

CONTINUUM OF PREVENTION AND CARE

**An Integrated Model of
HIV Prevention and Care
in the State of Minnesota**

**Minnesota HIV Services Planning Council
Commissioner's Task Force on HIV/STD Prevention Planning**

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EXECUTIVE SUMMARY

THE MINNESOTA HIV SERVICES PLANNING COUNCIL AND HIV CARE SERVICES

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is a federally funded program designed to provide health and support services to people living with HIV disease and AIDS (PLWH/A). The Minnesota HIV Services Planning Council (Planning Council) is the planning body which has responsibility for setting funding priorities for the use of Ryan White Title I & II funds as well as ensuring PLWH/A have access to needed services that are delivered within a planned and coordinated system.

The Planning and Priorities Committee is one of several committees of the Planning Council. The Planning and Priorities Committee is charged with developing and guiding the priority setting process and recommending funding allocations for Planning Council review and approval. This committee also has responsibility for long-range planning activities.

The Planning and Priorities Committee, through a series of efforts, has supported the development of a system of services for individuals and families with HIV infection in order to meet their service needs throughout all stages of illness. The model is one which is organized to respond to changing individual or family needs in a holistic, coordinated and timely manner, thus reducing fragmentation of care. The model is one that offers a “seamless” service delivery system for PLWH/A.

THE COMMISSIONER'S TASK FORCE ON HIV/STD PREVENTION PLANNING AND HIV PREVENTION SERVICES

The Commissioner's Task Force on HIV/STD Prevention Planning (Task Force) is the planning body that has responsibility for prioritizing the use of HIV prevention funds received from the state of Minnesota and from the Centers for Disease Control and Prevention (CDC). They are charged with determining which populations in Minnesota are most at risk for HIV infection or transmission, and for identifying the prevention interventions that would be most effective within each of the populations most at risk.

At the time this document was developed, the Prioritization Committee was one of several committees of the Task Force. The Prioritization Committee was responsible for developing recommendations as to which target populations are most at risk, and which interventions would be most effective based on research and community input. They developed and guided the priority setting process used by the full Task Force. This committee also had the responsibility of shepherding the process to integrate prevention into the Continuum of Prevention and Care.

THE CONTINUUM OF PREVENTION AND CARE

The Continuum of Prevention and Care was developed in several stages. It began in 1999 when the Planning Council developed the Continuum of Care as a model of the ideal system of care and support that should be available PLWH/A in Minnesota.

In 2002, a joint planning effort between the Planning Council and the Task Force was undertaken to identify the links between prevention and care services. The first recommendation that emerged out of this effort was to integrate prevention services into the Continuum of Care.

Based on the recommendation, the Task Force did the initial work to integrate prevention services into the existing continuum. A group made up of members from both the Planning Council and the Task Force then met to review the changes and develop this integrated document. Finally, the Continuum of Prevention and Care was presented to both the Planning Council and Task Force for approval and adoption.

The Continuum of Prevention and Care described in this document attempts to identify all essential, support and access services that might be needed to prevent HIV infection and to support individuals during the various states of HIV disease. The two planning bodies sought to identify a set of essential services (herein referred to as “essential care and prevention services”) that comprise those activities that are necessary to provide adequate care for HIV and those activities necessary to prevent HIV infection. This set of essential care and prevention services is not limited by the resources directly prioritized by the Planning Council and Task Force, but includes services and strategies to link services that are currently in place.

The many barriers and challenges to accessing HIV prevention and care services are well known and well documented. The Continuum of Prevention and Care model recognizes that many, if not most, at-risk individuals and/or PLWH/A will have difficulty getting to and using either essential care and prevention services or additional services without the assistance of one or more access services. Because the importance of these access services cannot be overstated, they are referred to as “essential access services.” While not all at-risk individuals and/or PLWH/A will need essential access services, for those who face barriers the availability of the essential access service can make the difference between adequate and inadequate services, or worse, not getting care at all.

The committee also identified services that are critical adjuncts to providing HIV prevention and care, here called “HIV additional services.” These activities provide stability and support to PLWH/A, general community and at-risk individuals and thereby increase the effectiveness of the essential care and prevention services.

The Planning Council and the Task Force invite you to share your feedback about the Continuum of Prevention and Care. You can do so by contacting:

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INTRODUCTION

The Continuum of Prevention and Care is a model of an ideal HIV services delivery system that is responsive to the needs of the general population, at-risk individuals and people living with HIV and AIDS (PLWH/A), throughout the state and across time, while efficiently utilizing resources. Developing this model for use as a long-range planning tool is a critical element of the work of the Minnesota HIV Services Planning Council (Planning Council) and the Commissioner's Task Force on HIV/STD Prevention Planning (Task Force) and will guide the further development of Minnesota's HIV prevention and care service system.

HISTORY OF HIV CARE IN MINNESOTA

It is helpful to understand the influences and history that paved the way for the work done by the Planning Council and Task Force in developing the Continuum of Prevention and Care. In 1985, the Minnesota Department of Human Services (DHS) began to utilize administrative funds from the Minnesota Medicaid program to fund HIV case management services. Also in 1985, the Minnesota Legislature allocated state funds to be administered through DHS for the purpose of continuing health insurance policies for low income PLWH/A who were in danger of losing their private health insurance. This funding continues today.

The DHS also receives state general fund allocations each year for HIV case management services. State funding is used within case management programs to increase access to cost effective health care services, reduce the risk of HIV transmission, ensure that basic client needs are met, and increase client access to needed community supports or services.

Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990. Minnesota began receiving funds under Title II of the Act in 1991. Title II funds are used to provide care services to PLWH/A throughout the state. Originally at the Minnesota Department of Health (MDH), grantee responsibilities for Title II switched to DHS in April 2002. Title I provides emergency assistance to areas that have been hit hardest by the HIV epidemic. These areas are called eligible metropolitan areas (EMAs) and are usually cities or counties. Minnesota received its Title I grant in 1996 after 2,000 cumulative AIDS cases were reported. Hennepin County Community Health Department (CHD) is the federal grantee for the Title I funds. (For further information about the CARE Act, see Appendix A.)

A federal requirement for EMAs receiving Title I funds is to establish a community based planning body to conduct needs assessments, identify and prioritize service needs, allocate funds to service areas, and monitor the administrative work of the CARE Act grantees. Although the requirement only pertains to Title I funds – Title II has its own set of guidelines related to planning – the State of Minnesota and CHD, the Title I grantee, chose to create a single, coordinated, statewide planning process by collaboratively working with a single community planning body. Thus, the Planning Council has planning responsibilities for the Twin Cities metropolitan area and the whole of Minnesota.

OVERVIEW OF THE PLANNING COUNCIL

The Planning Council was formed in 1995 when Minneapolis / St. Paul received notice that the metropolitan area had become eligible to receive Title I funds from the Ryan White CARE Act. The

Minneapolis/St. Paul EMA consists of 13 counties; Anoka, Carver, Chisago, Dakota, Hennepin, Isanti, Pierce, Ramsey, St. Croix, Scott, Sherburne, Washington and Wright (Pierce and St. Croix counties are in Wisconsin). Minnesota also receives Title II funds, which are targeted at the entire state.

Title I and Title II grantees worked cooperatively to establish the Planning Council. In December of 1995, the first members of the Minnesota HIV Services Planning Council were appointed and the first meeting was held. Since that time the Planning Council has been self-governing, using funds allowable under the grants for administration. The 2003 - 2004 budget period is the eighth year that the Planning Council has been in existence and prioritizing the funds. The Planning Council prioritized \$4,346,840 in Title I and Title II dollars for FY 2003.

The purpose of the Planning Council is to:

- Establish priorities for the allocation of Title I and Title II funds of the CARE Act within the 13 county EMA and the state of Minnesota. The Planning Council is responsible for deciding which [care] services are the most needed for PLWH/A and how much funding will be used for each of those [care] service areas.
- Develop a comprehensive [care] service plan for the Minneapolis / St. Paul EMA and the state of Minnesota.
- Assure community participation in the gathering of information related to needs assessment and service priorities.
- Assess the efficiency of the system the Title I and Title II grantees (Hennepin County Community Health Department and Minnesota Department of Human Services, respectively) use to distribute funds.
- Representatives of the Planning Council must participate in the development of the Statewide Coordinated Statement of Need in conjunction with representatives from all other CARE Act Titles funded in Minnesota.

Planning Council Statement of Vision

The vision of the Minnesota HIV Services Planning Council is to extend and improve the quality of life for PLWH/A in an accessible, fair, compassionate, flexible and efficient manner regardless of age, gender, culture, sexual orientation and means of transmission. This will be addressed through:

- Developing an effective system for assessing current and emerging need;
- Establishing funding priorities;
- Building the capacity of all health and social service providers;
- Responding comprehensively through the coordination of prevention, HIV health and support services, and housing;
- Advocating when appropriate for HIV-related issues in the metropolitan area and the State of Minnesota.

The vision statement of the Planning Council will be used to:

- Help members, groups, and individuals understand the work of the Planning Council;
- Help the Planning Council when establishing funding priorities; and
- Help service providers when competing for funding support.

Planning Council Statement of Values

In carrying out the work of the Minnesota HIV Services Planning Council, its members strive to:

- Conduct business in ways that are honest, respectful of diversity, compassionate, hopeful and nonjudgmental.
- Make decisions that are responsive, innovative and proactive and take into consideration the work of service providers in assisting the Planning Council in fulfilling its mission.
- Implement strategies that are comprehensive, integrated, accessible, responsible, accountable and realistic.
- **Planning Council Members are committed to building a coordinated continuum of care for PLWH/A.**

Planning Council values will be used to:

- Help Planning Council members, groups, and individuals understand the values of the Planning Council;
- Help the Planning Council when establishing funding priorities; and
- Help service providers when competing for funding support.

HISTORY OF HIV PREVENTION IN MINNESOTA

The Minnesota Department of Health (MDH) has been involved in the HIV epidemic since the first cases were reported in the United States in 1981. In 1985 specific funding was requested and received from the Legislative Advisory Committee. 1985 was also the year when the federal Centers for Disease Control and Prevention (CDC) established cooperative agreements with state health departments to establish alternative HIV Counseling and Testing sites.

Since 1985 a mix of federal and state funds has been made available to the MDH to implement a statewide continuum of HIV prevention activities, including:

- HIV surveillance
- HIV testing and counseling
- HIV partner counseling and referral services
- Targeted health education and risk reduction programs
- Public information and media activities
- Planning and evaluation activities

While the bulk of HIV prevention activities in Minnesota are supported through CDC and state funds made available by the MDH, the CDC and other federal agencies also provide a small portion of funds for targeted interventions, evaluation, and research directly to community based organizations. Local public health agencies, and private foundations also support some HIV prevention services in Minnesota.

The MDH has always sought community involvement in planning statewide HIV prevention programs. The first Commissioner's Task Force on AIDS developed a statewide AIDS plan in 1985. In 1993, however, the CDC established HIV prevention community planning as an eligibility requirement for federal HIV prevention funds. HIV prevention community planning places the responsibility for determining the most effective use of HIV prevention funds at the local level.

OVERVIEW OF THE TASK FORCE

In 1993, the Centers for Disease Prevention and Control (CDC) developed the HIV Prevention Community Planning Guidance to assist states in planning for HIV prevention services. The Task Force was established in 1994. The Task Force is responsible for determining which populations in Minnesota are most at risk for becoming infected with or transmitting HIV, and for identifying the prevention interventions that will be most effective in reducing or eliminating HIV infection or transmission in each of those populations.

The primary responsibility of the Task Force is to develop a comprehensive HIV prevention plan that includes prioritized target populations and prevention activities/interventions. The comprehensive HIV prevention plan is required to include the following components:

1. *Epidemiological Profile:* Assesses and describes the extent, distribution, and impact of HIV/AIDS in defined populations in the community, as well as relevant risk behaviors. This provides the foundation for prioritizing target populations.
2. *Community Services Assessment:* Describes the prevention needs of populations at risk for HIV infection, the prevention activities/interventions that have been implemented to address these needs, and gaps in prevention services that have been identified.
3. *Prioritized Target Populations:* Target populations are identified and prioritized through the use of the epidemiological profile and community services assessment that require prevention efforts due to high rates of HIV infection and high incidence of risky behaviors.
4. *Appropriate Science-based Prevention Activities/Interventions:* A set of prevention activities/interventions that are necessary to reduce transmission and infection in prioritized target populations are identified based on intervention effectiveness and culturally appropriateness.
5. *Letter of Concurrence/Concurrence with Reservations/Non-concurrence:* Describes whether the Task Force believes that the activities proposed in the health department's prevention grant application do or do not, and to what degree, match the priorities set forth in the comprehensive HIV prevention plan.

Task Force Vision Statement

The vision of the Task Force is to design a comprehensive and humanistic program promoting healthy communities free from HIV/STD transmission for all Minnesotans with specific emphasis on those at greatest risk through:

- removing barriers to HIV/STD prevention;
- advocating for system change;
- community input;
- representation and collaboration;
- encouraging behaviors that help people reduce their risk;
- prevention education, including culturally specific sexual health education;
- personal commitment;
- improving access to services; and
- empowering communities

with the benefit that Minnesotans will live longer and healthier lives due to shared community response and ownership.

