

Statewide Coordinated Statement of Need

Ryan White Title II



**Utah Department of Health
Bureau of Communicable Disease Control
HIV Treatment and Care Program**

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ACKNOWLEDGEMENTS

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*** Please see Appendix B for a complete list of attendees at the Statewide Coordinated Statement of Need Meeting held on Wednesday, October 12, 2005**

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EXECUTIVE SUMMARY

➤ INTRODUCTION

The Utah Department of Health, Division of Communicable Disease Control, HIV/AIDS Treatment and Care Program (Program), prepares the Statewide Coordinated Statement of Need (SCSN), every three years in accordance with the Ryan White CARE Act. According to the federal Health Resources and Services Administration (HRSA), “the purpose of the SCSN is to provide a collaborative mechanism to identify and address significant HIV care issues related to the needs of people living with HIV/AIDS (PLWH/A), and to maximize coordination, integration, and effective linkages across the CARE Act Titles related to such issues”. It is prepared through the collaborative efforts of:

- the Utah Department of Health (UDOH),
- members of the HIV Treatment and Care Planning Committee (HIV Treatment/Care Committee),
- select members of the HIV Prevention Community Planning Committee,
- a group of HIV service providers and consumers,
- and other interested community members.

In addition, the Program and the Committee participated in a facilitated process that involved:

- Data review and assessment
- Presentation and analysis of small group reports
- Lists of Service Needs, Gaps, Barriers and Emerging Needs, developed by consensus
- Evaluation of the process

➤ 2004 EPIDEMIOLOGY UPDATE

The number of persons living with HIV continues to increase each year. That increase is largely a result of improved treatment that has substantially delayed the onset of illness and death. Using methods recommended by the Centers for Disease Control (CDC), we estimate that at the end of 2003, there were about 2,000 persons (range from 1,700 to 2,600) living with HIV/AIDS in Utah. In addition to the increasing number of people in need of prevention and treatment and care services, these data suggest that there are a number of infected people who may not know they are infected. These people could benefit from treatment, and represent a risk of ongoing transmission.

Although most HIV/AIDS cases reported during 1998-2003 for both men and women have occurred among non-Hispanic White persons, the risk remains much higher for Hispanic and Black persons.

Most HIV/AIDS cases are men who have sex with men (MSM), but a notable increase occurred in 2002-2003 among MSM who inject drugs (MSM/IDU).

The age distribution of reported HIV/AIDS cases has changed little during the several years. The percentage of cases among women has increased slightly.

➤ **SERVICE NEEDS**

Utah's successful HIV testing program, which noted an increased HIV positivity rate of 0.4% in 1998 to 0.9% in 2003, and the continued focus on keeping PLWH/A in the system of care has led to an expanding need for a variety services. This is challenging since providers, especially in rural areas, may not be prepared to treat PLWH/A. The various data sources as well as the small group and large committee discussions from the SCSN meeting, call attention to these challenges. The SCSN committee determined the following list to be the community's top five current service needs:

1. Health Insurance
2. Ambulatory Medical Care
3. AIDS Drug Assistance Program (ADAP)
4. Case Management
5. Transportation

➤ **BARRIERS**

Information about the barriers related to HIV care came from a range of sources, however, much weight was given to the Needs Assessment as the small group assigned to Barriers discussed and ranked the top five barriers affecting PLWH/A in Utah. This group made the point that these five barriers are from the perspective of the client, not what the Ryan White CARE Act stipulates we spend on what services. The SCSN committee determined the following list to be the community's top five barriers related to HIV care:

1. Funding

2. Housing
3. Transportation
4. Substance Abuse/Mental Illness
5. Culture/Confidentiality

➤ **GAPS**

As the small group reported their top five gaps in services to the SCSN committee, they noted that they looked at these gaps with the perspective that something is available; there is just not enough of it. The SCSN committee determined the following list to be the community's top five gaps related to HIV care services:

1. Transportation
2. Ambulatory Medical Care
3. Health Insurance
4. Rural Health Care
5. AIDS Drug Assistance Program (ADAP)

➤ **EMERGING NEEDS BY POPULATION**

The SCSN Committee characterized Emerging Needs by analyzing service needs and gaps by sub-populations. Committee members separated into small groups, each targeting one of the four emerging communities: women, communities of color, rural communities, out-of-care PLWH/A. The following lists the sub-populations discussed and their specific needs.

Women

- Access to health care/reproductive health (including abortion & family planning)/STD
- Substance abuse/harm reduction, mental health
- Services for women of color
- Family and child issues
- Poverty/housing issues

Communities of Color

- Legal status/distrust of authority
- Multi-lingual services
- Cultural specific services

- Lack of gender/color specific providers
- Poverty

Rural communities

- Transportation
- Cultural issues unique to Utah
- Lack of confidentiality
- Lack of social support
- Lack of services/quality providers

Out-of-Care PLWH/A

* Note: this list is based on the participant's perspective because we don't know why these people are out of care. Outreach may be an important component in finding out why they are not in care. The reasons vary widely from person to person.

