

Statewide Coordinated Statement of Need

Ryan White HIV/AIDS Part B



**UTAH DEPARTMENT OF
HEALTH**

**Utah Department of Health
Division of Disease Prevention and Control
Bureau of Epidemiology
HIV Treatment and Care Services Program**

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*** Please see Appendix B for a complete list of attendees at the Statewide Coordinated Statement of Need Meeting held on Tuesday, January 31, 2012**

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EXECUTIVE SUMMARY

Introduction

The Utah Department of Health, Bureau of Epidemiology, Treatment and Care Services Program, prepares the Statewide Coordinated Statement of Need (SCSN), every three years in accordance with the Ryan White Treatment Modernization Act of 2006.

The SCSN is prepared through the collective efforts of:

- The Utah Department of Health (UDOH);
- Members from the HIV Treatment and Care Planning Committee;
- The Ryan White Part C Program;
- The Ryan White Part D Program;
- The AIDSETC Program;
- Members from the HIV Prevention Community Planning Committee;
- HIV/AIDS service providers;
- HIV+ consumers; and
- Other interested community members.

For this report, those data sources included the:

- 2011 HIV Surveillance Report and Community Epidemiology Profile Update
- 2009 Utah HIV/AIDS Treatment and Care Needs Assessment Report
- 2011 Utah HIV/AIDS Treatment and Care Unmet Need and Service Gap Report
- 2011-12 Utah Ryan White Part B HIV Treatment and Care Service Priorities and Resource Allocations
- 2009 Ryan White Part B Comprehensive HIV/AIDS Care and Services Plan

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

- Data review and assessment,
- Individual participation in small break-out groups,
- Presentations and discussion of small group work,
- Listing of cross-cutting issues, shortfalls in healthcare workforce, and anticipated trends developed by consensus, and
- Evaluation of the process.

Methods

The SCSN meeting was held on Tuesday, January 31, 2012 at the Utah Department of Health. The agenda for this SCSN meeting can be found in Appendix A. A list of participants in this process can be found in Appendix B.

Participants then spent much of their time contributing to small group discussions and evaluating specific SCSN topics including:

- Needs of individuals who are aware of their HIV-positive status but are not in care (with an emphasis on outreach, referral, and linkage to care needs),
- Needs of individuals who are unaware of their HIV-positive status (with an emphasis on outreach, counseling and testing, referral, and linkage to care needs),
- Obstacles to accessing care (including gaps and overlaps in care, as well as priorities in addressing underserved populations),
- Current/ Emerging Needs by Special Populations:
 - Homeless
 - Transgender
 - Rural
 - Injection Drug Users
 - Adolescents

Once all of the small group work was presented, the entire committee participated in a facilitated discussion of the following SCSN-related areas:

- Cross-Cutting Issues
- Shortfalls in Healthcare Workforce
- Anticipated Trends

HIV/AIDS in Utah – State Epidemiological Profile

At the end of 2010, there were a reported 1,169 individuals living with HIV. The majority (69%) of HIV (non-AIDS) positive individuals were White. As of December 31, 2010, there were 980 (84%) males and 189 (16%) females reported with HIV. The most common exposure category for HIV was men who have sex with men (MSM), this category comprised 636 of the cases (54%). Over the last eight years (2003-10), there has been a significant increase in the number of HIV cases reported among White males who have sex with men and inject drugs. The

increase is likely due to the increased use of methamphetamines in the MSM community. For women, the major risk factors were heterosexual contact and injecting drug use.

At the end of 2010, there were a reported 1382 individuals living with AIDS. The majority (70%) of individuals reported with AIDS were White. Although most HIV and AIDS cases in Utah occurred among White males, the number of cases that occurred among Black and Hispanic persons was disproportionate to the size of these two populations; thus, the risk for HIV and AIDS is higher in these populations. Most AIDS cases reported were in the risk group MSM (782 cases or 57%)

From January 1, 2009 through December 31, 2010, a total of 56 new AIDS cases and 152 HIV cases have been reported to the Utah Department of Health. During these two years, 28 individuals (50%) diagnosed with AIDS were White. Of the 56 individuals with AIDS, 49 (88%) were male and 7 (13%) were female. The most common risk group for HIV/AIDS cases was MSM (59%).