Task Force Values

The Task Force values are:

Realness	Integrity	Respect	Diversity
Passion	Collaboration	Faith/Trust	Service

Shared Vision Statement for the Planning Council and Task Force

In 2003, the Planning Council and Task Force developed a joint vision statement that reflects the spirit that has driven the development of the Continuum of Prevention and Care:

The Planning Council and Task Force share a common vision of a coordinated, comprehensive system of HIV prevention and care planning for the state of Minnesota.

DEVELOPMENT OF THE CONTINUUM OF PREVENTION AND CARE

The Continuum of Prevention and Care was developed in several stages. Originally, the document was called the Continuum of Care, and was developed in 1999 by the Planning Council via a process guided by the Planning and Priorities Committee. The Planning and Priorities Committee is one of several committees of the Planning Council. The Planning and Priorities Committee is charged with developing and guiding the priority setting process and recommending funding allocations for Planning Council review and approval. The committee also has responsibility for long-range planning activities.

Several community partners joined with the Planning and Priorities Committee to develop this model (see acknowledgements). Planning Council members, service consumers and service providers participated in the process through public forums, reviewing drafts, providing information and giving feedback. The Continuum of Care model was first adopted by the full Planning Council in November 1999. The Planning and Priorities Committee went through an in-depth process in 2001 - 2002 to review and update the Continuum of Care. The revised version was adopted in September 2002.

The Continuum of Care model developed by the Planning Council describes the care service needs for PLWH/A as those needs evolve in relation to a person's health status or "disease state." The five states of illness include:

- Undiagnosed infection
- Recently diagnosed
- Stable illness
- Progressive illness
- End of life

Across each of the five states of illness, the model identifies desired outcomes, essential services ("essential care and prevention services"), services that support access to the service continuum ("essential access services") and ancillary services ("HIV additional services").

In 2002, a joint planning effort between the Planning Council and the Task Force was undertaken to identify the links between prevention and care services. This effort was called the Linkages Workgroup. The first recommendation that emerged out of the Linkages Workgroup was to integrate prevention services into the Continuum of Care.

The initial step was to add two “states” prior to the five states of disease in the continuum. These were “general community” and “at-risk individuals.” Given that these two new categories do not fit within the label of “disease states,” it was recommended that, for consistency’s sake, the continuum address three populations: the general community, at-risk individuals and PLWH/A. To further describe the PLWH/A population, HIV disease is broken down into the five disease states in order to better define the service needs of this population.

At two meetings in early 2002, the full Task Force worked in small groups to identify prevention services that are needed by people throughout the continuum, whether they are HIV positive or HIV negative, within the categories of essential care and prevention services, essential access services, and HIV additional services. The Task Force also identified the short, intermediate, and ultimate outcomes desired for each of the populations in relation to prevention.

At the time of the development of this document, the Prioritization Committee was one of several committees of the Task Force. The Prioritization Committee was responsible for developing recommendations as to which target populations are most at risk for HIV infection or transmission, and which interventions would be most effective based on research and community input. They developed and guided the priority setting process used by the full Task Force. This committee also had the responsibility of shepherding the process to integrate prevention into the Continuum of Prevention and Care.

In the spring of 2003, members of the Planning and Priorities Committee of the Planning Council met with members of the Prioritization Committee of the Task Force. They jointly reviewed a draft of the Continuum of Prevention and Care, clarified how both the prevention and care components fit together, and made revisions as needed. The final integrated document was then brought forward to the Planning Council in October 2003 and the Task Force in November 2003. The Continuum of Prevention and Care was approved by both planning bodies.

For a much more in-depth description of the process used to develop and revise the Continuum of Prevention and Care, please refer to Appendix B.

DEFINITION OF THE CONTINUUM OF PREVENTION AND CARE

The Continuum of Prevention and Care is a model for comprehensively thinking about HIV services for the general community, at-risk individuals and PLWH/A across populations and across the various states of HIV disease. The model attempts to: 1) identify the array of prevention services needed in order to increase awareness of HIV, and support the general population, at-risk individuals, and PLWH/A in maintaining safe behaviors; and 2) identify the full battery of care services that need to be available throughout the state of Minnesota to support PLWH/A to attain their highest quality of life.

While the Planning Council only has authority to direct the use of CARE Act funds, and the Task Force only has the authority to prioritize the use of state and CDC HIV prevention funds, the Continuum of Prevention and Care model includes a comprehensive menu of HIV prevention and care services, regardless of possible sources of funding for those services.

In developing a statewide system of HIV prevention and care the Planning Council and Task Force must continually seek to answer three basic questions:

1. What would an ideal service model include?
2. What elements of that ideal already exist?
3. How do we move towards realizing this ideal system?

The Continuum of Prevention and Care is an attempt to answer the first question.

The Continuum of Prevention and Care is conceived of as a planning tool for the Planning Council and Task Force in developing a statewide system of HIV prevention and care. As part of that work, the Continuum of Prevention and Care is one of many pieces of information that is used by the two planning bodies in their prioritization and gap analysis processes. The Planning Council's priority setting process occurs biannually. The Task Force conducts priority setting every three years. Thus, while not a prescription for funding decisions, it is hoped that the Continuum of Prevention and Care will exert a positive influence on the quality of prevention and care services available to Minnesotans, both those living with HIV and those at risk for infection. The Continuum of Prevention and Care can also be used by the Planning Council, Task Force, government, HIV advocates, and other policy-making entities in doing long-range HIV planning for the state.

The Continuum of Prevention and Care includes all HIV-specific prevention and care services, including those that are not currently funded through the CARE Act, state care or prevention dollars, or CDC prevention funds, or are not eligible for funding through those sources. Such services are essential to the care and support of PLWH/A, and to supporting prevention efforts in the state. It is important to recognize that the CARE Act, state dollars, and CDC funds represent only several possible sources of funding for care and prevention services. It is essential that planning for CARE Act, state, and CDC funding is done in consideration of and in coordination with each other and with services funded through other mechanisms. These services can help identify opportunities for collaboration with service organizations outside of the current AIDS community and help the Planning Council and Task Force avoid a duplication of effort in funding decisions.

ELEMENTS OF THE CONTINUUM OF PREVENTION AND CARE MODEL

The first part of this section provides a narrative description of the various elements of the Continuum of Prevention and Care model. The Continuum of Prevention and Care Chart, on pages 13 - 19, enhances the narrative description by providing the information in a succinct format. In addition, the Continuum of Prevention and Care Flowchart on page 20 provides a visual representation of how all the elements of the Continuum of Prevention and Care fit together. Please note, however, that it was not possible to include all of the information pertaining to each element in the flowchart.

POPULATIONS

The Continuum of Prevention and Care model is developed as an ideal service delivery model that addresses the needs of three populations: general community, at-risk individuals, and PLWH/A. This model assumes that the needs of these three populations overlap in some areas and are quite different in others.

A. General Community

The general community includes everyone in the state of Minnesota. The service needs of this population are primarily related to general information and awareness about HIV. The intent is to provide information so that everyone in the state knows how to protect themselves and others with whom they interact from becoming infected with HIV. Another purpose of reaching the general community is to reduce fear, stigma and discrimination related to HIV by providing accurate and thorough information, education, and promoting discussion in appropriate venues.

B. At-risk Individuals

At-risk individuals are those who are at high risk for becoming infected with HIV based on a number of factors, including risk behaviors of self and partner(s); co-morbidities such as mental health issues, substance use, domestic abuse, etc.; socioeconomic status; and barriers to receiving prevention messages. While there is a need for general community awareness among at-risk individuals, the service needs of this population are more in-depth, may be longer-term, and often are related to other issues in their lives that affect their ability to engage in safe behavior. The focus of prevention services for this population is to give people tools to help them in maintaining safe behavior, and in addressing issues that make it difficult to do so.

C. People Living with HIV/AIDS

PLWH/A are individuals living with HIV disease or AIDS. This population is further described by states of disease that people move through as part of the progression of HIV disease. The service needs of this population have been identified based on which state of the disease an individual is in. The service needs of this population are related to both prevention and care.

DISEASE STATES

The Continuum of Prevention and Care model is built upon the concept of different states of HIV disease. The basic assumption of the model is that the needs and experiences of individuals are not the same at all points of living with the disease. Rather, the model assumes that there are certain identifiable states of HIV disease and that these various states each trigger their own sets of related needs. Thus, the model generalizes to the common experiences of many people with the same physical manifestations of the disease.

Another important element of the model design to understand is that although the model is called a “continuum” it is not assumed that people will pass through each state, nor that they will pass linearly through each state. People will jump into the model at different states. They may skip states entirely. They may cycle through one or more states repeatedly.

For the purposes of this model the five disease states are defined as follows:

A. Undiagnosed Infection

In this state the HIV positive person’s infection is undiagnosed. There is no formal HIV care strategy and the person may or may not be seeking medical care. Denial, avoidance, suspicion, and awareness of risk are characteristics that may be displayed. Some people may suspect that they have HIV and they may be taking steps to prepare themselves for being tested. Some people may actually be seeking medical care for HIV-related symptoms, but the possibility of HIV infection is overlooked by the medical provider. There is a danger that the undiagnosed person will continue to engage in risky behaviors that may lead to increased health complications for the individual and the potential for infecting someone else. New clinical tests and treatment options indicate that the earlier in the disease that one begins medical care, the better the chances are for successful management of the disease. This state of the disease calls for greater collaboration between HIV prevention efforts, HIV community service providers, and medical providers. Such collaboration would increase the number of potential points of entry whereby a PLWH/A can enter HIV services.

B. Recently Diagnosed

This is the state of HIV disease immediately following one’s diagnosis of HIV infection. This state also includes people who may have been diagnosed some time ago but are just entering the HIV service system. Most people upon being diagnosed with HIV go through a period of emotional upheaval, and often an interruption of their usual routines. Anger, grief, fear, confusion and denial are common emotional reactions. The emotional impact of a recent diagnosis may increase high-risk behavior. Some move through this state quickly while others take longer. The recently diagnosed state can, and does, occur at any point in the physical progression of HIV. Some people are diagnosed within weeks of infection; others may not know they have HIV until they are gravely ill with the disease. For purposes of this model, it is important to understand that the needs associated with this state occur in conjunction with the needs of any other state a person is in (i.e., stable illness or end of life). Although the characteristics of this state are most significant with a person’s initial HIV diagnosis, they may also be triggered by subsequent diagnosis, such as progressing from HIV to having AIDS or being diagnosed with a particular opportunistic infection.

C. Stable Illness

With the success of HIV treatments developed over the last few years, PLWH/A are living with longer periods of relatively good health and, in some cases, are recovering from periods of acute illness and interruption of daily functioning to enjoy a period of renewed health stability. However, this stability comes at a cost; HIV care treatments are complex and difficult to manage and maintain over long periods of time. The treatments themselves often have unpleasant and sometimes dangerous side effects. Thus, the stable illness state is marked by an established HIV diagnosis and controlled disease progression as indicated by managed values from measurement tests such as CD4 counts and viral load tests. The PLWH/A is likely to have established a care strategy and that person usually has some knowledge of the disease and the treatment options. Common illnesses may occur but they are generally manageable. Side effects of medications are a common problem. During this state, while there is an impact on the person's ability to function in usual life activities, the impact is usually manageable. The person in this state is likely to be capable of a high degree of self-care. The PLWH/A in this state may return to engaging in sexual activity and may struggle with long-term behavior change and risk reduction.

D. Progressive Illness

Some PLWH/A go through a period where the disease is difficult to control and their health status deteriorates. For some people this may happen because HIV treatments are not successful from the start. Others may have a long period of stable, managed illness, before the treatments "fail." Others may have chosen not to utilize HIV treatments earlier. Still others may not be diagnosed until they have already progressed to this state. In this state the person experiences HIV-related or AIDS-defining illnesses. The diagnostic values are progressively worsening. Life activities are impaired to a greater degree and the person's ability for self-care is challenged. These changes may trigger mental health and/or emotional support needs, which may in turn impact an individual's ability to maintain risk reduction strategies. The care strategy usually changes at this point to address emerging health issues.

E. End of Life

When advanced complications from HIV and/or AIDS-defining illnesses are experienced, the complications continue to escalate and recovery is unlikely, a PLWH/A enters the end of life state of the disease. The diagnostic values worsen and there are few treatment options available. In this state the PLWH/A is severely impaired in his/her ability to perform normal life activities and virtually incapable of self-care. At this point the focus of the care strategy may change from treatment to symptom relief and palliative care. The PLWH/A is faced with issues common to the end of life (spiritual, emotional support, physical care needs and family/social interactions).

Each disease state's defining characteristics were considered in this attempt to delineate what constitutes the passage from one state to the next for PLWH/A. It is somewhat difficult to determine when an individual moves from one state of illness to another and while some people will move sequentially through the five states of disease, others may move back and forth through the five states of the disease.