- Fear/Stigma
- Mental Health
- Case Manager
- Funding
- Transportation

➤ **CROSS CUTTING ISSUES**

Cross cutting issues are those factors affecting provision and access to HIV treatment and care, but are external to the direct delivery of health services. During the SCSN development meeting, the full Committee determined the following to be the most important cross cutting issues:

- Poverty/Funding
- Transportation
- Substance Abuse/Mental Health
- Cultural Issues
- Case Management

➤ **PARTICIPANT EVALUATION OF PROCESS**

In order to establish the Committee's assessment of the SCSN development procedure, attendees at the community meeting were surveyed at the completion of the process on their levels of satisfaction both with their individual participation and that of the community group as a whole. This assessment was included as documentation of the extent and quality of community involvement and as a quality assurance measure for future SCSN processes. With a score of 5 used to indicate, "very satisfied" and of 1, "very dissatisfied," the mean score for satisfaction with individual participation was 4.67 and for satisfaction with the group process, 4.76.

➤ **CONCLUSIONS**

Consistent with findings across the country, health disparities associated with the economic downturn, inadequate insurance coverage, changes in service eligibility criteria are increasing, especially among the working poor. PLWH/A may be disproportionately affected since they are also confronted with an acute or chronic illness, often with co-morbidities, whose management may require access to very costly medications, frequent contact with health care professionals and possible hospitalizations. Further, those who are eligible for CARE Act funding, are often also coping with low-income issues. To address these concerns, over the course of the year, the Treatment and Care Program will focus its planning and data collection efforts on:

- Defining and understanding the issues associated with those who are not in care
- Defining and proposing strategies for resolving unmet service needs
- Expanding the collaboration with the HIV Prevention Program and Planning Committee
- Client advocacy
- Program evaluation and recognition of best practices

UTAH DEPARTMENT OF HEALTH
STATEWIDE COORDINATED STATEMENT OF NEED

DECEMBER 2005

INTRODUCTION

The Utah Department of Health, Bureau of Communicable Disease Control, HIV/AIDS Treatment and Care Program, prepares the Statewide Coordinated Statement of Need (SCSN), every three years in accordance with the Ryan White CARE Act.

According to the federal Health Resources and Services Administration (HRSA):

“The SCSN is a written statement of need developed through a chosen SCSN process. The SCSN must reflect, without replicating, a discussion of existing needs assessments and should be a brief overview of the epidemiological data, existing quantitative and qualitative information, and emerging trends/issues affecting HIV care and service delivery in the State. The SCSN should consider the total CARE Act resources in the State, both the amount of funds and what services these funds are supporting.”

The SCSN is prepared through the collective efforts of the Utah Department of Health, the HIV Treatment and Care Planning Committee (HIV Treatment/Care Committee), select members of the HIV Prevention Community Planning Committee, a group of HIV service providers and consumers and other invited guests, who review several data sources.

For this report, those data sources included the:

- 2004 HIV Surveillance Report and Community Epidemiology Profile
 - This report provides detailed information about the current HIV/AIDS epidemic in Utah. Specifically this report describes the general population of Utah, HIV/AIDS infected persons living in Utah, and persons at risk for HIV infection. This report is an essential resource for planning HIV/AIDS prevention and treatment and care activities throughout the state. The data presented in this report serve to guide prevention and service efforts, justify and obtain funding for the implementation of prevention and service programs, and evaluate programs and policies for HIV/AIDS in Utah.

- 2004 Utah HIV/AIDS Treatment and Care Gap Analysis Report
 - This report is part of a comprehensive assessment of the needs of people at risk for HIV infection and PLWH/A in Utah.
- 2004 Utah HIV/AIDS Treatment and Care Needs Assessment Report
 - This report was designed to help make evidence based decisions concerning the needs of PLWH/A in Utah.
- 2005 Utah HIV/AIDS Treatment and Care Unmet Needs Report
 - The goal of this study was to identify people living with HIV or AIDS in Utah, who knew their HIV status, and are not receiving HIV-related services. This study seeks to identify people living with HIV who are not in care so that efforts can be made to get them into care.
- 2005 Utah HIV/AIDS Treatment and Care Service Priorities
 - This list is a result of the HIV Treatment and Care Committee's priority setting process.

In addition, the Department of Health and the Committee participated in a facilitated process that involved:

- Data review and assessment
- Presentation and analysis of small group reports
- Prioritized lists of Service Needs, Gaps, Barriers and Emerging Needs, developed by consensus
- Evaluation of the process

The resulting SCSN document presents the data the Committee reviewed, identifies the populations and services and documents the level and quality of community participation.

METHODS

Throughout the prior year, HIV Treatment & Care Committee members reviewed data relevant to HIV care in Utah. Monthly meetings from October 2004 to June 2005 were held where members were trained to interpret the data and to analyze the results relevant for developing the SCSN.

An all day meeting was held in October 2005, where data sources were again reviewed, participants worked in small groups to evaluate specific SCSN topics, lists of Service Needs, Gaps, Barriers and Emerging Needs were developed by consensus, and participants evaluated the process. The agenda for this meeting is found in Appendix A (pg 28). Participants included all members of the HIV Treatment and Care Planning Committee (including service providers and consumers), staff from the Utah Department of Health Bureau of Communicable Disease Control (HIV Treatment and Care Program, HIV Prevention Program, STD Control Program, Hepatitis C Prevention, and Tuberculosis Control/Refugee Health Program), select members of the HIV Prevention Community Planning Committee, community advocates, and providers of related services. A list of participants in this process can be found in Appendix B (pgs 29-30).