Obstacles to Accessing Care

1. Gaps

- Rural
- Transportation
- Lack of available services
- Lack of qualified providers
- Funding
- Stigma
- Education

2. Overlaps in care

- Very few

3. Priorities in Addressing Underserved Populations

- Access to adequate transportation
- Increased funding for services
- Increased education of available services

Needs of Individuals who are Aware of Their HIV Status But Not in Care

1. Outreach

- Fear of disclosing status
- Stigma
- Lack of privacy and confidentiality
- Unaware of available help
- Questions of how do I take care of myself?
- Fear of treatment itself
- Lack of skills to cope
- Cultural and/or linguistic barriers

2. Referral

- Limited number of services
- Lack of funding
- Education
- Trust

3. Linkage to Care

- Maintain relationships between program and providers
- Invite providers to meetings
- Attend lectures and presentations

Needs of Individuals who are Unaware of Their HIV Status

1. Outreach

- Access to the event/location
- Confidentiality if located in smaller communities
- Fear of individual finding out test results
- How to reach youth populations
- Including all populations in pre-screening (i.e. identifying as transgender, include male to female or female to male)

2. Counseling and Testing

- Low perception of risk
- Stigma

- Apathy, especially with youth
- Fear of finding out
- Denial issues – fear of facing reality, responsibility, and/or accountability
- Fear of losing insurance, and for young people, the fear of their parents finding out if they are on their parent’s insurance
- Disclosure issues
- Lack of education or awareness about HIV

3. Referral and Linkage to Care

- Positive test → Refer to Clinic 1A at University of Utah Hospital
- Clinic will refer to other doctor if needed (insurance issues)
- Not all private clinic and hospitals refer newly positive individuals to care
- Important for local disease investigation specialist to contact and refer all positive cases to care
- No activities in place to make sure individual went to their medical appointment

Needs of Special Populations

1. Adolescents

- Prevention education, especially since disease transmission is not taught in public schools
- Issues of exploitation (getting into bars, underage drinking)
- Issues related to “survival sex” (sex for food, shelter, drugs, etc.)
- Trust & confidentiality issues specific to this population
- Substance abuse services (specifically injection drug use)
- Youth friendly testing sites for testing, education and counseling
- Easy access to condoms and increasing the condom distribution sites
- Realizing that adolescent issues are likely underreported and the need is actually much higher than we have data for

2. Injection Drug Users

- Lack of substance abuse counseling and treatment options available
- No needle exchange programs in Utah
- Lack of resources for basic needs
- Relapse and cross addiction issues (coupling GHB and methamphetamines)

- Lack of social network and support
- Lack of motivation for change
- Issues of exchanging sex for drugs/money – doing things normally would not do
- Lack of advocates for IDU – lack of understanding of specific problems of this special population

3. Homeless

- Options for permanent affordable housing
- Treatment for mentally ill individuals
- Drug and alcohol abuse treatment
- Transportation, especially when it comes to medical care and treatment adherence
- Lack of support system
- Some individuals may face language barriers
- Education opportunities (difficult to contact them, may have distrust of authority)
- Lack of job/income

4. Transgender

- Issues of trust
- Not currently being identified appropriately in applications, etc.
- Not currently targeted for testing
- Training for providers to understand their issues
- Drug and alcohol abuse treatment
- Prevention education – don't see themselves as at risk for HIV

5. Rural

- Availability of HIV providers and services (may avoid local providers due to fear or stigma, and local providers don't want to be known as the "HIV Dr")
- Issues with denial and engaging in risky behavior – what happens in the big city stays in the big city
- Issues with confidentiality, stigma, and culture
- Community denial – we don't have a problem here, "not in my town" mentality
- Lack of case management services
- Issues with upcoming 2014 healthcare changes – treating HIV+ patient in community health centers (quality of care and training of doctors)

Shortfalls in Healthcare Workforce

- Health Care Reform in 2014
- Funding
- Legislative rules and laws

Cross-Cutting Issues

- Transportation
- Availability of resources
- Services cut from Ryan White Supported Services (dental, mental health, and substance abuse)
- Issues of trust and privacy
- Education – both for individuals and for providers
- Having multiple risks
- Stigma
- Self-efficacy and the willingness to advocate for improved change
- Lack of support systems
- Advocacy
- Improved access to testing and counseling services
- Culturally appropriate care
- Addressing language barriers