OUTCOMES

The outcomes for each disease state represent desired goals for each person living with the disease. Although the outcomes may be different in each of the disease states, the common thread is to maintain and improve a person's quality of care and quality of life. In addition to the outcomes developed for PLWH/A, outcomes have also been developed as desired goals for the general population and at-risk individuals, with the overall theme of uninfected individuals remaining uninfected.

SERVICE CATEGORIES

The Continuum of Prevention and Care model organizes services into three categories. Clearly, the general community, at-risk individuals and PLWH/A struggle with an array of needs, many times related to issues beyond HIV; however, the model focuses on service needs specific to HIV-infection that are likely to be needed. The three service categories are as follows:

A. Essential Care and Prevention Services

Essential care and prevention services are those that are considered essential services necessary to address prevention and care needs. The model assumes that essential prevention services should be available to the general community, at-risk individuals and PLWH/A across the state. The model also assumes that *at a minimum*, all Minnesotans living with HIV need the essential care services in order to receive adequate HIV care.

B. Essential Access Services

Essential access services help people get access to HIV care, support and prevention services. Because some people would never receive essential care or prevention services or HIV additional services without the assistance provided through essential access services, this model assumes that access services are essential services for people who otherwise experience barriers to service.

C. HIV Additional Services

HIV additional services are ancillary or “wrap-around” in supporting care and prevention needs of PLWH/A, and behavior change needs of the general population and at-risk individuals. The model assumes that these services are needed to provide full support to people. The number and types of secondary issues that an individual experiences will drive the array of HIV additional services that person needs to manage his or her illness and/or prevention efforts.

Essential prevention services address the basic HIV prevention needs of each population throughout the continuum. These services include, but are not limited to community awareness, public policy advocacy, comprehensive sexual education, sexual health promotion, prevention case management, partner counseling and referral services, health education and risk reduction, syringe distribution, substance use services, and mental health services. Essential care services address the basic needs of PLWH/A. These services include medical care, dental care, prescription drug services, medication adherence support, substance use services, mental health services, health education and risk reduction, emotional support, nutritional services, legal services, medically-based housing, and support services for affected individuals and caregivers.

Essential access services allow the general population, at-risk individuals and PLWH/A to address informational, geographic, financial, social and other barriers to accessing medical care, prevention, and support services. These include outreach, counseling and testing, care case management, care advocacy, discharge planning, interpretation/translation, health insurance, housing access and support, transportation, benefits counseling, information and referral, and child care. Essential access services are provided by a variety of organizations including governmental agencies, community based organizations and AIDS service organizations.

HIV additional services support the health care, HIV prevention, and social needs of PLWH/A. They also provide support for reducing risk behaviors in the general community and at-risk populations. These services include adult day care; complementary care; clinical trials; legal services; funeral arrangements; vocational rehabilitation; emergency financial assistance; nutritional services; dental care; mental health services; support services for affected individuals and caregivers; training targeting providers, physicians, and volunteers to build capacity for prevention and care; and domestic abuse services.

Many types of HIV additional services are provided through state and local departments of social services, health employment, development and rehabilitation, mental health, and regional centers for person with developmental disabilities. Other services, due to their particular nature, are provided by a variety of organizations, including community based AIDS service organizations and volunteers.

DESCRIPTION OF SERVICES

The Continuum of Prevention and Care model identifies the services that are essential for meeting the needs of the general community, at-risk individuals, and PLWH/A, including the basic HIV-related needs of HIV-infected individuals in each state of HIV disease. It is important to note that services may fall under essential care and prevention services or essential access services in one population or state of disease and under HIV additional services in another. This occurs when a service is considered to be essential to meeting the needs that arise in one population or disease state, while the same service plays more of a supportive role in meeting the needs experienced in another population or disease state.

All of the services are described in the Glossary (Appendix C). It is important to refer to the full description of each service as the terms used may be more encompassing than the usage of the term familiar to the reader. For example, the term “emotional support,” as used in this model, encompasses emotional and spiritual support. It also recognizes that there are several different models for providing emotional support, such as: informal/social relationships, support groups facilitated by non-licensed or peer counselors, and networks of caring professionals volunteering their time.

CONTINUUM OF PREVENTION AND CARE CHART

GENERAL COMMUNITY

POPULATIONS AND OUTCOMES	
Defining Characteristics	<p>May not have information about HIV disease, risks, or transmission</p> <p>May have inaccurate information about HIV disease, risks, or transmission</p> <p>May have biases, phobias, and prejudices</p> <p>May not be interested in or care about HIV</p> <p>Influence resource allocation through involvement in the political process</p> <p>Provide volunteer resources in a variety of settings and systems</p> <p>Very diverse population</p>
Ultimate Outcomes	<p>Reduce fear, stigma, discrimination, and internalized oppression in order to create a supportive environment for HIV prevention and for persons living with HIV</p> <p>Everyone is aware of their HIV risk and status. Referral into prevention programs for high-risk negatives (see At-Risk), and initiation of care strategy for people who test positive (see Undiagnosed and Recently Diagnosed)</p> <p>Uninfected individuals remain uninfected</p> <p>Increased awareness of risk</p> <p>Informed and healthy sexual life</p> <p>Consistent use of safer sex and needle use and exchange practices</p> <p>Everyone takes responsibility for reducing HIV infections</p> <p>Increased utilization of services</p>
Intermediate Outcomes	<p>Increased access to services, education and information</p> <p>Increased awareness of how individuals can get involved in prevention/care</p> <p>Recognize impact of HIV on health care system</p>
Short Term Outcomes	<p>Increased knowledge of HIV disease, HIV transmission, HIV testing, epi data and trends, sexual health, risk groups, perceived risk, and resources available</p>

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<p>Information and Referral</p> <p>Interpretation/Translation</p> <p>Culturally Appropriate Materials</p> <p>Counseling, Testing and Referral</p> <p>Community Awareness</p> <p>Screening and Treatment of STDs and Hep A, B, C</p>
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ESSENTIAL PREVENTION SERVICES

Service Needs	<p>Counseling, Testing and Referral</p> <p>Community Awareness</p> <p>Public Policy Advocacy</p> <p>Comprehensive Sexual Education (K-12)</p> <p>Sexual Health Promotion</p> <p>HIV Screening for Pregnant Women</p>
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HIV ADDITIONAL SERVICES

Additional Service Needs	<p>Training for Providers</p> <p>Training for Physicians</p> <p>Training for Volunteers</p> <p>Health Education & Risk Reduction</p> <p>Housing Access and Support Services</p>
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AT-RISK INDIVIDUALS

POPULATIONS AND OUTCOMES

Defining Characteristics	<p>Are not HIV positive, but engage in behaviors that present risk of HIV infection</p> <p>May have awareness of risk and experience denial, or are willing to take some degree of risk</p> <p>May be unaware of risk or risk behaviors</p> <p>May lack information and education on disease and transmission</p> <p>May experience issues related to mental health, substance abuse, domestic abuse, homelessness, institutionalized racism, homophobia, or other co-factors</p>
Ultimate Outcomes	<p>Everyone is aware of their HIV risk and status</p> <p>Early detection of HIV infection. Referral into prevention programs for high-risk negatives (see At-Risk), and initiation of care strategy for people who test positive (see Undiagnosed and Recently Diagnosed)</p> <p>Uninfected individuals remain uninfected</p> <p>Informed and healthy sexual life</p> <p>Consistent use of safer sex and needle use and exchange practices</p> <p>Increased access to and utilization of services</p>
Intermediate Outcomes	<p>Increased knowledge about HIV risk and potential characteristics of HIV infection</p> <p>Increased access to HIV testing</p>
Short Term Outcomes	<p>Increase knowledge among health care and social service providers and at-risk individuals</p> <p>Develop risk reduction strategies for at-risk individuals</p> <p>Connect at-risk individuals to prevention services and counseling and testing</p>

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<p>Information and Referral</p> <p>Interpretation/Translation</p> <p>Outreach</p> <p>Health Insurance</p> <p>Transportation</p> <p>Child Care</p>
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ESSENTIAL PREVENTION SERVICES

Service Needs	<p>Screening and Treatment for STDs and Hep A, B, C</p> <p>Counseling, Testing and Referral</p> <p>Partner Counseling and Referral Services</p> <p>Health Education & Risk Reduction</p> <p>Prevention Case Management</p> <p>Sexual Health Promotion</p> <p>Substance Use Services</p> <p>Mental Health Services</p> <p>Community Awareness</p> <p>Post Exposure Prophylaxis</p> <p>HIV Screening for Pregnant Women</p> <p>Syringe Distribution</p>
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HIV ADDITIONAL SERVICES

Additional Service Needs	<p>Domestic Abuse Services</p> <p>Training for Providers</p> <p>Housing Access and Support</p>
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PLWHA - UNDIAGNOSED INFECTION

This is a subset of the general community and at-risk populations

POPULATIONS AND OUTCOMES

Defining Characteristics	<ul style="list-style-type: none"> HIV infection and status undiagnosed May experience non-specific flu-like symptoms May experience opportunistic infection May experience sores or changes in the mouth May experience no symptoms May or may not seek medical care No formal HIV care strategy May have awareness of risk and experience denial, avoidance, and suspicion May be a time of strengthening in preparation for testing
Ultimate Outcomes	<ul style="list-style-type: none"> Early detection of HIV infection and initiation of care and prevention strategy Informed and healthy sexual life Consistent use of safer sex and needle use and exchange practices
Intermediate Outcome	<ul style="list-style-type: none"> Establish knowledge about HIV status and potential characteristics of HIV infection
Short Term Outcomes	<ul style="list-style-type: none"> Increase knowledge among providers and undiagnosed individuals Develop risk reduction strategies and coping capabilities for undiagnosed individuals Connect undiagnosed individuals to counseling and testing, and referrals into care and prevention services

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<ul style="list-style-type: none"> Health Insurance Information and Referral Interpretation/Translation Outreach Community Awareness 	<ul style="list-style-type: none"> Child Care Transportation
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ESSENTIAL CARE AND PREVENTION SERVICES

Service Needs	<ul style="list-style-type: none"> Medical Care Training of Providers Counseling, Testing and Referral Health Education & Risk Reduction Partner Counseling and Referral Services Prevention Case Management HIV Screening for Pregnant Women Screening and Treatment for STDs and Hep A, B, C 	<ul style="list-style-type: none"> Sexual Health Promotion Mental Health Services Substance Use Services Training of Physicians
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HIV ADDITIONAL SERVICES

Additional Service Needs	<ul style="list-style-type: none"> Housing Support & Access
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POINTS OF ENTRY

Typical Points of Entry for this state may include, but are not limited to:	<ul style="list-style-type: none"> Substance abuse treatment Correctional facilities Mental health treatment facilities Etc.
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PLWHA - RECENTLY DIAGNOSED

It is recognized that when a person is diagnosed, s/he will fall into one of the other states of HIV disease progression based on how healthy s/he is at the time of diagnosis. The services listed here are suggested as meeting the specific needs of a newly diagnosed person, but s/he also falls into another disease state and may need any of the services listed under that state.

POPULATIONS AND OUTCOMES

Defining Characteristics	HIV or AIDS infection has been diagnosed Person is newly diagnosed or new to HIV/AIDS care May experience no symptoms No HIV/AIDS care strategy is in place Can have characteristics of another disease state Person has not integrated HIV into his/her life; e.g., emotional, medical aspects May have little knowledge about HIV/AIDS
Ultimate Outcomes	Integration of HIV/AIDS into health care and daily living Informed and healthy sexual life Consistent use of safer sex and needle use and exchange practices
Intermediate Outcomes	Begin care strategy Establish coping capacities; e.g., spiritual, emotional, risk reduction Increase knowledge about HIV/AIDS care and prevention
Short Term Outcomes	Secure short-term intervention and medical care Establish ongoing medical and dental care Identify resources to pay for medical and dental care Establish professional and non-professional social and emotional supports Development of an individualized HIV risk reduction intervention plan

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<ul style="list-style-type: none"> Health Insurance Information and Referral Case Management Care Advocacy Benefits Counseling Partner Counseling and Referral Services Housing Access and Support Services 	<ul style="list-style-type: none"> Discharge Planning Child Care Outreach Transportation Community Awareness Interpretation/Translation
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ESSENTIAL CARE AND PREVENTION SERVICES

Service Needs	<ul style="list-style-type: none"> Medical Care Prescription Drugs Emotional Support Mental Health Services Substance Use Services Support Services for Affected Individuals and Care Givers Sexual Health Promotion Prevention Case Management Health Education & Risk Reduction
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HIV ADDITIONAL SERVICES

Additional Service Needs	<ul style="list-style-type: none"> Dental Care Legal Services Vocational Rehab Training to Prevention and Care Providers Emergency Financial Assistance Clinical Trials
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PLWHA – STABLE ILLNESS

