosed or new to HIV care. However, they report challenges finding individuals living with HIV who are skilled and experienced at providing peer-based support to participate in this process in a timely manner.

Prevention with Positives – Options for Action – Key Recommendations:

1. **Promote collaborative, integrated service delivery.** Budgeting, administration of the requests for proposal and contract management should encourage service providers to collaborate and deliver multi-level prevention intervention services for people living with HIV that integrate risk reduction and health education, psychosocial support, outreach and referral for health care and support services intended to aid self-care. A strong link with one or more primary care clinics is encouraged to be part of such collaborative efforts in order to promote referrals and coordination of efforts to promote and sustain primary and secondary prevention and wellness.
2. **Expand peer-based service capacity.** Capacity development services should be available to the network of people living with HIV who deliver services through the Ryan White Program. They should focus on developing professional skills and attributes to support delivery of services as peers, balancing professional and HIV self-care to promote retention, and developing skills to support quality management and improvement with an emphasis on including the perspectives of people living with HIV. While this effort should emphasize supporting development of peer-based service capacity in health education/risk reduction, psychosocial support, outreach and referral for health care and support services intended to aid self-care, there would be benefits to opening this opportunity to peer-based providers of other services. This should be a priority for any capacity development funds available to support health education/risk reduction, psychosocial support, outreach and referral for health care and support services.

Providers of Ryan White Program core services, particularly those providing primary care, early intervention and medical case management, indicate the need for peers to help their clients develop strategies for integrating primary and secondary prevention with general HIV self-care. They seek access to individuals living with HIV who have some training to provide peer support of consistent quality, can support introduction and navigation into the care system, and can be routinely accessed. Should short-term resources become available, it would be a worthy investment to develop this service on a pilot basis to assess its feasibility.

Prevention with Positives – Options for Action – Additional Recommendations:

3. **Provide training and capacity development.** Providers want to learn more about effective, research-based interventions and services that have been developed to support prevention with positives. A special effort should be made through quality management and improvement to respond to this interest for all providers, but particularly those who provide health education/risk reduction, psychosocial support, outreach and referral for health care and support services intended to aid self-care. This effort should be coordinated with the Minnesota Department of Health. [Also, see recommendation D, below.] These activities might be considered for support through existing quality management and administrative budgets.

4. **Reconvene the Prevention with Positives Work Group.** The co-chairs of the Minnesota HIV Services Planning Council and CCCHAP [formerly the Commissioners Task Force on HIV/STD Prevention Planning] convened the Prevention with Positives Work Group in 2000 and 2001. The group's work was coordinated by staff from Hennepin County, DHS and MDH. This group should be reconvened for a limited period of time for the purpose of reviewing and updating previous findings and recommendation, and to develop a strategic plan that the two planning groups and the agencies that support their work can use to improve and coordinate investments of public resources to advance prevention with positives initiatives in the state, and that providers can use to develop collaborative, integrated services. While administrative budgets are tight in the agencies responsible for administering the Ryan White Program and HIV prevention funds, the staffing and resources needed to reconvene this group for a limited period of time merit consideration.

SECTION VII: APPENDICIES

A. Interview and Group Meeting Participants

INTERVIEW PROFILE ORAL HEALTH & BEHAVIORAL HEALTH SERVICES ASSESSMENT

Individuals Interviews -		Category (1)	Focus (2)
Ansell,	Andy	Systems Mgr	OH, P+
Bjerke,	Colleen	Provider	OH, MH, CH, P+
Borgus,	Elizabeth	Provider	OH, MH, CH
Caruso,	Gayle	Provider	OH, MH, CH, P+
Ellis,	Howard	Provider	P+
Falkowski,	Carol	Systems Mgr	CH
Frank,	Rae Eden	Provider	MH, CH
Golden,	Peter	Provider	OH, MH, CH, P+
Hamza,	Redwan	Systems Mgr	OH, MH, CH, P+
Hanson Perez,	Julie	Systems Mgr	MH, P+
Hempeck,	Charles	Provider	OH, MH, CH, P+
Henry,	Keith	Provider	OH, MH, CH, P+
Hermes,	Diane	Provider	OH, MH, CH, P+
Houston,	Jennifer	Provider	OH, MH, CH, P+
Huber	James - TA Team	Systems Mgr	OH, MH, CH
Jeske,	Duane	Provider	OH
Kacheroski,	Rob	Consumer	OH, MH, CH, P+
Kroll,	Becky	Systems Mgr	OH, MH, CH, P+
Langworthy,	James	Provider	OH, MH, CH, P+
Lippert,	Lori – TA Team	Systems Mgr	OH, MH, CH, P+
Lyne,	Will	Provider	MH
Marshall,	Judi - TA Team	Systems Mgr	OH
Ness,	Becky	Provider	OH, MH, CH, P+
Novotny,	Gary	Systems Mgr	OH, MH, CH, P+
Nygekundi,	Japhet	Provider	MH, P+
Olander,	Bob	Systems Mgr	CH
Olani,	Ephraim	Provider	OH, MH, CH, P+
Pioli,	Rob	Consumer	OH, MH, CH, P+
Purchase,	Sue	Provider	MH, CH
Ramos,	Elliot	Consumer	OH, MH, CH, P+
Rompa,	Dave	Systems Mgr	OH, MH, CH, P+
Rybicki,	Sarah - TA Team	Systems Mgr	OH, MH, CH, P+
Sabey,	Karin	Provider	OH, MH, CH, P+
St. Marie	Mary	Provider	OH, MH, CH, P+
Strobel,	Cathy	Provider	MH, CH, P+
Tyrrell,	Gerry	Provider	OH, MH, CH, P+
Group Interviews -		Category (1)	Focus (2)
Twin Cities HOPE Advisory Committee		Provider	CH
Planning Council (3)		Systems Mgr	OH, MH
Planning Council - Needs Assessment (3)		Systems Mgr	OH, MH, CH, P+