Anticipated Trends

- Health Care Reform
- Politics – different views, shifts in elected officials, balance in power
- Decreased funding
- Population changes – influx of people to Utah
- Needs of undocumented individuals
- Advances in treatment, increased costs associated with new treatments
- New illegal drugs – how they affect the mind and behavior risks
- Hooking up online – advancing technology
- Increased apathy

Participant Input Incorporated into the SCSN Process

1. Entities

The following entities participated in the SCSN process:

- Ryan White Part B Program
- Ryan White Part C Program
- Ryan White Part D Program
- AETC Administrators
- People Living with HIV/AIDS
- Providers and Advocates

2. Evaluation of process

- 100% of participants expressed satisfaction with their level of involvement in the SCSN process.
- The degree of satisfaction with the small group process was consistent with that of the individual participation. 100% of attendees expressed satisfaction and none indicated dissatisfaction.

Utah Department of Health
Statewide Coordinated Statement of Need
June 2012

Introduction

The Utah Department of Health, Bureau of Epidemiology, Treatment and Care Services Program, prepares the Statewide Coordinated Statement of Need (SCSN), every three years in accordance with the Ryan White Treatment Modernization Act of 2006.

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 Ryan White HIV/AIDS Program Parts.”

The SCSN is prepared through the collective efforts of the Utah Department of Health (UDOH), members from the HIV Treatment and Care Planning Committee, the Ryan White Part C Program, the Ryan White Part D Program, the AIDSETC Program (Ryan White Part F), members from the HIV Prevention Community Planning Committee, HIV/AIDS service providers, HIV+ consumers, and other interested community members.

For this report, those data sources included the:

- 2011 HIV Surveillance Report and Community Epidemiology Profile Update
 - 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.

- 2009 Utah HIV/AIDS Treatment and Care Needs Assessment Report
 - The primary goal of the Needs Assessment Survey is to enable the Treatment and Care Services Program, the Communicable Disease Prevention Program, and each of their respective planning committees to make evidence-based decisions concerning the needs of PLWHA in Utah. Other goals were to identify disproportionate need between demographic groups and to identify barriers to service that PLWHA might encounter.
- 2011 Utah HIV/AIDS Treatment and Care Unmet Need and Service Gap Report
 - The goal of this study is to identify people living with HIV or AIDS in Utah, who know 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.
- 2011-12 Utah Ryan White Part B HIV Treatment and Care Service Priorities and Resource Allocations
 - This list is a result of the HIV Treatment and Care Committee's priority setting and resource allocation process.
- 2009 Ryan White Part B Comprehensive HIV/AIDS Care and Services Plan
 - The Comprehensive Plan provides a road map for developing a system of care over time. It does so by reviewing needs assessment data, existing resources to meet those needs, and barriers to care. This information is used to set out long-term goals, objectives, and strategies for delivering services. The plan also reflects the community's vision and values about how best to deliver HIV/AIDS care, particularly in light of limited resources.

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

- Data review and assessment,
- Individual participation in small break-out groups,
- Presentations and discussion of small group work,
- Listing of cross-cutting issues, shortfalls in healthcare workforce, and anticipated trends developed by consensus, and
- 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

The SCSN meeting was held on Tuesday, January 31, 2012 at the Utah Department of Health. Participants included members of the HIV Treatment and Care Planning Committee (including service providers and consumers), staff from the Utah Department of Health Bureau of Epidemiology (Treatment and Care Services Program and Communicable Disease Prevention Program), staff from the Ryan White Part C Program, staff from the Ryan White Part D Program, staff from the AIDS ETC Program (Ryan White Part F), community advocates, and providers of related services. The agenda for this SCSN meeting can be found in Appendix A. A list of participants in this process can be found in Appendix B.

SCSN committee members were first 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,
- Highlights from the data sources, with an emphasis regarding the requirements of the SCSN, and
- The definitions and tasks required for each working group were presented to the participants.