At the beginning of the SCSN meeting, participants were presented with:

- An overview of the purpose of the SCSN, a description of the SCSN process and the importance of participants role in the process,
- A review of the data sources, with an emphasis regarding the requirements of the SCSN.
- The definitions and tasks required for each working groups were presented to the participants. These groups would focus on the needs of PLWH/A for primary medical care/related services and support services, as well as the gaps in those services and the barriers to their access.

Following the review of the data, participants were each assigned one of three SCSN topics: 1) Service Needs, 2) Gaps, or 3) Barriers. Before separating into small groups to discuss their assigned topic, each participant completed individual worksheets which asked them to document: 1) the data that they reviewed; 2) the issues that they perceived to be the most important (ranked in order); and 3) to identify the most important points for each issue listed. A copy of the worksheets can be found in Appendix C (pgs 31-36). Using these worksheets as the basis for their discussion, each small group then reached consensus on the top five most important points for their assigned topic. Finally each group selected a spokesperson and presented their findings to the entire committee.

Next each participant was assigned to one of four specific populations relating to emerging needs: 1) Women, 2) Rural, 3) Communities of Color or 4) Out of Care PLWH/A. Again they were asked to complete a set of individual worksheets before discussing their population topic in

the small group setting. Then, using these worksheets as the basis for their discussion, each small group reached consensus on their top five most important emerging needs for their population. Each group selected a spokesperson and presented their findings to the entire committee.

Once all of the small group work was presented, the entire committee participated in a consensus-based discussion of cross cutting issues, again beginning with individual worksheets. A scribe recorded the most important issues from each members list and each member of the committee was given two votes to select the top five cross cutting issues. Using all the presented information and following some additional discussion, a list of anticipated trends was also generated.

Finally, each member, using an evaluation worksheet, rated the quality of both their participation in the groups and the group process as a whole.

Data from the groups were compiled, analyzed and presented within this document.

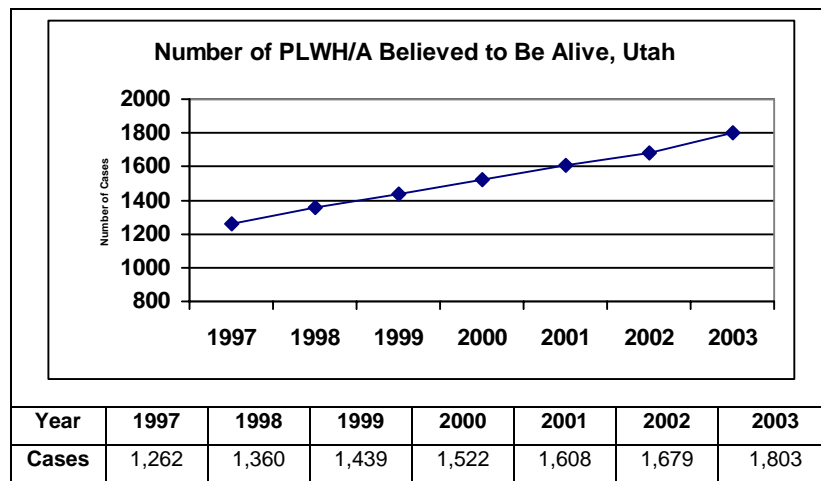
EPIDEMIOLOGY PROFILE

2004 Epidemiology Profile Data

Data from the 2004 HIV Surveillance Report and Community Epidemiology Profile (Epi Profile) provides the core data about the scope of the epidemic in Utah upon which the SCSN is based. The Profile reports combined rates of HIV and AIDS and offers the following key findings:

- The number of HIV infections and AIDS cases has declined steadily since 1993. This trend has also occurred nationally. Incidence rates have decreased from a peak of 14.4 cases per 100,000 persons in 1990, to 3.4 cases per 100,000 in 2002. An increase was observed, however, during the 2002-2003 time period among both men and women. The increase was more pronounced for men than women. The 2003 case rate was 4.7 cases per 100,000 persons.

- The number of deaths from HIV/AIDS in Utah decreased by 84% from a peak of 137 in 1995 to 22 in 2003. This decline continues to mirror national trends and is largely the result of newer and more effective antiviral treatments.
- The number of people living with HIV and AIDS continues to increase. The number of people living with HIV infection who require treatment and care, and who carry the potential for further transmission will continue to increase during the years to come. The following chart illustrates the number of presumed living cases of HIV/AIDS.



- Although most HIV/AIDS cases reported during 1998-2003 for both men and women have occurred among non-Hispanic White persons, the number of cases that occurred among Hispanic and Black people were greatly disproportionate to the size of those two populations.