POPULATIONS AND OUTCOMES

Defining Characteristics	<p>Has HIV or AIDS diagnosis</p> <p>CD4 counts and viral load are stable</p> <p>Established care strategy (e.g., HAART, complementary, no antivirals, monitoring of CD4 counts and viral loads) is in place and is informed by greater knowledge of disease and treatment options</p> <p>May experience common illnesses and/or treatment side effects</p> <p>May experience oral infections</p> <p>Impact of HIV/AIDS on life activities is manageable</p> <p>Little or no physical or cognitive impairment</p> <p>Person is able to care for him/her self</p>
Ultimate Outcomes	<p>Independent management of HIV/AIDS' impact on health and daily living</p> <p>Maintain independent functioning</p> <p>Informed and healthy sexual life</p> <p>Consistent use of safer sex and needle use and exchange practices</p>
Intermediate Outcomes	<p>Maintain or improve health</p> <p>Maintain risk reduction strategies</p> <p>Achieve daily living adjustments (e.g., vocational, occupational)</p>
Short Term Outcomes	<p>Establish care strategy and capacity to manage side effects of treatment</p> <p>Increase knowledge about access to care and prevention resources</p> <p>Increase knowledge and skills related to HIV transmission and prevention strategies</p> <p>Development of an individualized HIV risk reduction intervention plan</p>

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<p>Information and Referral</p> <p>Health Insurance</p> <p>Case Management</p> <p>Transportation</p> <p>Care Advocacy</p> <p>Housing Access and Support Services</p>	<p>Sexual Health Promotion</p> <p>Outreach</p> <p>Child Care</p> <p>Discharge Planning</p> <p>Interpretation/Translation</p> <p>Benefits Counseling</p>
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ESSENTIAL CARE AND PREVENTION SERVICES

Service Needs	<p>Medical Care</p> <p>Medication Adherence Support</p> <p>Mental Health</p> <p>Health Education & Risk Reduction</p> <p>Prescription Drugs</p> <p>Prevention Case Management</p>	<p>Dental Care</p> <p>Substance Use Services</p> <p>Emotional Support</p>
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HIV ADDITIONAL SERVICES

Additional Service Needs	<p>Complementary Care</p> <p>Nutritional Services</p> <p>Legal Services</p> <p>Vocational Rehabilitation</p> <p>Emergency Financial Assistance</p> <p>Support Services for Affected Individuals and Care Givers</p> <p>Training to Prevention and Care Providers</p> <p>Community Awareness</p> <p>Clinical Trials</p>
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PLWH/A - PROGRESSIVE ILLNESS

POPULATIONS AND OUTCOMES

Defining Characteristics	<ul style="list-style-type: none"> Has HIV or AIDS diagnosis CD4 counts and viral load are problematic, unstable Changing care strategy (e.g., HAART, complementary, no antivirals, monitoring of CD4 counts and viral loads) Experiences HIV-related or AIDS-defining illnesses Changing health status may trigger mental health and/or emotional support needs Person may be willing to try experimental or extraordinary care measures Illness impairs life activities Limitations on capacity for self care
Ultimate Outcomes	<ul style="list-style-type: none"> Stabilize health Maximize quality of life Informed and healthy sexual life Consistent use of safer sex and needle use and exchange practices
Intermediate Outcomes	<ul style="list-style-type: none"> Achieve medical adjustments that stabilize health Achieve daily living adjustments Achieve psychological and coping adjustments Maintain risk reduction strategies
Short Term Outcomes	<ul style="list-style-type: none"> End of life needs assessed and planned for Revise and intensify care and prevention strategies Resource planning Increase use and coordination of medical and social services Development of individualized HIV risk reduction intervention plan

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<ul style="list-style-type: none"> Information and Referral Health Insurance Case Management Benefits Counseling Transportation Interpretation/Translation 	<ul style="list-style-type: none"> Child Care Housing Access and Support Care Advocacy Discharge Planning
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ESSENTIAL CARE AND PREVENTION SERVICES

Service Needs	<ul style="list-style-type: none"> Medical Care Dental Care Medically-based Housing Services Mental Health Medication Adherence Support Prescription Drugs Emotional Support Nutritional Services Health Education & Risk Reduction 	<ul style="list-style-type: none"> Rehabilitation Prevention Case Management Sexual Health Promotion Substance Use Services
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HIV ADDITIONAL SERVICES

Additional Service Needs	<ul style="list-style-type: none"> Clinical Trials Complementary Care Legal Services Adult Day Care Support Services for Affected Individuals and Care Givers
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PLWH/A - END OF LIFE

POPULATIONS AND OUTCOMES

Defining Characteristics	<p>AIDS diagnosis</p> <p>CD4 counts and viral load are problematic</p> <p>Changing care strategy. Limited HIV/AIDS treatment options are available</p> <p>Experiences advanced HIV-related complications and/or AIDS defining illnesses</p> <p>Illness significantly or completely impairs life activities</p> <p>Person may be willing to try experimental or extraordinary care measures</p> <p>Focus of care can change</p> <p>End of life issues (spiritual, emotional support, physical, family/social)</p>
Ultimate Outcomes	<p>A good (peaceful, planned) death</p> <p>Relieve pain and health symptoms</p> <p>Maximize individual's control over the end of his/her life</p> <p>Revert back to stable or progressive state</p>
Intermediate Outcomes	<p>Adequate pain and symptom control</p> <p>Individual is emotionally prepared for death</p> <p>Individual's practical/financial/legal matters are taken care of before death</p> <p>Daily living activities and care transfer to others</p>
Short Term Outcome	<p>Assess need for individualized HIV risk reduction intervention plan</p>

All services delivered in a culturally appropriate manner with culturally appropriate materials

ESSENTIAL ACCESS SERVICES

Access Needs	<p>Health Insurance</p> <p>Information and Referral</p> <p>Transportation</p> <p>Housing Access and Support</p> <p>Interpretation/Translation</p> <p>Case Management</p>
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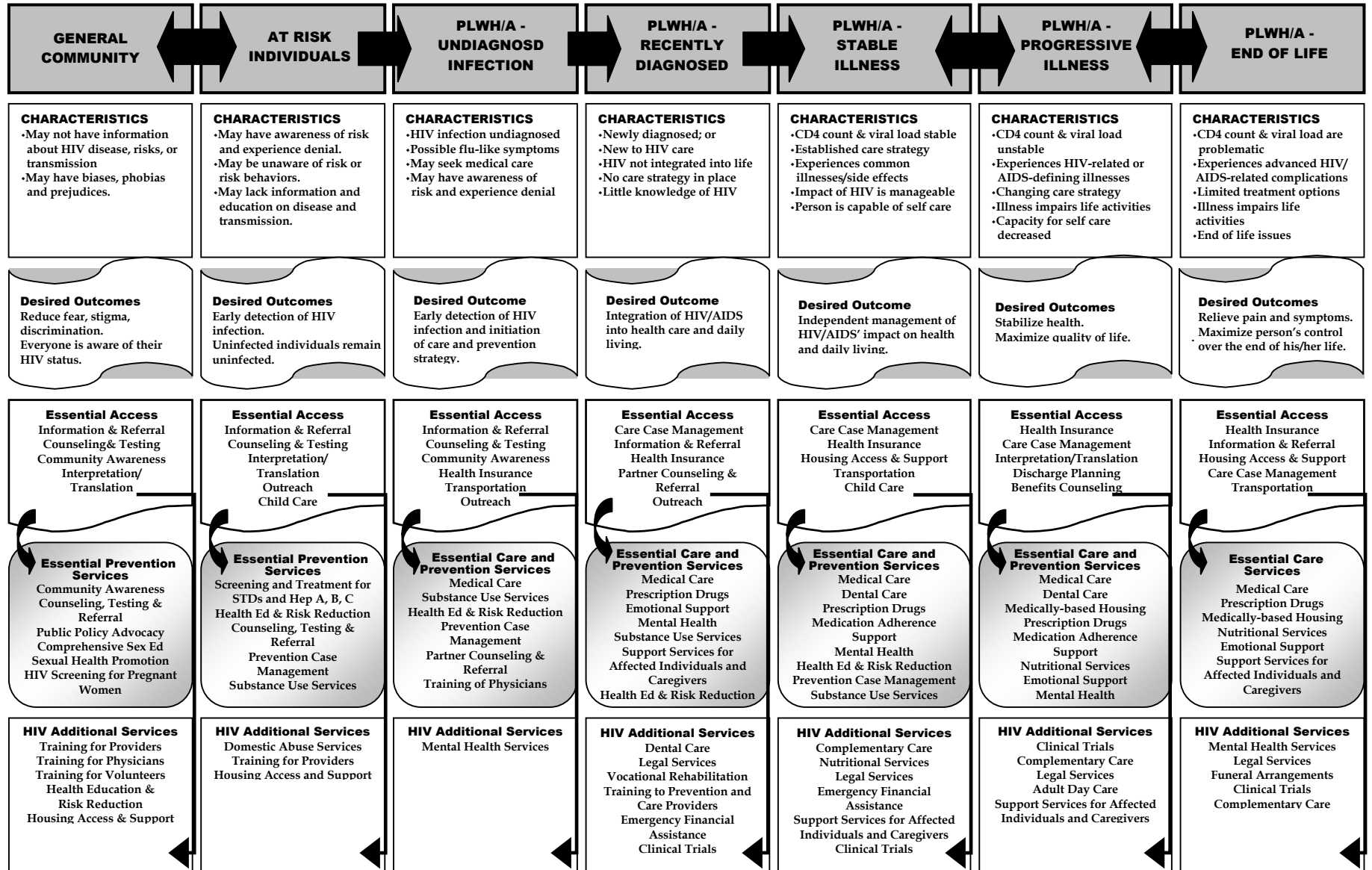
ESSENTIAL CARE SERVICES

Service Needs	<p>Prescription Drugs</p> <p>Medically-based Housing Services</p> <p>Medical Care</p> <p>Nutritional Services</p> <p>Emotional Support</p> <p>Support Services for Affected Individuals and Care Givers</p>
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HIV ADDITIONAL SERVICES

Additional Service Needs	<p>Mental Health Services</p> <p>Legal Services</p> <p>Funeral Arrangements</p> <p>Clinical Trials</p> <p>Complementary Care</p>
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CONTINUUM OF PREVENTION AND CARE FLOWCHART



NOTE: Due to insufficient space, this flowchart does not contain a complete listing of all services described in the Continuum of Prevention and Care

FACTORS POTENTIALLY AFFECTING ACCESS TO SERVICE

The Continuum of Prevention and Care model lays out prevention needs of the general community and at-risk individuals, and the care and prevention needs of PLWH/A as triggered by different states of the disease. Critical to understanding this model is that while the broad categories of service are common to most people within each of the three populations, not all people's needs are met in the same way. Thus the design of the specific services within each category of service must be responsive to the needs of all.

This is not to say that each service provider needs to design their service to equally serve all people. Some providers may be particularly adept at serving one or two target populations. However, for the ideal continuum of care to be realized, all people with “factors that potentially affect access to service” (i.e., race/ethnicity, gender, age, economic status, sexual orientation, immigration status, physical disabilities, etc.) need to be equally served somewhere in the system. That is, as a totality, the services provided in this model need to meet the needs of people in the general community, all individuals at-risk, and all PLWH/A.

All care and prevention services should be delivered in a manner that is culturally appropriate to the population being served. Materials used should also be appropriate and understandable to the population. Appropriateness of services and materials may be defined by characteristics of consumers such as race/ethnicity, country of birth, gender, age, sexual orientation, immigration status, religion, socioeconomic status, level of education, etc.

This model is built upon the premise that all PLWH/A should have access to the essential care and prevention services listed in the model. It also assumes that the essential prevention services will be available to the general community, individuals most at-risk, and PLWH/A. People with barriers to service should be able to receive essential access services. If, for example, people in some parts of the state do not have access to HIV specialty medical care, Minnesota is failing in its goal of achieving this model.

As another example, if women are accessing HIV medications in numbers disproportionately low compared to their representation in the epidemic, we need to look at the structure of the service to evaluate whether there are ways to deliver it that would provide equal accessibility to women. The model gives us the ideal for which to strive and a yardstick against which to measure our success in meeting the needs of the general community, at-risk individuals and PLWH/A.

Following is a list of the various factors that potentially affect a person's access to services:

Demographic Attributes:

- Age
- Gender
- Race/Ethnicity
- Culture
- Language
- Sexual Orientation
- Marital Status
- Family Status
- Dependent Children

HIV Transmission Risk:

- Intravenous Drug Use
- Commercial Sex Work
- Survival Sex
- Sexual Behavior
- Substance Use
- Chronic and Persistent Mental Illness
- HIV Status Undisclosed

Socio-Economic Factors:

- Income
- Education
- Homelessness
- Literacy
- Insured/Non-insured

Other Factors:

- Religion
- Geography
- Immigration Status
- Information Access
- Other Illnesses
- Fear of Disclosure
- Degree of Acculturation
- Access to Services
- Urban/rural
- Availability of Service
- Language
- Technology
- Travel
- Incarceration
- Migrant Farm Work

FUNDED PREVENTION AND CARE SERVICES

The following table describes the funding sources currently being used in Minnesota to support the care and prevention services in the Continuum of Prevention and Care.