Participants then spent much of their time contributing to small group discussions and evaluating specific SCSN topics including:

- Needs of individuals who are aware of their HIV-positive status but are not in care (with an emphasis on outreach, referral, and linkage to care needs),
- Needs of individuals who are unaware of their HIV-positive status (with an emphasis on outreach, counseling and testing, referral, and linkage to care needs),
- Obstacles to accessing care (including gaps and overlaps in care, as well as priorities in addressing underserved populations),
- Current/ Emerging Needs by Special Populations:
 - Homeless
 - Transgender
 - Rural

- Injection Drug Users
- Adolescents

Through facilitated discussion, each small group explored important points for their assigned topic. Time was allowed for everyone to share their views and expertise. A scribe within each small group took notes to capture the important points of these discussions on a large poster sized paper (See Appendix C). Finally 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 facilitated discussion of the following SCSN-related areas:

- Cross-Cutting Issues
- Shortfalls in Healthcare Workforce
- Anticipated Trends

Using all the presented information and group discussion, a scribe again took notes to capture the important points of these discussions on three large poster sized papers (See Appendix C).

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 have been compiled, analyzed and presented within this document.

HIV/AIDS in Utah – State Epidemiological Profile

At the end of 2010, there were a reported 1,169 individuals living with HIV. The majority (69%) of HIV (non-AIDS) positive individuals were White; Hispanics comprised 18% of the cases; Black persons comprised 10% of the cases; American Indians comprised 1% of the cases; Asian/Pacific Islanders comprised 1% of the cases; and unknown race/ethnicity comprised 2%. As of December 31, 2010, there were 980 (84%) males and 189 (16%) females reported with HIV. The most common exposure category for HIV was men who have sex with men (MSM); this category comprised 636 of the cases (54%). The following were the rankings of the remaining exposure categories for HIV (not AIDS): men who have sex with men/injecting drug users (173 cases, 15%), injecting drug users (109 cases, 9%), and heterosexual risk (99 cases, 9%). The other/undetermined exposure category included 152 cases (13%). Over the last eight

years (2003-10), there has been a significant increase in the number of HIV cases reported among White males who have sex with men and inject drugs. The increase is likely due to the increased use of methamphetamines in the MSM community. For women, the major risk factors were heterosexual contact and injecting drug use.

Starting in 2003, the number of HIV infection reports has exceeded the number of AIDS case reports over the last eight years. This trend may be due to an increase in the number of HIV tests performed, the introduction of the HIV rapid-testing in mid-2003, and more effective anti-retroviral drugs which keep an HIV positive person in the HIV (non-AIDS) category longer.

At the end of 2010, there were a reported 1382 individuals living with AIDS. The majority (70%) of individuals reported with AIDS were White; Hispanics comprised 19% of the cases; Black persons comprised 8% of the cases; American Indians comprised 2% of the cases; and Asian/Pacific Islanders comprised 1% of the cases. Although most HIV and AIDS cases in Utah occurred among White males, the number of cases that occurred among Black and Hispanic persons was disproportionate to the size of these two populations; thus, the risk for HIV and AIDS is higher in these populations.

Most AIDS cases reported were in the risk group MSM (782 cases or 57%), followed by injecting drug users (187 cases or 14%), MSM/IDU (175 cases or 13%), heterosexual contact (126 cases or 9%), and risk not specified (112 cases or 8%). The risk factors for women by order of magnitude were heterosexual contact, injecting drug use, and risk not specified.

From January 1, 2009 through December 31, 2010, a total of 56 new AIDS cases and 152 HIV cases have been reported to the Utah Department of Health. During these two years, 28 individuals (50%) diagnosed with AIDS were White, 23 individuals (14%) were Hispanic, four individuals (7%) were black, one individual (2%) was Asian/Pacific Islander, and no individuals (0%) were American Indians or had an unknown ethnicity/race. Of the 56 individuals with AIDS, 49 (88%) were male and 7 (13%) were female. The most common risk group for HIV/AIDS cases was MSM (59%), followed by MSM/IDU (9%), and injecting drug users (5%).

Obstacles to Accessing Care

1. Gaps

The 2011 Utah HIV/AIDS Unmet Need and Service Gap Report (Unmet Needs Report) shows that of the 2,540 known PLWH/A within the state, 11.4% (289 cases) are not receiving medical care. The 2009 Needs Assessment showed that medical visits and related service were the most used of the Ryan White programs (medical visits, 97.5%; CD4 counts or viral load test, 96.7%). In Utah, there is only one medical facility who receives Ryan White HIV/AIDS Treatment Modernization Act funds and that clinic serves a majority of all Ryan White clients in the state.