POPULATION	NUMBER (%)
African/African-American	84 (7%)
American Indian	16 (1%)
Asian-Pacific Islander	14 (1%)
Hispanic	186 (15%)
White	937 (75%)
Unknown	6 (<1%)
Total	1,243

Active Cases through December 31, 2003

- Overall, few changes have occurred in the statewide pattern of HIV/AIDS cases when examined by age, sex, race/ethnic groups and exposure groups.
 - The majority of cases continue to occur among men who have sex with men.
 - The second largest group is related to injecting drug use, including injecting drug users and those who acquired the infection through sexual contact with injecting drug users.

RISK GROUP	NUMBER (%)
MSM	723 (58%)
IDU	177 (14%)
MSM/IDU	115 (9%)
Heterosexual Contact	120 (10%)
Other Risk	31 (2%)
Not Specified	77 (6%)
Total	1,243

Active Cases through December 31, 2003

- Most persons living with HIV or AIDS in Utah are between the ages of 20 and 39 years. This is consistent with findings in most US communities. A concern that arises in these statistics is the possibility that those PLWH/A who are diagnosed in their 20s may have actually been infected in their teens.

AGE RANGE	NUMBER (%)
0-12	10 (1%)
13-19	48 (4%)
20-29	417 (34%)
30-39	502 (40%)
40-49	198 (16%)
50+	68 (5%)
Total	1,243

Active Cases through December 31, 2003

- There has been a gradual shift toward an increased percentage of cases occurring among women and people of color. The following chart shows the

distribution of new cases of HIV/AIDS by gender and race and ethnicity from 1998-2001. Rates are calculated per 100,000 persons.

GROUP	MALE			FEMALE		
	#	%	RATE	#	%	RATE
African/African-American	48	8%	75.3	34	28%	53.4
American Indian	10	2%	10.8	2	2%	2.2
Asian/Pacific Islander	9	1%	5.5	4	3%	2.4
Hispanic	137	22%	22.4	26	21%	4.3
White	411	66%	7.0	54	44%	0.9
Total	620	100%	9.1	123	100%	1.8

SERVICE NEEDS

Utah's successful HIV testing program, which noted an increased HIV positivity rate of 0.4% in 1998 to 0.9% in 2003, and the continued focus on keeping PLWH/A in the system of care has led to an expanding need for a variety services. This is challenging since providers, especially in rural areas, may not be prepared to treat PLWH/A. The various data sources as well as the small group and large committee discussions from the SCSN meeting, call attention to these challenges. The SCSN committee determined the following list to be the community's top five current service needs:

1. Health Insurance
2. Ambulatory Medical Care
3. AIDS Drug Assistance Program (ADAP)
4. Case Management
5. Transportation

Health Insurance

The Gap Analysis assesses need, availability and accessibility when ranking the needs of people at risk for HIV infection and people living with HIV/AIDS in Utah. According to the

findings in this report, the number one priority for Treatment and Care services in Utah is health insurance. The HIV Treatment and Care Committee also ranked health insurance services as the first priority for PLWH/A in Utah. Allocations for this service are strained and have often reached capacity.

Not only is having health insurance important to PLWH/A, but having adequate health insurance is important. One member in the small group discussion brought up the point, “not all health insurance is good health insurance”.

The ability to afford adequate health insurance is also an issue. Premiums, co-pays and Medicaid spend downs can be a huge burden for PLWH/A, especially those living on a fixed income and already facing financial challenges. The 2004 Utah HIV/AIDS Needs Assessment reported that one of the top five barriers to receiving HIV related services is the costs of co-pays or Medicaid spend down.

Ambulatory Medical Care

The Unmet Needs Report shows that 24.2% of the known PLWH/A in Utah are not receiving medical care. The Needs Assessment Report shows that medical visits and related services are the most used of the Ryan White programs. In Utah, there is only one medical provider who receives Ryan White CARE Act funds and that clinic treats more than 60% of those with HIV/AIDS. The HIV Treatment and Care Committee ranked Ambulatory Medical Care as the number one important service priority.

Primary medical care will become an even more critical issue as the current trends of longer life spans for PLWH/A continue. Additionally, vigorous efforts to bring those not receiving treatment into care and a successful HIV testing program could also impact this service.

ADAP

Throughout the country community planners are documenting a crisis in ADAP. Utah is no exception. In July 2004, the Utah ADAP system had reached capacity. In 2003, the ADAP expenditures had climbed to \$1.13 million serving 321 unduplicated clients to whom 105 were new clients. With rates of HIV climbing in Utah, it is anticipated that the need for services will continue. The HIV Treatment and Care Committee ranked ADAP as the number two important service priority.

Case Management

Effective case managers have the ability to connect their clients to available HIV services and keep them in care. One member of the small group said that “case managers play a key part in keeping clients healthy”. Another member noted that “not all case managers are the same – they all need to be aware of the services available and be easily accessible to their clients”. The Needs Assessment states that Utah lacks an adequate number of specially trained case managers offering services to PLWH/A. That and the crucial lack of knowledge is a major barrier to clients attempting to access services.

Case management for PLWH/A is among the most used services, as indicated by service utilization records and by nearly 40% of the Needs Assessment respondents who ranked it 9th among frequency of use. The HIV Treatment and Care Committee ranked case management services as the number three important service priority.