PREVENTION AND CARE SERVICES	FUNDING SOURCE						
	State and CDC HIV Prevention Dollars	CARE Act Title I/II	ADAP	State HIV Care Dollars	CARE Act Title III	CARE Act Title IV	Other Funding
Adult Day Health Care							X
Benefits Counseling		X					
Care Advocacy		X					X
Care Case Management		X		X	X	X	
Child Care		X					X
Clinical Trials							X
Community Awareness	X				X		
Complementary Care		X					
Comprehensive Sex Education							X
Counseling, Testing & Referral	X				X		X
Dental Care		X			X		X
Discharge Planning							
Domestic Abuse Services							X
Emergency Financial Assistance		X					X
Emotional Support	X	X					
Funeral Arrangements							
Health Ed & Risk Reduction	X	X			X	X	
Health Insurance			X	X			
HIV Screening Pregnant Women							X
Housing Access and Support		X					X
Information and Referral	X	X					
Interpretation & Translation		X			X		X
Legal Services		X			X		
Medically-based Housing		X					X
Medical Care		X			X	X	X
Medication Adherence			X		X		
Mental Health		X			X		X
Nutritional Services		X			X		
Outreach	X	X			X	X	
Partner Counseling & Referral	X				X		
Post Exposure Prophylaxis							
Prescription Drugs			X		X		
Prevention Case Management	X						

PREVENTION AND CARE SERVICES	FUNDING SOURCE						
	State and CDC HIV Prevention Dollars	CARE Act Title I/II	ADAP	State HIV Care Dollars	CARE Act Title III	CARE Act Title IV	Other Funding
Public Policy Advocacy							X
Screening/Treatment of STDs					X		X
Sexual Health Promotion	X						
Substance Use Services		X			X		X
Support for Affected/Caregivers		X					X
Syringe Distribution							X
Training	X	X			X		
Transportation		X					
Vocational Rehabilitation							X

CONCLUSIONS

The Continuum of Prevention and Care model looks at populations, and within the population of PLWH/A, at the states of the HIV disease. It is intended to identify all essential and support services that might be needed for each population and during the various states of HIV disease. The Planning and Priorities Committee of the Planning Council and the Prioritization Committee of the Task Force sought to develop a set of essential services that should be available to all persons in Minnesota living with HIV. This set of essential services is not limited by the resources directly available to the Planning Council and Task Force, but includes a set of services and strategies to link services that are currently in place. Although HIV seems to change rapidly over time, the hope of the Planning and Priorities Committee and the Prioritization Committee is that the Continuum of Prevention and Care responds to the changing dynamics of the illness and factors that put people at risk for infection.

The health, well-being and quality of life of all Minnesotans, and particularly PLWH/A, are directly affected by the continuum of prevention and care available to them. While every individual may not need all the services identified in the continuum, every effort must be made to ensure that these services are available when needed.

OVERVIEW OF THE RYAN WHITE CARE ACT AND TITLES

The Ryan White Comprehensive AIDS Resources Emergency Act (usually called the Ryan White CARE Act, or the CARE Act) is a Federal law that was first passed by Congress in 1990. Congress passed it again in 1996 and 2000, each time with some new requirements. The CARE Act will be up for reauthorization again in 2005. The CARE Act provides Federal government funds that are used to develop systems of care and to pay for medical and social support services for people living with HIV disease and their families. The CARE Act identifies who can receive this money and describes how the money can be used.

The CARE Act mandates that each state and Title I eligible metropolitan area have a community and provider based planning process whereby the affected communities are responsible for directing use of the federal funds and overseeing the administration provided by the federal grantees. In Minnesota these functions are carried out for both the Title I and Title II funds by the Minnesota HIV Services Planning Council.

Title I: Emergency Relief to Eligible Metropolitan Areas

Title I funds go to metropolitan areas that have been hardest hit by the HIV epidemic, as defined by federal guidelines. They are usually cities or counties and called eligible metropolitan areas (EMAs).

Title I funds can be used for HIV outpatient health and support services, case management, and comprehensive treatment services. The funds can also be used for case management services in hospitals. Title I funds cannot be used to replace existing local/state funds or be used to pay for services which can be covered through other sources.

Title II: Support to States

Title II funds go to all states, the District of Columbia, Puerto Rico and some territories.

Title II funds can be used for medical and social support services, home care services, continuation of health insurance coverage and to purchase medications used to treat HIV.

Title II grant includes specific subset of funds referred to as the AIDS Drug Assistance Program (ADAP) dollars. ADAP funds can only be used to pay for HIV-related medications, health insurance for PLWH/A, as well as services that enable individuals to gain access to drugs, support adherence to medication regimens, and services to monitor progress in taking HIV-related medications.

Title III: Community Based Programs

Title III funds go to public and private non-profit primary care providers. The funds can be used for outpatient HIV early intervention; substance use and primary care services.

Title IV: Children, Youth, and Women with HIV Disease and Their Families

Title IV funds go to public and private non-profit entities. The funds can be used to provide medical and social services for women, children and youth and access to research.

Part F: SPNS, AETC, Dental Reimbursement

Special Projects of National Significance (SPNS)

SPNS funds go to organizations that are creating new and better ways to serve people living with HIV.

AIDS Education and Training Centers (AETCs)

AETC funds go to training centers to educate doctors, nurses and other health professionals about HIV and current treatments.

Dental Reimbursement Program

Dental Reimbursement funds go to dental schools to help pay for dental care for people living with HIV.

The Planning Council is only responsible for establishing priorities for the allocation of Title I and II funds. Minnesota receives funding from all titles.

DEVELOPMENT OF THE CONTINUUM OF PREVENTION AND CARE

Initial development of the original Continuum of Care of 1999 by the Planning Council included five data collection activities. The collection of information was carried out over a six-month period beginning in March 1999. The Planning and Priorities Committee felt that it was essential to hear from various public contingents about their needs and concerns related to the care that is currently being provided for PLWH/A. The information, which was pieced together from a variety of sources, allowed the Planning and Priorities Committee to construct a realistic picture of the kind of care needed through the states of the illness based on projected service needs.

The data collection process included five activities.

1. Recruiting community partners representing broad HIV expertise to participate in the development of the model.
2. Reviewing available data from existing reports.
3. Surveying other cities from around the country to learn from their experience in developing their Continuum of Care models.
4. Community dialogue.
5. Reporting the work of the Planning Council back to the community for feedback before finalizing the model.

A. Recruitment of Community Partners

People with areas of expertise in different areas of HIV were recruited to join with the Planning and Priorities Committee in developing this model. Their participation was sought to increase the representation of various communities and to expand and enhance the discussion. This effort yielded participation by persons with expertise in serving PLWH/A outside the Twin Cities metropolitan area, providing medical services to PLWH/A, as well as the expertise of PLWH/A, including persons of color. In addition to the expertise of the regular members of the Planning and Priorities Committee, this group of new recruits brought a total of many years of experience of living with and serving PLWH/A.

B. Review of Existing Reports

The original Continuum of Care was built upon reviewing the existing work of the Planning Council. By reviewing previous reports, the Planning and Priorities Committee was reminded of the service needs of the various populations of PLWH/A in Minnesota. The following reports were reviewed:

- Minnesota HIV Services Consumer Survey, 1998
(*Consumers were asked how they felt about services they were receiving.*)
- HIV Services Needs Assessment Report 1996
(*A comprehensive assessment of the service needs of PLWH/A.*)

- Black HIV/AIDS Services Needs Assessment July, 1998
(A yearlong needs assessment project that sought services information from HIV positive Africans & African Americans living in the Twin Cities metropolitan area.)
- Focus Group reports April 25-26, 1997
(Findings from a focus group held at the 1997 HIV Positive Retreat. Participants were asked for feedback regarding the Planning Council's planning & priority setting activities.)
- Report on HIV Services Public Workshops in Greater Minnesota - June & July 1998
(Summary of feedback from participants who identified rural needs, barriers & solutions.)
- 1998 Comprehensive Plan
(A document that highlights the changing trends of the HIV epidemic.)
- Title I & II Application for CARE Act Funding
(The applications provided information about existing services, populations served and populations with special needs.)
- Statewide Coordinated Statement of Need 1997-1998
(A statement that was jointly developed for the State of Minnesota by the Ryan White Title I & II CARE Act grantees, as well as representatives from all other titles of the CARE Act funded in Minnesota.)
- HIV Mental Health Report March, 1999
(A report which explains the historic under spending of mental health funds and provides direction for meeting mental health needs in the future.)

C. Survey of Other Eligible Metropolitan Areas

The Planning and Priorities Committee also wanted to look at how other cities in the U.S. had approached developing a continuum of care. Twelve cities that receive CARE Act Title I funds responded to a targeted survey sent out by the Committee. (Refer to Appendix D for a copy of the survey.)

The responses were reviewed for their classifications of service, types of activities, ease of rating tools, graphic illustration, and patterns of need identified. The Riverside / San Bernardino model was most favored for its graphic illustration and patterns of need identified and became a model for Minnesota's Continuum of Care.

D. Engaging in a Community Dialogue

In reviewing the studies and assessments previously conducted by the Planning Council, the Planning and Priorities Committee felt that the one major area that had yet to be explored in depth was HIV specialty medical care. At the same time, the Health Resources Services Administration (HRSA), the federal agency responsible for administration of the CARE Act, has been directing states and EMAs to focus CARE Act funds on services to ensure that PLWH/A have access to medical care and HIV therapies. Thus, the committee, as part of the process of developing the Continuum of Care, chose to hold public hearings addressing the issues of access to and quality of medical care.

The Planning and Priorities Committee held five public hearings from April to June 1999. The objective of the hearings was to understand the strengths and weaknesses of medical care for PLWH/A in Minnesota. The comments gathered during these public hearings are included in Appendices E, F, and G.

E. Reporting Back To The Community

In September, the final public forum was held in Minneapolis at the Aliveness Project. The purpose of the forum was to report back to the community on the preliminary development of the Continuum of Care model and to engage the community in a dialogue about the strengths and limitations of the model.

F. Review and Update of the Continuum of Care

When the Continuum of Care was first developed in 1999, the Planning and Priorities Committee decided to review and revise it in two years. In 2001, the Planning and Priorities Committee began the process of reviewing the Continuum of Care. Based on a recommendation from the Linkages Workgroup, a joint ad hoc effort between the Planning Council and Task Force to identify areas for overlap between prevention and care, one of the committee's first decisions was to work with the Task Force to revise the model so that prevention services would be integrated with care services into the continuum.

The initial work toward integrating prevention into the soon-to-be re-named Continuum of Prevention and Care was undertaken by the Task Force. The first step was to recommend the addition of two "states" prior to the five states of disease in the continuum (undiagnosed, recently diagnosed, stable illness, progressive illness, end of life). The "states" added by the Task Force were "general community" and "at-risk individuals."

At two meetings in early 2002, the full Task Force worked in small groups to identify prevention services that are needed by people throughout the continuum, whether they are HIV positive or HIV negative, within the categories of essential care and prevention services, essential access services, and HIV additional services. The Task Force also identified the short, intermediate, and ultimate outcomes desired for each of the populations in relation to prevention.

After this initial work was completed by the full Task Force, the Prioritization Committee of the Task Force took on the responsibility of shepherding the process to integrate prevention into the Continuum of Prevention and Care.

While the Task Force was working on integrating prevention into the model, the Priorities and Planning Committee followed a multi-step review process:

Step One: After the Continuum of Care was adopted, it was presented at community forums for discussion. The first step of the 2001 review process was to review the comments made during those forums.

Step Two: The next steps of the process involved reviewing the document itself. First, the committee looked at ways in which the language could be simplified and clarified with the following results:

- Terms were changed to reduce confusion (for example, “HIV plus services” was changed to “HIV additional services”).
- Related services were grouped together under one umbrella term rather than being listed in specific detail (for example, home-delivered meals, on-site meals, food shelf, and nutritional supplements were all grouped together under a service category called “nutritional services”). All individual components are still listed under the umbrella term in the Glossary (Appendix C).
- Distinctions between non-HIV and HIV services were eliminated (for example “HIV medical care” and “non-HIV medical care” were combined under the name “medical care”).

Step Three: Next categories were reviewed to see if anything should be added or eliminated. Nothing was eliminated (though items were combined, as described above). Three services were added:

- Clinical trials
- Prescription drugs
- Support services for affected individuals

Step Four: The Planning and Priorities Committee then reviewed services according to state of disease to see if these categories were still relevant and accurate given changes in the epidemic over the last two years. In conjunction with the work of the Task Force the “states” were revised as follows.

- “General community” was added to the start of the continuum to address the prevention needs of the population at large, regardless of HIV status.
- The disease state called “undiagnosed/at-risk/acute infection” in the original version was changed to be two states: “at-risk individuals” and “undiagnosed.” This was done to acknowledge the fact that many people remain undiagnosed long after the acute infection state. The undiagnosed state is viewed as a subset of the general community and at-risk individuals. Typical points of entry for people in this state may include, but are not limited to: substance abuse treatment centers, correctional facilities, mental health treatment facilities, etc.
- The “chronic” state was changed to “stable illness.” This was done to reduce confusion since the term “chronic” has a specific meaning in reference to long-term, manageable diseases.
- It was recognized that general community and at-risk individuals do not fit under the heading of “states of disease.” It was recommended by the Task Force that the Continuum of Prevention and Care consider three populations: general community, at-risk individuals, and PLWH/A. Within the PLWH/A population, there are five states of disease: undiagnosed, recently diagnosed, stable illness, progressive illness, and end of life, which better help define the services needed throughout the course of the disease.