Individuals Interviews -

Planning Council - Community Voice (3)
RAAN - West Central Regional Group Meeting
RAAN - South Central Regional Group Meeting

Category (1)	Focus (2)
Consumer	OH, MH, CH, P+
Consumer	OH, MH, CH, P+
Consumer	OH, MH, CH, P+

(1) *Category* – Denotes the *primary* perspective the interviewee brought to the process. However, some of the interviewees had experiences allowing them to draw upon two categories for the knowledge and opinions they shared through their interview.

(2) *Focus* - Denotes the focus for the interview, i.e. OH = Oral Health; MH = Mental Health; CH = Chemical Health; P+ = Prevention with Positives.

(3) Periodic meetings were held between May 2007 and May 2008 with the Minnesota HIV Services Planning Council and its Needs Assessment and Evaluation Committee and Community Voice Committee to receive input into service assessment design, to participate in Service Area Review discussions, to conduct group interviews, and to collect input into preliminary findings and recommendations.



SECTION VII: APPENDICIES

B. Schedule of Group Meetings

December 4, 2007

Consumer Input – Minnesota HIV Services Planning Council’s Community Voice Committee.

December 12, 2007

Technical Input – Service Assessment Technical Advisory Team.

January 18, 2008

Provider Input – Providers Retreat.

January 22, 2008

Government Systems Managers Input – Systems Managers Retreat.

January 24, 2008

Consumer Input – Community Forum.

SECTION VII: APPENDICIES

C. Endnotes & Resources

ENDNOTES -

- ¹ New York State Department of Health AIDS Institute, Measuring Clinical Performance: A Guide for HIV Health Care Providers, 2006 New York, New York.
- ² Ibid.
- ³ Ibid.
- ⁴ Ibid.
- ⁵ Ibid.
- ⁶ National Quality Assurance Committee, *HIV Expert Advisors Working Group*, 2007, Washington, D.C.
- ⁷ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ⁸ Minnesota HIV Services Planning Council, *Service Area Review – Oral Health*, 2008, Minneapolis, MN.
- ⁹ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ¹⁰ Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ¹¹ Minnesota HIV Services Planning Council, *Service Area Review – Mental Health*, 2008, Minneapolis, MN.
- ¹² New York State Department of Health AIDS Institute, Measuring Clinical Performance: A Guide for HIV Health Care Providers, 2006 New York, New York.
- ¹³ Ibid.
- ¹⁴ Ibid.
- ¹⁵ Ibid.
- ¹⁶ Ibid.
- ¹⁷ Ibid.
- ¹⁸ Ibid.
- ¹⁹ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ²⁰ Calabash: Learning, Evaluation, Assessment, Research [CLEAR], *HIV Mental Health Report*, Minnesota HIV Services Planning Council, 1999, Minneapolis, MN.
- ²¹ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ²² Calabash: Learning, Evaluation, Assessment, Research [CLEAR], Needs Assessment of HIV Positive Minnesotans, Minnesota HIV Services Planning Council, 2003, Minneapolis, MN.
- ²³ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ²⁴ Minnesota HIV Services Planning Council, *Service Area Review – Mental Health Care*, 2008, Minneapolis, MN.
- ²⁵ Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ²⁶ Minnesota HIV Services Planning Council, *Service Area Review – Mental Health Care*, 2008, Minneapolis, MN.
- ²⁷ Minnesota HIV Services Planning Council, *Service Area Review – Mental Health & Emotional Support*, 2006, Minneapolis, MN.
- ²⁸ Hennepin County Human Services and Public Health Ryan White Program, *Minneapolis-St. Paul TGA Application for 2008 Ryan White Treatment Modernization Act Part A Funding*, November 2007, Minneapolis, MN.
- ²⁹ New York State Department of Health AIDS Institute, Measuring Clinical Performance: A Guide for HIV Health Care Providers, 2006 New York, New York
- ³⁰ Ibid.
- ³¹ Ibid.
- ³² Ibid.
- ³³ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.
- ³⁴ Calabash: Learning, Evaluation, Assessment, Research [CLEAR], Needs Assessment of HIV Positive Minnesotans, Minnesota HIV Services Planning Council, 2003, Minneapolis, MN.
- ³⁵ Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN. Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ³⁶ Thompson, Jennifer, *Assessment of Minnesota AIDS Project's Substance Use Systems Development Program*, Minnesota AIDS Project, February 2004, Minneapolis, MN.
- ³⁷ Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ³⁸ Minnesota HIV Services Planning Council, *Service Area Review – Substance Abuse Services*, 2006, Minneapolis, MN.