One of the first issues discussed in this small group setting was the issue of rural areas in Utah. Rural areas are any areas that are not considered to be along the Wasatch Front. The Wasatch Front consists of four neighboring counties in Utah (Salt Lake, Weber, Davis, and Utah) that comprise the urban center, where the majority of the state's population resides. Of the 208 Utah individuals reported with HIV/AIDS in 2010, 187 (90%) live along the Wasatch Front. Sixty-five percent of these individuals live in Salt Lake County. The majority of individuals from rural areas continue to come to Salt Lake City for their medical treatment. Many PLWH/A are at or below poverty which makes it difficult to own, operate and/or maintain a vehicle. Public transportation may not be easily accessible, especially for rural clients needing to travel to Salt Lake for appointments. In recent years, public transportation has increased in cost and many PLWH/A just cannot afford it. People living in rural communities can feel isolated and reluctant to seek appropriate care. In addition, 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.

Funding was also a highly discussed topic in this group. Reduced and level federal funding combined with lack of funding support from the state makes it difficult to keep programs open and services available. Increased utilization in recent years has further stressed this funding situation and many services were discontinued due to cost containment strategies. Dental services, mental health counseling, and substance abuse services are a few of the services no longer offered through the Ryan White Part B Supportive Services Program. The complex issues associated with mental health and substance abuse further complicate efforts with medication adherence. Additionally, HIV medications are expensive. The ADAP Program has been intermittently closed over the past 3 years due to lack of funding to

sustain clients on the program. The eligibility requirements for all Part B programs, including lowering the federal poverty level from 400% to 250% to qualify for services has made it difficult for many to obtain services. Access to costly medications is a rising concern.

Utah has a very conservative mindset. The stigma associated with HIV/AIDS can make disclosing HIV status to friends and family, even medical providers difficult. Education is always a crucial need for individuals who don't know where to go to obtain services and what services are available.

2. Overlaps in care

The group discussed the issue of overlaps in care and felt that there was very little of this going on in Utah. They could not think of any examples of overlaps in care.

3. Priorities in Addressing Underserved Populations

Top priorities include:

- Access to adequate transportation
- Increased funding for services
- Increased education of available services

Needs of Individuals who are Aware of Their HIV Status But Not in Care

1. Outreach

According to the 2011 Unmet Needs Report, it is estimated there are 289 (11.4%) HIV+/aware individuals in Utah that are not in care. This number includes 250 PLWH and 39 PLWA. The PLWH population demonstrated a higher level of unmet need ($n = 250$; 23.4%) than the PLWA population ($n = 39$; 2.6%). This means that there are more people out of care in the PLWH population than in the PLWA population. One possible explanation is that PLWH are not as likely to experience symptoms that would persuade them to seek primary medical care. As a result, PLWH have a higher level of unmet need. The opposite is true for the PLWA population. PLWA are more likely to experience symptoms that would persuade them to seek primary medical care.

The small group discussion for this topic included several possible reasons why these individuals are not in care. Since this population is difficult to question and survey, we can

only assume what some of the reasons are why they are not in care. Possible explanations include:

- Fear of disclosing status
- Stigma
- Lack of privacy and confidentiality
- Unaware of available help
- Questions of how do I take care of myself?
- Fear of treatment itself
- Lack of skills to cope
- Cultural and/or linguistic barriers

The Utah Part B Program and the Communicable Disease Prevention Program collaborate together to find people who are aware of their status but are not in medical care.

Collaboration activities include joint trainings and activities, and the bi-annual needs assessment for HIV positive people in Utah. Staff from the Utah Part B Program are involved in outreach activities such as HIV testing in the communities along the Utah-Nevada border, which traditionally has high rates of HIV.

Every two to three years the two programs conduct a needs assessment of PLWHA. The primary goal of this study is to enable the Utah Part B Program, the Communicable Disease Prevention Program, and each of their respective planning committees to make evidence-based decisions concerning the needs of PLWHA in Utah. Other goals are to identify disproportionate need between demographic groups and to identify barriers to service that PLWHA might encounter. Information from the needs assessment surveys can be useful for linking people into care. For example, past needs assessment surveys have shown that survey respondents in rural areas were more likely to wait more than six months after diagnosis to enter into medical care and youth and women of color were less likely to have received primary medical care in the past 12 months. Case management was also rated highly by these three groups and could be used to help link these groups to primary medical care.