Step Five: Once the populations and disease states had been revised, the committee reviewed the services listed within each state of disease and the classification of each of those services in terms of being access, core or HIV additional services. Some services were added to certain states because the committee felt that they had been left out in the earlier version by oversight, not because the needs in any disease state had changed significantly. Some

services were moved between categories to better reflect the current thinking of the committee.

- “Substance abuse services” was moved from HIV additional services to core services. In the assessment of the committee, the abuse of drugs and alcohol negates or works against the efficacy of other HIV care and, thus, treating substance abuse is an essential service in providing adequate care.
- “Mental health services” was also moved from HIV additional services to core services. A person with mental illness who is not receiving mental health services is not receiving adequate HIV care.
- “Housing access and support” was moved from HIV additional services to access services as the committee considered having adequate housing to be a pre-cursor to being able to access health and support services.

In the spring of 2003, members of the Planning and Priorities Committee of the Planning Council met with members of the Prioritization Committee of the Task Force. They jointly reviewed a draft of the Continuum of Prevention and Care, clarified how both the prevention and care components fit together, and made revisions as needed.

The major revision that occurred during the joint meetings was a change in the names of the services categories. “Core services” became “essential care and prevention services.” “Access services” became “essential access services.” “HIV additional services” remained the same. This was done to clarify that what were previously called “access” and “core” services are both essential.

The final integrated document was then brought forward to the Planning Council in October 2003 and the Task Force in November 2003. The Continuum of Prevention and Care was approved by both planning bodies.

G. Review of Recent Reports

The Continuum of Prevention and Care continues to be based on the research studies commissioned by the Planning Council and by the Comprehensive Minnesota HIV Prevention Plan. The Planning & Priorities Committee scheduled several meetings to review and discuss recent studies related to local issues. They are:

- Minnesota HIV Services Consumer Satisfaction Survey, 2002
- Voices of Latinos: An In-depth Study of the Health Needs and Issues of Latinos Living with HIV in Minnesota, 2000
- HIV Comprehensive Needs Assessment Report, 2000
- Gender Analysis of HIV Comprehensive Needs Assessment, 2000
- HIV Services GAP Analysis of Greater Minnesota, 2000
- Fighting Twin Epidemics: Substance Abuse and HIV, 2000
- Overview of HIV Service Needs of Women and Children in Minnesota, 2000
- Statewide Coordinated Statement of Need, 2001
- HIV Medical Care in Minnesota According to HIVQUAL2: A Baseline Study of Quality of Care in Minnesota, 2002
- An Assessment of Uncompensated HIV Health Care, 2002

GLOSSARY OF PREVENTION AND CARE SERVICES

Adult Day Health Care

HIV Additional

Adult day health care centers enhance quality of life, promote independence, and minimize the incidence of hospitalization and institutionalization. Adult day health care is a structured program that often provides skilled nursing care (including medication adherence support), psychosocial support, complementary therapies, nutrition, assistance with daily living activities, and collaborative treatment planning with physicians and case managers.

Benefits Counseling

Essential Access

Programs that provide information related to employment benefits, health insurance and disability benefits, and public health care and income assistance programs to people living with HIV/AIDS. Systems advocacy is also provided through interactions with HIV/AIDS-specific and non-HIV/AIDS specific providers.

Care Advocacy

Essential Access

Care advocacy includes a brief assessment of immediate needs. Advice and assistance are provided in obtaining services to meet those needs. Care advocacy does not involve ongoing coordination and follow-up. Systems advocacy is also provided through interaction with HIV/AIDS specific and non-HIV/AIDS specific providers.

Care Case Management

Essential Access

Services include: 1) Initial and ongoing assessment of needs, especially focused on access to care; 2) Individual care plan addressing mutually identified needs and tasks for client and case manager to resolve the problem; 3) Referrals to other services to address the needs identified in the assessment; 4) Planning for the receipt of cost effective health care and support services; 5) Monitoring and coordination of the delivery of health care and social services; and 6) Initial and ongoing assessment of sexual and drug related transmission issues and the provision of education and counseling.

Child Care

Essential Access

Services include the provision of intermittent or continuing care of HIV/AIDS positive children by a licensed/registered child care provider. Services also include the provision of child care in order to enable: 1) HIV infected adults or children to access needed medical or social services; 2) HIV positive or at-risk individuals to attend prevention services; and 3) HIV positive or at-risk individuals to attend CARE Act or prevention related meetings, groups or trainings. Services are provided by a licensed/registered provider or through an informal source such as a neighbor, family member, or other. This does not include child care provided while the adult is at work.

Clinical Trials

HIV Additional

Research studies that examine medications used to manage HIV disease. Studies may: 1) test new medications to treat HIV/AIDS; 2) discover how to use older medications in new ways or combinations; 3) study medications to prevent or treat related infections; and 4) identify ways to assist people in managing their HIV/AIDS medications.

Community Awareness (Public Information)

Essential Access, Essential Care and Prevention, HIV Additional

The delivery of planned HIV/AIDS prevention and care messages through one or more channels to target audiences in order to: 1) build general support for safe behavior; 2) support personal risk reduction; 3) inform persons at risk about HIV infection and how to obtain specific prevention services; 4) inform persons who are positive about available care and prevention services; 5) encourage volunteerism; and 6) decrease prejudice against persons with HIV disease. Community awareness interventions seek to reduce risk behavior and increase knowledge of HIV by changing attitudes, norms, and practices through health communications, prevention marketing, community mobilization/organization, and community events. Examples include electronic media, print media, hotline, clearinghouse of information, presentations/lectures, web sites and chat rooms. Community awareness materials are culturally appropriate for targeted audiences. The wording and/or pictures used are appropriate and meaningful for the target population.

Some messages that community awareness may include are: what is HIV, how it is transmitted, what questions to ask your doctor if you think you're at risk or have symptoms, education about the testing process, changing community norms around testing, the relation of co-factors (STDs, substance use, mental health, etc.) to HIV, support for dealing with stigma around HIV and stigma around behaviors, and building pride within community groups.

Complementary Care

HIV Additional

Complementary therapies provided upon written referral by the client's primary health care provider (or substance abuse counselor in the case of referrals for acupuncture associated with substance abuse treatment). Therapies include, but are not limited to massage, Reiki, acupuncture, acupressure, chiropractic care, herbal medicine and Native healers.

Comprehensive Sexual Education (K-12)

Essential Prevention

Comprehensive sexual education provided through schools, grades K through 12, that is age appropriate and medically accurate. Comprehensive sexual education includes messages about abstinence, and provides young people with information about contraception for the prevention of teen pregnancy, HIV/AIDS and other sexually transmitted diseases (STDs).

Counseling, Testing and Referral

Essential Access, Essential Prevention

Confidential (and anonymous) testing for HIV/AIDS that is voluntary, informed, and consent-based. The testing process includes information about the HIV test and pre- and post-test counseling. High-risk individuals who test negative are given referrals into prevention programs. Individuals who test positive are given referrals into medical care, prevention and risk reduction programs, and support services. They are also given information and patient education on living with HIV disease and managing therapeutic regimens, and counseling on modifying behaviors that compromise their own or others' health status. Individuals who test positive are also given counseling regarding notification of partners.

Dental Care

Essential Care and Prevention, HIV Additional

Screening for and treatment of oral lesions associated with HIV/AIDS. Treatment of all non-HIV/AIDS related oral infections and establishment of optimal oral health.

Discharge Planning

Essential Access

Information and referral services provided to persons being released from an institution such as a hospital, nursing home, adult foster care setting, or prison, and ensuring that the persons have a connection to a support system.

Domestic Abuse Services

HIV Additional

Support and assistance provided to men and women that have been physically and/or verbally abused by their partners.

Emergency Financial Assistance

HIV Additional

Financial assistance provided to people living with HIV/AIDS who are low-income. Assistance in the following areas will be offered: utilities, phone, food, and medical costs. Assistance will be given in the form of vouchers or payment of bills. Money will not be given directly to the client.

Emotional Support

Essential Care and Prevention

Individual and or group counseling, other than mental health counseling, provided to persons living with HIV/AIDS, friends, partners and/or family by non-licensed counselors. Services providing emotional support can include, but is not limited to: peer counseling, support groups, supportive networks, buddy programs, grief counseling, and spiritual support.

Funeral Arrangements

HIV Additional

Services to assist clients and/or their family, partners and friends with planning funeral arrangements. Funerary and memorial information and referral are provided.

Health Education & Risk Reduction

Essential Care and Prevention

For individuals who are HIV negative and HIV positive:

Health education and risk reduction efforts aimed at reducing transmission of HIV/AIDS.

Education is focused on safer sex issues, including using condoms and dental dams, negotiating with partner around use of protection, reducing the number of sexual partners, and not engaging in sexual behavior under the influence of alcohol or drugs. As appropriate, education will also focus on injecting drug use, the need to use clean needles and how that can be done.

These interventions must include a skills building component. They may be delivered through individual level counseling, couples counseling, group counseling, and support groups. Peer and non-peer models may be used. Individual level interventions include assisting clients in making plans for individual level behavior change and ongoing appraisals of their own behavior. They also facilitate linkages to services in clinic and community settings in support of behaviors and practices that prevent transmission of HIV, and help clients make plans to obtain these services.

For individuals who are HIV positive and their partners, family, caregivers:

Health education and risk reduction that focuses on education about the disease and management of the disease, including transmission, progression, treatment options, side effects, etc.

Education about remaining healthy and promoting self care; i.e., how to lead a healthier lifestyle, stress reduction, smoke cessation, harm reduction, good nutrition, and water purification.

Health Insurance

Essential Access

Service to assist clients in finding the health insurance option that best suits them and, if needed, assistance in completing the necessary forms for enrollment. Services for individuals living with HIV/AIDS also include coverage of costs associated with obtaining and maintaining health insurance coverage for clients that meet eligibility criteria. Costs that are eligible for coverage under this program are monthly premiums, deductibles and copays.

HIV Screening of Pregnant Women

Essential Prevention

Voluntary HIV testing offered as a routine part of prenatal care. HIV testing should be offered and performed as early as possible during the pregnancy to promote timely antiretroviral treatment to women who test positive. Prevention counseling is recommended for pregnant women who test positive. Providers are encouraged to explore and address reasons for refusal of testing. HIV testing and treatment is emphasized for women who have neither received prenatal testing nor antiretroviral drugs, if HIV positive. The importance of follow-up medical care for HIV-infected mothers and perinatally-exposed children is emphasized by the physician.

Housing Access and Support Services

Essential Access, HIV Additional

Services to assist individuals to access and/or maintain housing. These services can include, but are not limited to, the payment of rent, application fees, moving costs, mortgage payments, and shelter services. Support may also include assessment, search, placement and advocacy services provided by professionals who possess an extensive knowledge of local, state and federal housing programs and know how they can be accessed. *For CARE Act funding, housing support must be certified as essential to a client's ability to gain and/or maintain access to HIV/AIDS-related medical care or treatment.*

Information and Referral

Essential Access

Provision of information about HIV, as well as information and referral to local testing, prevention, care, medical and support services. Referrals may be made to both HIV/AIDS-related and non HIV/AIDS-specific services.

Interpretation and Translation

Essential Access

Interpretation - Services of a trained interpreter to interpret during medical or social service appointments. This includes sign language as well as spoken languages.

Translation - The translation of written documents providing information about HIV/AIDS and HIV/AIDS-related services into languages other than English.

Legal Services

Essential Care and Prevention, HIV Additional

Volunteer or non-volunteer legal services directly necessitated by an individual's HIV/AIDS status, such as preparation of: 1) powers of attorney, disability planning, do not resuscitate orders, health care directives, wills, estate planning, permanency planning, trusts, etc.; 2) bankruptcy proceedings; and 3) interventions necessary to ensure access to benefits for which an individual may be eligible, including discrimination, work re-entry issues, non-citizen rights, or breach of confidentiality litigation.

Medically Based Housing and Home Based Care

Essential Care and Prevention

Includes the provision of hospice care, adult foster care, home health care, nursing home care, and durable medical equipment.

Home-Based Hospice Care: Nursing care, counseling, physician services, and palliative therapeutics provided by a hospice program to patients in the terminal stages of illness in their home setting.

Residential Hospice Care: Room, board, nursing care, counseling, physician services, and palliative therapeutics provided to patients in the terminal stages of illness in a residential setting, including a non-acute care section of a hospital that has been designated and staffed to provide hospice services for terminal patients. (HRSA definition for CARE Act funding)

Medically Based Housing and Home Based Care, *cont.*

Adult Foster Care: Room, board, nursing care, personal care attendant services, nutritional counseling, and emotional support provided to patients in an adult foster care setting.

Home Health Care: Therapeutic, nursing, supportive and/or compensatory health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professionals. Components of service include: 1) Homemaker or home health aide services and personal care services furnished in the home of the individual; 2) Day treatment or other partial hospitalization services; 3) Home intravenous and aerosolized drug therapy, including prescription drugs administered as part of such therapy; 4) Routine diagnostic testing administered in the home of the individual; and 5) Appropriate mental health, developmental and rehabilitation services.