-
- ³⁹ Centers for Disease Control and Prevention, “*Advancing HIV Prevention: New Strategies for A Changing Epidemic*,” Morbidity and Mortality Weekly Review, April, 18, 2003, Atlanta, GA.
- ⁴⁰ National Association of People with AIDS, “Principles of Prevention with Positives,” 2003, Washington, D.C.
- ⁴¹ Ibid.
- ⁴² National Quality Assurance Committee, *HIV Expert Advisors Working Group*, 2007, Washington, D.C.
- ⁴³ Minnesota HIV Services Planning Council, 2006-2008 Comprehensive Plan: Ryan White Care Act Title I – Minneapolis/St. Paul Eligible Metropolitan Area, December, 2005, Minneapolis, MN.
- ⁴⁴ Minnesota Department of Health, Comprehensive HIV Prevention Plan 2006 – 2008: Revised 2007, 2007, Saint Paul, MN.
- ⁴⁵ Centers for Disease Control and Prevention, “*Advancing HIV Prevention: New Strategies for A Changing Epidemic*,” Morbidity and Mortality Weekly Review, April, 18, 2003, Atlanta, GA. Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ⁴⁶ National Association of People with AIDS, “Principles of Prevention with Positives,” 2003, Washington, D.C.
- ⁴⁷ Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.
- ⁴⁸ Ibid.
- ⁴⁹ Ibid.
- ⁵⁰ Hennepin County Human Services and Public Health Ryan White Program, *Minneapolis-St. Paul TGA Application for 2008 Ryan White Treatment Modernization Act Part A Funding*, November 2007, Minneapolis, MN.
- ⁵¹ Minnesota Department of Health, Minnesota Comprehensive HIV Prevention Plan 2006-2008 – Updated 2007, 2007, Saint Paul, MN.

RESOURCES –

Calabash: Learning, Evaluation, Assessment, Research [CLEAR], Needs Assessment of HIV Positive Minnesotans, Minnesota HIV Services Planning Council, 2003, Minneapolis, MN.

Centers for Disease Control and Prevention, “*Advancing HIV Prevention: New Strategies for A Changing Epidemic*,” Morbidity and Mortality Weekly Review, April, 18, 2003, Atlanta, GA. Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.

Hennepin County Human Services and Public Health Ryan White Program, *Minneapolis-St. Paul TGA Application for 2008 Ryan White Treatment Modernization Act Part A Funding*, November 2007, Minneapolis, MN.

Minnesota Department of Health, Minnesota Comprehensive HIV Prevention Plan 2006-2008 – Updated 2007, 2007, Saint Paul, MN.

Minnesota HIV Services Planning Council, *Service Area Reviews*, 2005, 2006, 2007 and 2008, Minneapolis, MN.

Minnesota HIV Services Planning Council, 2006-2008 Comprehensive Plan: Ryan White Care Act Title I – Minneapolis/St. Paul Eligible Metropolitan Area, December, 2005, Minneapolis, MN.

Minnesota HIV Services Planning Council, *Ryan White Program Services Definitions*, 2007, Minneapolis, MN.

National Association of People with AIDS, “Principles of Prevention with Positives,” 2003, Washington, D.C.

New York State Department of Health AIDS Institute, Measuring Clinical Performance: A Guide for HIV Health Care Providers, 2006, New York, New York.

Positive Outcomes, Inc. and Community Consulting Group, LLC, *Assessing the Needs of Minnesotans Living With HIV or AIDS: Results of a Community Survey*, Minnesota HIV Services Planning Council, August, 2006, Minneapolis, MN.

Thompson, Jennifer, *Assessment of Minnesota AIDS Project’s Substance Use Systems Development Program*, Minnesota AIDS Project, February 2004, Minneapolis, MN.