2. Referral

The Utah Part B Program coordinates with the prevention and disease control programs in referring individuals to appropriate supportive services; however this is weakest link in the

identifying, informing, referring, and linking chain. One reason for weak referrals is the limited number of services that exist for HIV positive individuals and negative individuals who engage in high-risk behaviors. Besides case management and some money for transportation to medical appointments, the Utah Part B Program has no supportive services to offer individuals. A lack of funds eliminated the majority of services and funding limitations have also affected the other HIV service organizations.

Individuals who are aware of their HIV status but not in care may have a variety of reasons for choosing to remain untreated. One of which may be not knowing what services are available to help (even beyond Ryan White Part B services). Educating this population on what their options are and having case managers available to guide them through the process of obtaining financial help and services is important. Building trust with these individuals is also a huge obstacle in referring them to care.

3. Linkage to Care

The Utah Part B Program works to form and maintain relationships with private HIV health care providers. Every quarter there is a community ADAP advisory board meeting that is open to the public and HIV care providers are invited. Every other month there is a Ryan White coordination meeting between the Part B, C, and D Programs that is attended by case managers, support staff, and medical providers. The Program invites HIV providers to the annual community priority setting and resource allocation meetings, although these meetings are usually attended by case managers and program managers and often not by persons who provide direct patient care. The ADAP administrator and other program staff attend lectures and presentations that are clinically-oriented, in part, to establish relationships with HIV medical care providers in the area.

Needs of Individuals who are Unaware of Their HIV Status

1. Outreach

The Utah Part B Program and the Communicable Disease Prevention Program collaborate together to find people who are unaware of their HIV status. As testing events and places to hold these events are planned, many factors need to be considered, including:

- Access to the event/location;
- Confidentiality if located in smaller communities;
- Fear of individual finding out test results;

- How to reach youth populations; and
- Including all populations in pre-screening (i.e. identifying as transgender, include male to female or female to male).

2. Counseling and Testing

One advantage Utah has as a low incidence state with the majority of the population concentrated in one geographic area is that there are relatively few HIV tests given each year and the number of community organizations, clinics, and hospitals and the associated staff that have to give the test and then provide the result is also relatively small compared with high incidence states. This is one of the reasons why there are so few unaware individuals who are not informed of their positive HIV test results.

Encouraging everyone to get tested and know their HIV status is essential. People have many excuses why they do not want to get tested. Some of those may include:

- Low perception of risk;
- Stigma;
- Apathy, especially with youth;
- Fear of finding out;
- Denial issues – fear of facing reality, responsibility, and/or accountability;
- Fear of losing insurance, and for young people, the fear of their parents finding out if they are on their parent's insurance;
- Disclosure issues; and
- Lack of education or awareness about HIV.

Even individuals who do decide to test for HIV may not wait for their results, missing a post-counseling opportunity, or they may not be truthful in giving personal information. It may be helpful to have one person helping them throughout the testing and counseling process to build trust, educate and ease fears.

3. Referral and Linkage to Care

The current referral process in place now is a relatively straight-forward system. The guidelines are that everyone who gives a positive test result in Salt Lake City and the surrounding area needs to set up an appointment at Clinic 1A, the infectious disease clinic at the University of Utah Hospital, and then the case managers at Clinic 1A can determine if

the person can best be served at Clinic 1A or if he or she needs to go to another doctor based on the newly identified person's insurance, area of residence, or some other factor. If individuals are given a positive test result outside of Salt Lake, the counselor who is providing the result will refer the individual to medical care at the closest doctor or if the counselor is unfamiliar with HIV medical care providers in the area, the counselor will call up the Utah Department of Health and ask about nearby resources.

Individuals who test positive for HIV at private clinics or hospitals often do not go through the same set process as described above. Hopefully the health care provider is familiar with HIV medical providers in the area or has access to this information. Since this is not always the case, the essential piece is to make sure the newly diagnosed individual is contacted by a local disease investigation specialist who can ensure the individual has access to needed services including medical care. When a person is newly identified as HIV positive at a state-funded test site, a form is filled out for the new positive individual and one of the questions on the form asks if a referral into care been made. The next step to take, as taught in the HIV Prevention Counseling class and communicated to local health department nurses, is to make an appointment for every new positive at Clinic 1A, which is described in the above section. Ideally the person making the referral would then call the newly identified positive person in a week or two and see how he or she is doing and if the appointment was kept. However some people who complete the form will simply answer 'yes' if a referral was made and then turn it in to the Communicable Disease Prevention Program without waiting or checking up to see if the appointment was made. There are no other activities in place to ensure that a person made it to the medical appointment.