Nursing Home Care: Inpatient facility where skilled nursing and custodial care are provided for patients who are unable to live at home.

Durable Medical Equipment: Adaptive equipment used by persons with disabilities to increase, maintain or improve their ability to function.

Medical Care

Essential Care and Prevention

Services can include physician and other professional staff (nurse practitioner, nurse, psychologist, PharmD, dietician, etc.); clinic services; reproductive health/obstetrics and gynecology; lab, radiology & diagnostic services; ambulatory surgical services; hospital services; chiropractic services; rehabilitation services, eyeglass and vision care; pharmacy; nutritional counseling, screening for co-infections (STDs, Hep A, B, C), non-durable medical equipment and supplies.

Medication Adherence Support

Essential Care and Prevention

Programs designed to help people adhere to their HIV/AIDS treatment regimen. May include working with PharmD and/or nurse, counseling, peer support, and provision of equipment/supplies such as beepers, pill boxes, etc.

Mental Health

Essential Care and Prevention, HIV Additional

Mental health services encompass psychological and psychiatric treatment and counseling services, including individual and group counseling, for mental health issues with the goal of improving overall health, reducing risk-taking behaviors and/or assisting individuals in coping with the impact of HIV on their lives. Services must be provided by a mental health professional licensed or authorized within the state, including psychiatrists, psychologists, clinical nurse specialists, social workers and counselors. Pastoral care must be provided by an institutional pastoral care program and should be licensed or accredited.

Nutritional Services

Essential Care and Prevention, HIV Additional

Nutritional services include food shelf, home-delivered meals, congregate meals, and nutritional supplements.

Food Shelf: Purchase of food and non-food items, office expense and salaries for the operation of a food shelf. Distributions should provide a minimum of 2 days worth of food items for eligible individuals.

Home Delivered Meals: Meals are delivered to people who are home bound and unable to prepare home meals due to HIV/AIDS illness. Meals must be nutritionally balanced and the menu must be reviewed and approved by a registered dietician.

Congregate Meals: Meals are provided on-site. Meals must be nutritionally balanced and reviewed/approved by a registered dietician. Agencies must comply with all state and local health laws and ordinances concerning preparation, handling and serving of food.

Nutritional Supplements: Natural and nutritional supplements are provided for people who are experiencing HIV/AIDS-related wasting/metabolic changes. Products covered include enteral supplements (i.e., Ensure, Sustacal), multi-vitamins, lactase enzyme, and herbal treatments.

Outreach

Essential Access

Prevention Focused Outreach

HIV/AIDS educational interventions generally conducted by peer or para-professional educators face to face with high risk individuals in the clients' neighborhoods or other areas where clients typically congregate. Outreach usually includes the distribution of condoms, bleach kits, sexual responsibility kits, and educational materials. Outreach may include field based testing as a component.

Care Focused Outreach

The main purpose of outreach programs is to identify individuals with HIV disease, particularly those who know their HIV status so that they may become aware of, and enroll in, ongoing care and treatment services (i.e., case finding). Outreach does not include HIV counseling and testing or HIV prevention education. Outreach programs must be: 1) planned and delivered in coordination with state and local HIV prevention outreach programs to avoid duplication of effort; 2) targeted to populations known through local epidemiological data to be at disproportionate risk for HIV infection; 3) conducted at times and in places where there is a high probability that HIV-infected individuals will be reached; and 4) designed with quantified program reporting that will accommodate local effectiveness evaluation. (HRSA definition for CARE Act funding)

Partner Counseling and Referral Services (PCRS)

Essential Care and Prevention

A systematic approach to notifying sexual and needle sharing partners of HIV-infected and STD-infected individuals of their possible exposure to HIV or an STD so they can avoid infection or, if already infected, can prevent transmission to others. PCRS helps partners gain earlier access to individualized counseling, HIV and STD testing, medical evaluation, treatment, and other prevention and care services. PCRS also provides information and referrals into medical care and support services to individuals who have tested positive with HIV.

Post Exposure Prophylaxis

Essential Prevention

A short course of HIV medications provided to an individual after a suspected exposure to HIV in order to reduce the possibility of transmission.

Prescription Drugs

Essential Care and Prevention

Programs that provide payment for the cost of HIV-related medications for people who are uninsured, and for the cost of copayments and deductibles related to HIV medications for individuals who have insurance.

Prevention Case Management

Essential Care and Prevention

Client centered HIV prevention activity for HIV negative or HIV positive individuals who are having or who are likely to have difficulty initiating and sustaining safer behavior. It is a hybrid of HIV risk reduction counseling and traditional case management that provides intensive, ongoing, and individualized prevention counseling, support and service brokerage. It involves the assessment of HIV risk behavior, the assessment of other psychosocial and health service needs, and the development of a care plan. The care plan is then used to ensure that risk reduction counseling and referrals to medical and other support services are provided according to the individual's needs.

Public Policy Advocacy

Essential Prevention

Public policy advocacy around issues that relate to HIV prevention and care; i.e., programs targeting MSM, same sex marriages, comprehensive sex education, universal health care, etc.

Screening and Treatment of STDs and Hepatitis A, B, C

Essential Prevention, Essential Access

Services that provide screening and treatment of STDs and Hepatitis A, B, and C. The screening process includes a risk assessment and prevention counseling on STDs, Hepatitis, and HIV. An HIV test is recommended for persons who test positive for an STD or Hepatitis. Treatment is provided as appropriate, and a referral made for further medical care, if needed.

Sexual Health Promotion

Essential Care and Prevention

Sexual health promotion focuses on positive, health-enhancing sexual practices and promotes communication with family and partners around sex and sexuality, awareness of STDs and HIV, and competence in making safer sex decisions. It includes policy, education, health services, and family/community components. Sexual health promotion occurs over the lifespan and the continuum by providing information, knowledge and resources to people at all stages of sexual health. It includes risk reduction strategies, as well screening and treatment to stop or decrease disease or other adverse outcomes.

Substance Use Services

Essential Care and Prevention

Services that provide care to individuals to deal with symptoms or maladaptive behaviors that occur with regular use of legal or illegal substances that affect the central nervous system. Eligible treatment models/settings include: outpatient or inpatient, residential or day care, group, individual and family counseling, methadone maintenance, harm reduction, detoxification, therapeutic/residential communities, self help groups, combination of therapies and medication. Substance use treatment or risk reduction services are provided with the goal of improving a person's overall health and reducing risk-taking behavior influenced by substance use.

Support Services for Affected Individuals and Caregivers

Essential Care and Prevention, HIV Additional

Support given to the family, partners, friends, and caregivers of people living with HIV/AIDS. This may be given in the form of emotional support or relief of caregiving duties for a period of time.

Syringe Distribution

Essential Prevention

Distribution of clean syringes through such means as needle exchange programs or pharmacy-based syringe access programs.

Needle Exchange Programs – Programs that provide clean needles in exchange for used needles.

Syringe Access Programs – Pharmacy-based programs that allow for the legal purchase of syringes without a prescription.

Training

HIV Additional

Training provided to various audiences to increase knowledge and skills related to HIV.

Training for Physicians - Training to help physicians learn how to talk with patients about sexual and substance using behaviors, how to conduct a risk assessment, how to talk to patients about getting tested for HIV, how to talk about prevention, and where to refer patients for prevention and care services. Training also focuses on teaching physicians to recognize co-factors, and to recognize symptoms of HIV, both acute infection and opportunistic infections.

Training, cont.

Training for Prevention and Care Providers – Training provided specifically to prevention-funded and CARE Act-funded providers. This type of training may be used to increase familiarity with the prevention and care service system, strengthen referrals between prevention and care services, increase understanding of how each type of service is delivered, and to assist care providers in integrating prevention messages into their work, as appropriate.

Training for Providers – Training to help a variety of providers (including all staff of health care facilities, mental health, substance use, STD, social service, corrections, etc.) to learn about HIV, risk factors, stigma, how to do a risk assessment, how to talk about prevention, and where to refer people for testing, or prevention and care services. Training also focuses on the relationship between co-factors of HIV such as mental health, substance use, STDs, homelessness, etc.

Training for Volunteers - Training to help volunteers (including volunteers in health care facilities, mental health, substance use, STD, social service, corrections, etc.) learn about HIV, risk factors, how to do a risk assessment, how to talk about prevention, and where to refer people for testing, or prevention or care services. Training varies according to the specific type of volunteer work involved, and can also include a component of networking and recruitment.

Transportation

Essential Access

Transportation services provided to persons with HIV/AIDS to assist them in going to medical, social service, and prevention service appointments, to the pharmacy to fill or pick up prescriptions, and to assist with grocery shopping. Services also include transportation services provided to at-risk individuals to assist them in going to prevention services. Services may be provided directly, as in giving people rides, or indirectly through bus passes, mileage reimbursement or taxi vouchers.

Vocational Rehabilitation

HIV Additional

Services include vocational counseling, skill or academic training, assistive technology (equipment, etc., that makes it easier to work), job placement, employer education about HIV/AIDS, and assistance in securing financial resources to pay for the services.

CONTINUUM OF CARE SURVEY

April 14, 1999

EMA: _____
 Name: _____
 Phone: _____
 Fax: _____
 Date: _____

Affiliation: Circle one of the following:
 Planning Council
 Title I Grantee
 Other: _____

Introduction: The MN HIV Services Planning Council is in the process of developing its continuum of care. We are interested in learning how other EMA's have approached this project. We would appreciate if you could spend five minutes sharing your experiences.

1. Has your EMA (Planning Council?) developed any visual aids to better understand your continuum of care?

1a. If so, could you share them with us?

2. What process did your EMA go through to develop the continuum of care? Who was involved?

3. Has your EMA come to consensus on a core set of services which should be available to people living with HIV?

3a. If so, what is included?

4. Do you have a completed continuum of care document?

4a. Could you share it with us?

MINNESOTA HIV SERVICES PLANNING COUNCIL

Results of April 27, 1999 Public Hearing

NOON PUBLIC HEARING

Listed below are the responses to the questions asked at the public forum. There were 26 people in attendance at the noon hearing.

1. Do you feel that your doctor knows all that he or she needs to know about HIV?

Yes. Why?

- Dr. Keith Henry is great. He treats the whole person. The clinic is also great.
- My doctor is Frank Rhame. He knows what is going on with me. He suggests and recommends new medicines and has decreased my dosage of medicines. He is also familiar with alternative forms of medicine, vitamins. His interest is in my total well being.
- Hennepin County team has been good. I feel that they are interested in me.
- My doctor has a great nursing staff.
- Dr. Rhame's office calls to remind me of my appointments
- If I miss an appointment there is not an unreasonable waiting period.
- Park Nicollet has total involvement. I feel that I can ask questions and get answers.
- The whole team is available.
- Park Nicollet holds forums to educate consumers. The team is there as a panel. Questions are asked and information is shared.
- The evening with doctors was great I learned of the current trends.
- My physician is Margaret Simpson. I've been with her for 10 years. She is fantastic and gives good information.
- The African American AIDS Task Force has helped me a lot by giving me good information.
- When I went to a private physician vs. the county my care improved.
- I felt that a private physician focused on me, the individual.
- I have had doctors over the years that did not know as much about the disease as I did.
- The individual has to take some responsibility for educating himself.
- At Clinic 42 the care is high quality.
- Sharing with doctors has helped to encourage them to provide better service.

No. Why?

- Hennepin County calls after I miss my appointment. After I missed my appointment there was a 45 day waiting period.
- I felt like I became a number.
- I felt that Hennepin County had a lack of focus on me as the client.
- Treatment can be bad both public and private without someone to advocate. People with HIV are being treated like people of color / minorities are in other situations.
- I felt that my provider had little knowledge of how the disease affects women.
- I felt that my provider had little knowledge of the disease and Hepatitis C.

2. Are you getting the healthcare services you want i.e., lab tests and medication?

Yes. Why?

- I use mail order for getting prescriptions.
- Stadtlanders is good. They are proactive in filling prescriptions. They phone to let me know that it is nearly time to fill my prescription.
- My dentist, Dr. Duane Jeske, cares about his patients.
- Doctors need to keep pharmacies aware of changes in the dosage of medication or any other changes that occur.
- It's important for the individual to have surrogate support to ask questions. This helps if you have forgotten to ask questions that you need answers to.

No. Why?

- Walgreen pharmacists are awful. Sometimes they don't have the drugs in stock. They have filled my prescription and given me the wrong medication. The staff is often not friendly.
- When visiting the lab to give a blood sample, often they make multiple attempts to get a blood sample.
- Sometimes when waiting at the lab, I have had lab staff look at my chart and put it down and go to the next person so that they won't have to draw my blood.
- Additional mental stress because of the way I am treated by medical staff.
- Pilot City dental staff are not properly educated on how Hepatitis C is spread. The staff, through their actions, led me to believe that they thought the spread of the disease occurred by breathing on someone.
- Medical staff don't always properly inform clients of test results and the significance of the results.
- Clients have to be assertive.
- I have been given the wrong medication.
- Technicians' attitudes are bad.
- When drawing blood I request that the technician use a butterfly. This makes the procedure less painful. Sometimes the technicians don't want to because it takes longer and they will say it costs more.
- The difference between using a butterfly can mean the difference between comfort and discomfort.