Transportation

Access to available services can be difficult for both rural and urban residents. HIV related services are concentrated within the few urban areas in Utah, especially the Wasatch Front, and most specifically in Salt Lake City. This places rural residents without reliable transportation at a particular disadvantage, especially with long distances to travel and severe seasonal weather conditions.

Urban residents also have transportation challenges when providers of HIV services are located far from their residences and not accessible through public transportation lines. The HIV Treatment and Care Committee ranked transportation services as the number seven important service priority.

BARRIERS

Information about the barriers related to HIV care came from a range of sources, however, much weight was given to the Needs Assessment as the small group assigned to Barriers discussed and ranked the top five barriers affecting PLWH/A in Utah. This group made the

point that these five barriers are from the perspective of the client, not what the Ryan White CARE Act stipulates we spend on what services. The SCSN committee determined the following list to be the community's top five barriers related to HIV care:

1. Funding
2. Housing
3. Transportation
4. Substance Abuse/Mental Illness
5. Culture/Confidentiality

Funding

There are a broad range of issues relating to funding, including, but not limited to: federal funding, co-pays, and spend-down. Several members of the small group pointed out the issue that federal funding has not increased as the number of people living with HIV has increased. As stated in the Needs Assessment, providers want to help, but they don't have the resources. The cost of HIV care is a barrier for consumers, providers and programs. The cost of co-pays and spend downs leave little money for consumers to live on and consumers are less likely to access medical care if they are concerned about the cost of co-pays or have no income for co-pays.

The HIV Treatment and Care Program encourages case managers to effectively screen clients for eligibility for the range of potential sources of treatment funding, such as Medicare, Medicaid and Veteran's Administration funds. Doing so can enhance access to treatment, helps reduce disparities and effectively leverages CARE Act funds, assuring that they are applied as the payment of last resort.

Housing

The following point was highly stressed by the small group: If you are homeless, getting into care or keeping an appointment is NOT a priority. Additionally, it is difficult for providers to help those that are homeless when they are unable to contact them for appointment reminders and case managers are not able to adequately link them to care.

Transportation

There are different issues for people in rural vs. urban areas, but issues are difficult for each, just a different set of challenges. The 2004 Needs Assessment ranked transportation as the number two barrier identified in the consumer focus groups, and stated that transportation was especially a concern if the individual did not live in the Salt Lake area.

A member of the small group stressed that many consumers are unable to afford bus tokens or they cannot afford gas if they have transportation available. There is also a lack of knowledge regarding available transportation resources.

Substance Abuse/Mental Illness

These are separate services, but need to be dually treated, which makes it even harder for PLWH/A to get care. The HIV Treatment and Care Committee ranked both of these services in the top ten priorities (Substance Abuse: #6 and Mental Health: #8).

The Epidemiology Profile indicates that among all admissions in Utah for substance abuse treatment into publicly funded agencies, 44% were for alcohol abuse and 36% were for injection drug use. A comment from the small group discussion was that “PLWH/A who have substance abuse issues are more likely to miss appointments when they are high or using frequently because they tend to over-sleep or forget”. Clearly, active substance use can compromise treatment adherence, general physical and emotional well-being and places PLWH/A at higher risk of unemployment and homelessness.

Another small group member noted that “those with mental health issues are less likely to seek care due to the nature of their illness”. Even mild depression and anxiety can compromise adherence and can adversely affect immunity.

Culture/Confidentiality

Both of these are huge issues and were felt to go hand in hand by the small group. One of the biggest problems is that many doctors don't understand the patient's culture and that there is often a language barrier. Other problems can include: stigma of being HIV+, age, ethnic group, jail inmate, and IDU.

Gaps

As the small group reported their top five gaps in services to the SCSN committee, they noted that they looked at these gaps with the perspective that something is available; there is just not enough of it. The SCSN committee determined the following list to be the community's top five gaps related to HIV care services:

1. Transportation
2. Ambulatory Medical Care
3. Health Insurance
4. Rural Health Care
5. AIDS Drug Assistance Program (ADAP)

Transportation

All PLWH/A need reliable and affordable means of transportation to access HIV related services. There are several reasons why this service is not available to all those who need it. For many, the price of gas is just too expensive to travel, especially for rural clients. Rural clients do not have access to public transportation, but even for urban clients, public transportation isn't always available. Location may prevent clients from easily accessing it and many times PLWH/A are simply too ill to use public transportation. There are limited bus tokens available and cab vouchers are scarce. The demand for transportation far outweighs the availability of resources.

Ambulatory Medical Care

Level funding limits access to medical services needed by PLWH/A and prevents those services from further expansion. Among current medical providers, the incorporation of prevention services and partner referral and counseling for PLWH/A adds to the time required per patient visit and may require additional staff. These conditions are occurring during times of level and even reduced federal funding for HIV-related services. This could potentially lead to providers not competent to give adequate health care.

Statistics in the Unmet Needs report estimate that as much as 24% of known PLWH/A are not currently receiving HIV medical care. As outreach efforts continue to bring these individuals

back into care, the question is raised, how do we pay for their services with no additional funding? In addition to the increasing number of people in need of medical care services, there are a number of infected people who may not know they are infected. As these individuals are tested, how will their medical costs be paid for?