Needs of Special Populations

1. Adolescents

According to the 2009 Needs Assessment, adolescents consistently responded they were more likely to engage in high risk behavior that put them at risk for contracting HIV disease. Some of these high risk behaviors included:

- Adolescents reported they were more likely to have sex under the influence of drugs and/or alcohol, as compared to the entire sample.
- Adolescents reported they were more likely, as compared to the entire sample, to report that they never ask the HIV status of their internet or non-internet sex partner.

- Adolescents had higher percentages within their group reporting that they did not know whether or not they had had unprotected sex within the past 12 months with a primary, internet, or non-internet sex partner who has HIV or AIDS. An interesting trend is among youth and rural groups; as the sex becomes more anonymous, the likelihood of asking about HIV status decreases.
- Adolescents reported they were more likely, as compared to the entire sample, to trade sex for money during the last 12 months.

In regards to Treatment and Care, adolescents reported through the 2009 Needs Assessment Survey that they were less likely to have received primary medical care and were less likely to have received antiretroviral therapy, as compared to the entire sample. Adolescents were the most likely to report they didn't know if they had a case manager, as compared to the entire sample. Complicating treatment and care efforts even further, adolescents were more likely to report that they have been homeless at least once during the past 12 months.

The SCSN Committee small group assigned to discuss the needs of adolescents presented the following list of potential needs for this special population to the full committee:

- Prevention education, especially since disease transmission is not taught in public schools;
- Issues of exploitation (getting into bars, underage drinking);
- Issues related to "survival sex" (sex for food, shelter, drugs, etc.);
- Trust & confidentiality issues specific to this population;
- Substance abuse services (specifically injection drug use);
- Youth friendly testing sites for testing, education and counseling;
- Easy access to condoms and increasing the condom distribution sites; and
- Realizing that adolescent issues are likely underreported and the need is actually much higher than we have data for.

2. Injection Drug Users

Injection drug users (IDU) appeared more likely to wait more than six months after diagnosis to receive medical care, are less likely to remain in primary medical care, and were less likely to have received antiretroviral therapy, according to the 2009 Needs Assessment results. IDUs also had higher percentages reporting that they had skipped or stopped taking

HIV/AIDS medication at least once. IDUs were more likely to be uninsured and IDU were the group most likely to have been in prison or jail, stayed in a hotel or motel, been homeless or in a shelter, or been in a half-way house. They were also least likely to have rented or owned a home.

IDUs were less likely to have a case manager, and those who did have a case manager were the least likely to have seen their case manager within the last six months. This population was more likely to have someone other than a case manager who helps them get services, as compared to the entire needs assessment sample.

Approximately 31.0% of the entire needs assessment sample report having used injecting drugs at least once. Not surprisingly, MSM/IDU (60.7%), white MSM (34.9%), IDU (not MSM) (33.3%), and youth (33.3%) had substantially higher percentages within their respective groups indicating that they had used injecting drugs within the past 12 months and MSM/IDU were more likely to have shared needles at least once, compared with the entire sample. IDU populations also responded they were more likely to either “most of the time” or “some of the time” have sex under the influence of drugs than the entire sample.

The SCSN Committee small group assigned to discuss the needs of IDUs presented the following list of potential needs for this special population to the full committee:

- Lack of substance abuse counseling and treatment option available;
- No needle exchange programs in Utah;
- Lack of resources for basic needs;
- Relapse and cross addiction issues (coupling GhB and methamphetamines);
- Lack of social network and support;
- Lack of motivation for change;
- Issues of exchanging sex for drugs/money – doing things normally would not do; and
- Lack of advocates for IDU – lack of understanding of specific problems of this special population.

3. Homeless

Several of the other special populations discussed during this SCSN committee meeting can also fit into either temporary or permanent classifications of homelessness. According to the 2009 Needs Assessment report, IDU, women from communities of color, MSM/IDU,

heterosexuals from communities of color, and youth were more likely, as compared to the entire sample, to report that they have been homeless at least once during the past 12 months. A trend in the data was that communities of color were more likely to have been homeless at least once during the past 12 months, as compared to the entire sample. Respondents in rural areas and respondents that were white were more likely to own a home, as compared to the entire sample. IDU were the group most likely to have been in prison or jail, stayed in a hotel or motel, been homeless or in a shelter, or been in a half-way house. They were also least likely to have rented or owned a home.