3. Do you have trouble getting your healthcare paid for?

Yes. Why?

- People need education on how to access insurance coverage to prevent gaps in insurance coverage when starting or ending a job.
- Deductibles need to be re-evaluated; they may delay a client getting care. (Medicaid buy-in provision)
- There is new legislation (Medical Buy-In Provision) to help people get coverage. I learned this through Courage Center.

4. How do other services you receive help you gain access to or help support your use of health care services?

- DHS is supportive, programs interact well.
- MAP has connected me to many services.
- Good case management has allowed me to get other services.
- You can't leave everything up to your case manager. The client must be proactive.
- MAP and HCMC are working better together.
- Case manager is not supportive.
- Case managers don't always share information.

Additional comments

- Need more alternative care for things like chiropractic care, mental health (mentioned by a provider) therapy, acupuncture, medicines, chemical dependency, assessments.
- More input and support for alternative care.
- There is less funding for alternative care.
- There have been cutbacks in alternative services that are valuable like acupuncture.
- We need to get people to come out and get involved.

EVENING PUBLIC HEARING

Listed below are the responses to the questions asked at the evening public forum.

There were six people in attendance.

1. Do you feel that your doctor knows all that he or she needs to know about HIV?

Yes. Why?

- My doctor answers my questions.
- I have been living with AIDS doctors for years (1987).
- I increased my own knowledge by reading, attending forums and talking to people.

No. Why?

- My primary care physician is not informed.
- My private care physician has to refer me to my HIV specialist. The bureaucracy is really bad.
- My primary care physician has to ask my HIV specialist what lab work I need. Often the lab does not know what to do because they have not been informed.
- I often end up with double lab work.
- The primary clinic does not provide any educational knowledge to me.
- The primary physician does not share information with me.
- Some doctors do not keep themselves informed about HIV.
- Some social services don't ask all the right questions.
- Some case managers in hospital settings don't know what's available.
- Some don't know anything about veterans' benefits.

2. Are you getting the healthcare services you want i.e., lab tests and medication?

Yes. Why?

- Getting everything, lab work. I get a massage on my own.

No. Why?

- Benefits are limited.
- Alternative medicine is limited.

3. Can you talk to your doctor about anything?

Yes. Why?

- I see a social worker regularly. I can talk about anything, mostly finances.

No. Why?

- The doctor is very busy.
- I have learned to write down my questions before I go for my appointment to make sure that I ask everything.
- Those people who challenge the doctors have a better chance for survival.

4. Do you have trouble getting your healthcare paid for?

Yes. Why?

- There was a point in the progression of my disease where insurance coverage was not sufficient.

No. Why?

- My MAP caseworker was informed and told me of insurance coverage.

5. How do other services you receive help you gain access to or help you support your use of healthcare services?

- Case manager helps fill out required forms.
- MAP case manager has access to all services and helps me find out about other services.
- I have access to all the services I need through VA forums and medical services.
- There may be more creative ways to get information to all the people who come for food only while they are eating at Aliveness.
- I learn of services available through group therapy, Aliveness, MAP, Homeless Project, DHS.

MINNESOTA HIV SERVICES PLANNING COUNCIL

Results of June 7, 1999 Duluth Provider Public Hearing

Listed below are the responses to the questions asked at the public forum. There were eight people in attendance. Of those in attendance two were physicians, one was HIV positive and five were a mixture of nurses, a case manager and technicians.

1. Describe your clinic and the services you provide?

- I am in the Duluth Clinic - Infectious Disease section
 - ✓ 68 patients from Minnesota and Wisconsin
 - ✓ Seen the disease from the beginning
 - ✓ See patients as needed, offer full line of services
 - ✓ Minnesota Aids Project for case management
 - ✓ Provide primary care
 - ✓ In rural areas primary physician will see them and then send them to the clinic; i.e., Ely
 - ✓ Provide hospice and respite care

- Residential facility - 3 bedroom apartment, 3 people live there, \$100/mo. rent, no rental history taken, furnished, no rules about drug/alcohol, men occupy the facility, currently no women and children, stage of disease makes no difference, people have to be self-sufficient.

- St. Louis County Health Department
 - ✓ 5 offices in Duluth, Ely or Eveleth, Hibbing, Virginia and Meadowlands
 - ✓ Maternal health
 - ✓ Education in the community
 - ✓ Epidemiologist, does any CD reports and follow-up
 - ✓ Started HIV task force 1½ years ago, comprised of community people, agency representatives and Rural AIDS Action Network (RAAN).
 - ✓ Sponsored one large conference in Virginia and over 180 people attended (seeking funding to do something similar in the future)
 - ✓ Provide med setups
 - ✓ Provide homecare
 - ✓ Prenatal care training incorporates HIV
 - ✓ Sponsors “Superior Babies” where chemically dependent women are educated

- Minnesota AIDS Project
 - ✓ Case management
 - ✓ Support eight counties
 - ✓ Provide assistance in housing, insurance, medical, social security, healthcare referral, advocacy, education and other services needed such as emotional support

2. What are the strengths and weaknesses of the medical care system for PLWH in Minnesota?

Strengths

- Enrolled large number of people in state as compared to Rochester.
- Conference in Virginia funded by one time only grant from Minnesota Department of Health (struggle to get reimbursement as promised).
- Infection disease physicians are phenomenal. Four ID physicians serve huge region and are willing to drive to see patients.
- No one is homeless in Duluth area.

Weaknesses

- Transportation
- No funding for pharmacist.
- No funding for AIDS clinic.
- Not able to do research due to no funding.
- Denied funding by Ryan White for HIV clinic. Would like to bring in pharmacy, nursing, nutrition, and social services.
- Need one-stop shopping for people driving in.
- No means for organized communication.
- Funding dollars are metrocentric.
- Funding has been pulled for educating people.
- St. Louis County is huge.
- Those who are living with HIV are afraid to come out.
- Excellent documentary done by KUWS – Mike Simonsen on PLWH in rural areas.

3. What do you see as emerging issues in medical care for PLWH in Minnesota?

- Complexity of the disease.
- Would like to bring pharmacist on board.
- Medication adherence (people are trying to hide or escape).
- Effective strategies for promoting adherence are:
 - a. Patient education
 - b. Boxes for pills
 - c. Pagers
 - d. Helpful if pharmacy, clinic's nurse, case managers had a tracking system (could remind people)
- Asking pharmacist - the pharmacist may know them or may not have the necessary drugs.
- Acupuncture or complementary care - need for these services in outstate Minnesota.
- Case workers in cities - do **not** suggest that patients move to Duluth without the funding dollars coming with them.
- Person gets subsidized benefits, gets a job and then gets cut off.
- Medicaid work re-entry.
- Due to two state lines, people get caught in the middle. Some people live in Superior because it's cheaper, but get service in Duluth.
- Emergency Fund Assistance (EFA) difficult; i.e., if someone is given a Rainbow voucher, it could take three hours to get to a Rainbow store.
- One case manager for the entire area.

- Greater Minnesota participation on the Planning Council is not adequate.
 - Could get participation through phone conference, videoconference, rotation of seats based on the number of people.
4. What role do collateral services play in medical care for PLWH in Minnesota?
- Collateral or team care is really important and would be better.
 - There is a need for **Money**.
 - Need seed/start money for social worker, nurse, coordinator at time and with a certain number of hours.
 - There are finance issues around the health system.
 - a. Budget cuts
 - b. Cutting additional personnel
 - c. Transportation to cities; people are tired and have unreliable transportation
 - d. Revenue not being brought in

Comments

Is there an inequity in the funding system statewide?

Yes.

- Reimbursement takes too long
- Need cash now
- Have some bus tokens - not enough
- Housing money available for rent not for mortgages
- No food vouchers. Rainbow won't work. Need Cub or Super Valu.

Do Regional Centers make sense?

Yes.

MINNESOTA HIV SERVICES PLANNING COUNCIL
Results of June 21, 1999 Minneapolis Provider Public Hearing

Listed below are the responses to the questions asked at the public forum. There were nine people in attendance.

1. What are the strengths and weaknesses of the medical care system for PLWH in Minnesota?
Responder: Dr. Henry

Strengths

- Lots of major and other providers.
- Ability to see patients from outstate and other neighboring states.
- Never turned any patients away; 77% of the patients are below the poverty level of those who are seen.
- Good access to health care.

Weaknesses

- Uncompensated care; a problem for health care reform.
- Problem with the terminology “Specialist” for reimbursement.
- Trapped with low level repayment.
- Don’t get reimbursed for ancillary care.
- Revenue sources have diminished for sick patients.
- Under pressure to break even or be closed down.

Question

How much of Ryan White goes towards care?

2. What do you see as emerging issues in medical care for PLWH in Minnesota?
Responder: Dr. Schut

- Treatment requiring clinical expertise.
- Need pharmacist on site.
- Resistance - involves experts’ input and time.
- Language barriers - 26 languages spoken by patients; of those whom are treated there are 7 to 8 different languages. No reimbursement.
- Unforeseen complications.
- Optimal care requires team approach - not reimbursed.
- 75% self identified MI (mental illness) treatment.
- 25% unstable housing impacts ability to provide quality care.

3. What do you see as the barriers between optimal care and the care PLWH in Minnesota receive and/or need?

Responder: Dr. Rhame

- Where money comes into the system
 - a. 1 MD - RVU’s 99213 or 99314 submitted
 - b. Procedurist

- c. Hospitalization
- d. Lab test
- e. Drugs
- f. Research
- Most of the money comes from 99213 and from this everything gets funded. No primary provider really makes it on 99213 or 99214. Money is made from other billings.
- To make money you have to generate seeing 6 to 8 people per hour.
- A new patient takes approximately 1/2 hour.
- There is one minute of activity for every minute of interaction.
- HCFA - says a physician can only bill for face to face time with the patient.
- Incentive is to only take care of well patients; which can be done in faster time.
- If person is hospitalized physician can see them quicker.
- HIV is an example of where “complex illness” loses dollars compared to seeing well patients.

What will happen:

- Given pharm D is the question now.
- Convert nurses to medical assistants.
- Not enough support.
- System will tighten.
- Quality of care will deteriorate.
- Physicians will not be able to tolerate treatment given to HIV patients.
- 90% of HIV business loses money. Receiving training on how to turn people away.
- Take away the ability to provide quality care; physicians will leave.

OPEN MIKE

This discussion was free flowing. The responses are captured conversation without a targeted response. There was not a question asked prior to the comments listed below.

- Interest in women and children; issues magnified by ancillary support social work, transportation.
- Worried about young women not accessing health care anywhere.
- 1/6 of the time with HIV patients is paid for. Not making much money.
- New York has a higher payment rate for RVU's; about 150%.
- Pharmacies need help.
- Problem is deeper than Pharm D.
- Latinos
 - Without the help of Dr. Henry could not have done it or survived.
 - Significant cultural barriers.
- MAP
 - Same pressures because the system is designed for chronically ill patients.
 - People are chronically poor.
 - Trying to fix a number of broken systems (transportation, housing, racism, homehelper, comprehensive medical care).
 - Have used Ryan White dollars for a shadow system. Little difference from Catholic Charities. Only difference is that MAP focuses on HIV/AIDS.

- Pressure asking for some funding from Ryan White for Primary Care (Title I).
- Not adequate input from providers as they are busy meeting clinical demands. Should not be seen as not caring.
- Input from providers and patients is different.
- Should look at other models; i.e., Wisconsin, Kansas, Des Moines.
- Minnesota case management, housing etc. is culturally sensitive system/model.
- Third party reimbursement how can it be influenced?
- Look at what other states have done with Medicaid and Medicare.
- Will still lose dollars on private patients.
- Subsidy system necessary trend is changing.
- Not saying not to be more creative but be thoughtful. There is a need to educate community about challenges.
- Population accustomed to complementary care.
- I have been funded 5 - 6 years to do acupuncture. I need to look at the big/long term picture. Like to be included in discussion on role that complementary care can play.
- How can we do it? Hitching the wagon to Ryan White may not be the answer.
- Health care is being managed by accountants.
- Concern for people who are low income.
- Will continue to target those who have money.
- Minnesota has accessed care but physicians are under paid; many are seeing patients without insurance.
- RVU's rewards people for seeing patients.

Closing Comments by Bob Tracy and Commissioner Malcolm

Bob Tracy

We are looking at ways for people to be involved with the Planning Council. We need to create different terms. What we have to look at is how do we balance the investment of Ryan White dollars to provide balance to current systems. Systems change needed in three areas; Medicaid reimbursement, uncompensated care and people living with chronic illnesses.

Commissioner Malcolm

Humbling to hear depth of concern by providers. Get back to how incentives designed throughout the system. Feel a responsibility to look at what care will be like in ten years. It's good to assume that there will be more uncompensated care. Acknowledge the reality. All the issues are on the radar screen. This will help focus the urgency of the need.