Health Insurance

Economic declines have resulted in reductions in the workforce, reduced wages, removal or reduction of employee benefits, and changes in federal and state policies for service eligibility. Even those lucky enough to have some form of health insurance face increased co-pays, deductibles and spend downs leading to unaffordable out-of-pocket expenses. Also, because many PLWH/A are unable to work or are employed for short periods of time, it is difficult to obtain adequate and complete health coverage.

Rural Health Care

People living in rural communities can feel isolated and reluctant to seek appropriate care. Providers in those areas may not have adequate specialized training for HIV care and/or they may be reluctant to treat patients with HIV for fear of losing other clients.

AIDS Drug Assistance Program (ADAP)

The number of individuals requesting assistance from the ADAP program has significantly grown in the last few years. A total of 322 clients accessed ADAP during 2004. This is almost a 58% increase from 2002 (203 clients). ADAP was forced to close enrollment for all new clients in July 2004 due to the dramatic increases in drug costs, insurance premiums and numbers of individuals requesting assistance. Enrollment for ADAP opened in October 2004 because of carry forward. Without additional financial assistance, these programs could again be closed to new clients.

EMERGING NEEDS BY POPULATION

The SCSN Committee characterized Emerging Needs by analyzing service needs and gaps by sub-populations. Committee members separated into small groups, each targeting one of the four emerging communities: women, communities of color, rural communities, out-of-care

PLWH/A. Their data sources included the Comprehensive Plan, Unmet Needs Report and the Needs Assessment. They also relied a great deal on the data previously presented by the small groups and the subsequent committee discussions. The populations were selected based on increasing rates of disease, degree to which they are receiving services and the presence of barriers to services. During the SCSN planning meeting, the Committee's findings were explored, compared to field reports and summarized. The following lists the sub-populations discussed and their specific needs.

Women

- Access to health care/reproductive health (including abortion & family planning)/STD
- Substance abuse/harm reduction, mental health
- Services for women of color
 - Target in HIV Prevention
- Family and child issues
 - Poverty issues with children
- Poverty/housing issues

Communities of Color

- Legal status/distrust of authority
- Multi lingual services
- Cultural specific services
 - Educational materials
 - Illiteracy and inability to understand the process to receive services, may not know what their needs are
- Lack of gender/color specific providers
- Poverty

Rural communities

- Transportation
- Cultural issues unique to Utah
- Lack of confidentiality
- Lack of social support
- Lack of services/quality providers

Out-of-Care PLWH/A

* Note: this list is based on the participant's perspective because we don't know why these people are out of care. Outreach may be an important component in finding out why they are not in care. The reasons vary widely from person to person.

- Fear/Stigma
- Mental Health
 - Especially in the transient community
- Case Manager
- Funding
 - Finding out if they are eligible for services
- Transportation

CROSS CUTTING ISSUES

Cross cutting issues are those factors affecting provision and access to HIV treatment and care, but are external to the direct delivery of health services. During the SCSN development meeting, the full Committee used a set of worksheets (Appendix D, pgs 37-39) to determine the following to be the most important cross-cutting issues:

- Poverty/Funding
- Transportation
- Substance Abuse/Mental Health
- Cultural Issues
- Case Management

Poverty/Funding

Economic downturns have resulted in reductions in the workforce, reduced wages and elimination or curtailing of employee benefits changes in federal as well as state policies for service eligibility. These have significantly decreased the number of clients who hold health care insurance. Those eligible for CARE Act funds—most of whom already face financial challenges—are among the most vulnerable. As many as 305,000 residents of Utah are uninsured. Further, these changes in eligibility criteria in both the private and public sectors have led to confusion among both clients and providers, leaving some without services even if

they are potentially eligible. Further, additional costs, such as “co-insurance”, “prescription co-pay” etc. can transform a \$500 yearly deductible to more than \$3,000 in out-of pocket in addition to the premiums.

Transportation

Lack of reliable transportation or access to public transportation pose challenges to both rural clients and those who live in more urban communities. Population dispersal in Utah is consistent with other Western states with quite long distances between often very small communities and the majority of health care and supportive services located in the few larger cities. Within those cities, public transportation options are minimal and services are not consistently reachable by public transportation. Fear of being stigmatized often prevents clients from using such services to attend appointments to HIV-specific service providers.

Substance Abuse/Mental Health

The combination of these services is best described in three circumstances. First, these services are offered in the treatment of existing mental illness and substance abuse among clients. Secondly, they are a critical means for enhancing medical treatment adherence. Finally, the services are necessary in the prevention of mental disorders and/or substance abuse that may appear as a result of an HIV diagnosis.

Cultural Issues

Competent services are modified by population. For instance, care for mothers who are HIV positive should include provisions for childcare. Nutritional counseling for the family and supportive services that address the issues of parenting as it is affected by chronic disease should also be available. Services for immigrants must include patient education materials that are in the appropriate language. Interpreters who are linguistically and culturally competent, and also understand and can adhere to the standards of confidentiality, are necessary for appropriate treatment.

Case Management

There needs to be improved coordination within the case management system, especially for people initially entering the system of care. More focus needs to be placed on reaching people who are in crisis or not familiar with the system. However, the need for effective case management is essential to clients in any stage of the disease. Clients with HIV are best served

hen they are paired with case managers who assist them in understanding what services they need and how to most effectively access them.

PARTICIPANT EVALUATION OF PROCESS

Attendees at the SCSN community meeting were surveyed at the completion of the process on their levels of satisfaction with their individual participation and that of the SCSN committee as a whole. A copy of the Evaluation Worksheet can be found in Appendix E (pg 40). This assessment was included as documentation of the depth and quality of community involvement. It also serves as a quality assurance measure for future SCSN processes. A 5-point Likert scale was used to evaluate these parameters, a summary of which is found in the following table. For this purpose, a value of 5 indicated that the respondent was "Very Satisfied" and of 1 that the respondent was "Very Dissatisfied."

Topic	N	Minimum score	Maximum score	Mean
Satisfaction with individual Participation	21	4	5	4.67
Satisfaction with group Participation	21	4	5	4.76

The range of scores is shown in the following chart. As indicated, 100% of participants expressed satisfaction with their level of involvement in the SCSN process. They elaborated in the following comments:

"The individual groups worked well."

"The groups I attended were very active and each member provided their perspective and viewpoint."

"I was highly involved in the discussions."

Level of Satisfaction with Individual Participation

Rating	Frequency	Percent	Cumulative Percent
Very Satisfied	14	66.7%	66.7%
Satisfied	7	33.3%	100.0%

The degree of satisfaction with the group process was consistent with that of the individual participation. Here, too, 100% of attendees expressed satisfaction and none indicated dissatisfaction. Among the comments about the group functioning were the following:

“Both groups had excellent participation – we needed more discussion time for the 2nd group.”

“My ideas were included and were affected by the discussion – good conversation.”

“Understood process fairly well. Good discussion and sharing of ideas and opinions. Enriching.”

Level of Satisfaction with Group Participation

Rating	Frequency	Percent	Cumulative Percent
Very Satisfied	16	76.2%	76.2%
Satisfied	5	23.8%	100.0%

CONCLUSIONS

Consistent with findings across the country, health disparities associated with the economic downturn, inadequate insurance coverage, changes in service eligibility criteria are increasing, especially among the working poor. PLWH/A may be disproportionately affected since they are also confronted with an acute or chronic illness, often with co-morbidities, whose management may require access to very costly medications, frequent contact with health care professionals and possible hospitalizations. Further, those who are eligible for CARE Act funding, are often also coping with low-income issues. To address these concerns, over the course of the year, the Treatment and Care Program will focus its planning and data collection efforts on:

- Defining and understanding the issues associated with those who are not in care
- Defining and proposing strategies for resolving unmet service needs
- Expanding the collaboration with the HIV Prevention Program and Planning Committee
- Client advocacy
- Program evaluation and recognition of best practices

The HIV Treatment and Care Planning Committee and the HIV Prevention Community Planning Committee believe that these measures will allow them to better implement their essential goal of assuring that all people affected by HIV/AIDS have access to highest quality treatment, care and support.

REFERENCES

- 2004 HIV Surveillance Report and Community Epidemiology Profile
- 2004 Utah HIV/AIDS Treatment and Care Gap Analysis Report
- 2004 Utah HIV/AIDS Treatment and Care Needs Assessment Report
- 2005 Utah HIV/AIDS Treatment and Care Unmet Needs Report
- 2005 Utah HIV/AIDS Treatment and Care Service Priorities

APPENDIX A

Utah Statewide Coordinated Statement of Need (SCSN)

Wednesday, October 12, 2005
Utah Dept. of Health (288 N 1460 W),
Room 125

AGENDA

9:00 a.m. – 9:15 a.m.	Welcome & Continental Breakfast
9:15 a.m. – 9:30 a.m.	Purpose of SCSN – Jodie Pond
9:30 a.m. – 10:45 a.m.	Background Information <ul style="list-style-type: none">• Epi Profile – George Usher (30 min)• Gap Analysis – Rachel Reynolds (10 min)• Needs Assessment – Rob Sonoda (20 min)• Unmet Need Report – Rachel Reynolds (10 min)• 2005 Service Priorities – Rachel Reynolds (5 min)
10:45 a.m. – 11:00 a.m.	Break
11:00 a.m. – 11:15 p.m.	2003 SCSN Results – Jodie Pond <ul style="list-style-type: none">• Service Needs• Emerging Needs by Population• Barriers• Cross Cutting Issues
11:15 p.m. – 12:00 p.m.	Break into small groups representing: <ol style="list-style-type: none">1. Service Needs – Janene Fontaine2. Gaps – Rachel Reynolds3. Barriers – Heather Bush Small group discussion
12:00 p.m. – 12:30 p.m.	Boxed Lunches
12:30 p.m. – 1:00 p.m.	Reports from small groups (10 minutes each)
1:00 p.m. – 1:30 p.m.	Break into small groups - Emerging Needs by Population representing: <ol style="list-style-type: none">1. Women – Heather Bush2. Communities of color – Rob Sonoda3. Rural communities – Rachel Reynolds4. Out of care PLWH/A – Janene Fontaine
1:30 p.m. – 2:10 p.m.	Reports from small groups (10 minutes each)
2:10 p.m. – 2:50 p.m.	Discussion – Jodie Pond <ul style="list-style-type: none">• Cross-cutting Issues• Anticipated Trends (4-6 years)
2:50 p.m. – 3:00 p.m.	SCSN Process Evaluation Wrap-up & Adjourn

APPENDIX B

Statewide Coordinated Statement of Need Meeting - List of Attendees

Wednesday, October 12, 2005

Adams, Ruthann	HIV/AIDS Task Force of Washington County Member, HIV Prevention Community Planning Committee
Brown, Jennifer	Utah Department of Health, Communicable Disease Control Bureau Director
Bush, Heather	Utah Department of Health, HIV Prevention Program Member, HIV Prevention Community Planning Committee
Chesler, Cristie	Utah Department of Health, TB Control and Refugee Health Program
Day, Curtis	Consumer Member, HIV Treatment and Care Planning Committee
DeWitt, M. Jann	University of Utah Health Science Center, Dept of Family & Preventative Medicine Ryan White Title V Member, HIV Prevention Community Planning Committee
Ferguson, David	Utah AIDS Foundation (Case Management) Member, HIV Prevention Community Planning Committee
Fontaine, Janene	Utah Department of Health, HIV Treatment and Care Program
Fronberg, Rebecca	Utah Department of Health, HIV Prevention Program
Garrett, Teresa	Utah Department of Health, Epidemiology Division Director
Gotchy, Dan	Catholic Community Services (Housing Provider)
Jarman, John	Consumer Member, HIV Treatment and Care Planning Committee
Johnson, Linda	Health Insight (Quality Management) Member, HIV Treatment and Care Planning Committee
Kone, Karen	VA Medical Center Member, HIV Treatment and Care Planning Committee
McClellan, Sarah	Northern Utah Coalition, Inc (Outreach) Member, HIV Prevention Community Planning Committee
Norris, Erin	Project Reality (Mental Health Counseling)
Parker, Karin	Utah Department of Health, HIV Treatment and Care Program
Pond, Jodie	Utah Department of Health, HIV Treatment and Care Program Member, HIV Treatment and Care Planning Committee

Reynolds, Rachel	Utah Department of Health, HIV Treatment and Care Program
Rood, Brian	University of Utah Health Science Center, Division of Infectious Diseases Ryan White Title III Member, HIV Treatment and Care Planning Committee
Shaw, Jennifer	Community Nursing Services (Home Health Care) Member, HIV Treatment and Care Planning Committee
Sonoda, Rob	Utah Department of Health, HIV Prevention Program
Schluter, Rita	Advocate Member, HIV Treatment and Care Planning Committee
Smith, Dana	University of Utah Health Science Center, Division of Infectious Diseases Member, HIV Treatment and Care Planning Committee
Sturdy, Pauline	Utah State Prison, Clinical Services Member, HIV Treatment and Care Planning Committee
Taylor-Martinez, Katie	University of Utah Health Science Center, Division of Infectious Diseases
Usher, George	Utah Department of Health, HIV Surveillance Program
Wallentine, Melanie	Utah Department of Health, Hepatitis C Coordinator
Wheeler, Cliff	Consumer Member, HIV Treatment and Care Planning Committee
Wiley, Karen	Salt Lake City Corporation (Housing Provider) Member, HIV Treatment and Care Planning Committee
Wilson, Ryan	Utah Department of Health, Sexually Transmitted Disease Control Program

APPENDIX C

Group Worksheet 1

- Topic _____
- List data reviewed

Group Worksheet 2

- Topic _____
- List all issues and number of persons who included each in her/his list

Group Worksheet 3

- Topic _____
- Rank top 5 items and number of votes associated with each

Personal Worksheet 1

- Affiliation _____
- Topic _____
- List data reviewed

Personal Worksheet 2

- Affiliation _____
- Topic _____
- List Your issues
 - Rank in importance (1 = highest priority)

Personal Worksheet 3

- Affiliation _____
- Topic _____
- For each item generated:
 - Identify most important points

APPENDIX D

Cross cutting Issue Worksheet 1

- List any factors that you believe influence treatment, care and services delivery to PLWH/A in Utah.

Cross cutting Issue Worksheet 2

- From your list, please select the 5 most important issues and rank the 1-5; (5 = most important).

Cross cutting Issue Worksheet 3

- From the worksheet 2 list, please select the 5 most important issues and rank them 1-5 (5 = most important).

APPENDIX E

Personal Evaluation Worksheet

Topic _____

- Please describe your level of participation in the SCSN process:

- _____

- Satisfaction with your level of participation:
(Please check one)

- Very satisfied _____
- Satisfied _____
- Neutral _____
- Dissatisfied _____
- Very dissatisfied _____

- Please describe the effectiveness of your group in the SCSN process:

- _____

- Satisfaction with the group:
(Please check one)

- Very satisfied _____
- Satisfied _____
- Neutral _____
- Dissatisfied _____
- Very dissatisfied _____