The SCSN Committee small group assigned to discuss the needs of individuals who are homeless presented the following list of potential needs for this special population to the full committee:

- Options for permanent affordable housing;
- Treatment for mentally ill individuals;
- Drug and alcohol abuse treatment;
- Transportation, especially when it comes to medical care and treatment adherence;
- Lack of support system;
- Some individuals may face language barriers;
- Education opportunities (difficult to contact them, may have distrust of authority); and
- Lack of job/income.

4. Transgender

Unfortunately there is little data to report the needs of transgender in Utah. Possible explanations to this discrepancy could be this population does not feel comfortable identifying themselves as transgender or we as a program are not doing a good job of making them feel understood. It is probably a little of both. It is important to further explore this issue and make sure reports, surveys, applications, etc. include a transgender option for this population to identify with, and to further break that option down into identifying as a male or identifying as a female.

The SCSN Committee small group assigned to discuss the needs of transgender individuals presented the following list of potential needs for this special population to the full committee:

- Issues of trust;

- Not currently being identified appropriately in applications, etc.;
- Not currently targeted for testing;
- Training for providers to understand their issues;
- Drug and alcohol abuse treatment; and
- Prevention education – don't see themselves as at risk for HIV.

This committee also discussed that this is a fairly large community and mentioned they have a large Facebook network. There is a new Transgender Clinic located in Midvale (a Salt Lake City suburb) and there are provider trainings available at the Utah Pride Center. Transgender people of color are also a special subpopulation that has specific needs to be addressed.

5. Rural

Rural areas are any areas that are not considered to be along the Wasatch Front. The Wasatch Front consists of four neighboring counties in Utah (Salt Lake, Weber, Davis, and Utah) that comprise the urban center, where the majority of the state's population resides. According to the 2009 Ryan White Part B Comprehensive HIV/AIDS Plan, people living with HIV/AIDS in rural communities face particular problems in accessing medical care. Approximately 10% of the PLWH/A, in Utah, live in rural communities and the majority of these individuals come to Salt Lake City for their medical treatment. The need to come to Salt Lake City creates financial and logistical issues with transportation and overnight lodging.

The 2009 Needs Assessment Report identified additional concerns from respondents from rural areas. Respondents from rural areas were less likely to have received primary medical care, including CD4 Count, viral load test, and antiretroviral therapy as compared to the entire sample. Those from rural areas were more likely to be uninsured, less likely to have a case manager, and had higher percentages who reported that they had skipped or stopped taking HIV/AIDS medication at least once. Respondents in rural areas were slightly more likely to have sex under the influence of drugs 'most of the time'. They were also more likely to have ever traded sex for money or drugs, compared with the entire sample. Overall, when compared to the entire sample, respondents living in rural areas had lower usage, lower importance ratings, and lower satisfaction ratings.

The SCSN Committee small group assigned to discuss the needs of rural individuals presented the following list of potential needs for this special population to the full committee:

- Availability of HIV providers and services (may avoid local providers due to fear or stigma, and local providers don't want to be known as the "HIV Dr");
- Issues with denial and engaging in risky behavior – what happens in the big city stays in the big city;
- Issues with confidentiality, stigma, and culture;
- Community denial – we don't have a problem here, "not in my town" mentality;
- Lack of case management services; and
- Issues with upcoming 2014 healthcare changes – treating HIV+ patient in community health centers (quality of care and training of doctors).

Shortfalls in Healthcare Workforce

A big issue that is forthcoming and that will affect the continuum of care is the changes in 2014 with Health Care Reform. With these changes are the issues that continually impact HIV Treatment and Care: 1) funding, and 2) legislative rules and laws. Continued efforts in training and education remain important, especially as the HIV epidemic changes and treatment options improve.

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. The following list was generated from a large group discussion and determined to be the most important cross-cutting issues:

- Transportation
- Availability of resources
- Services cut from Ryan White Supported Services (dental, mental health, and substance abuse)
- Issues of trust and privacy
- Education – both for individuals and for providers
- Having multiple risks
- Stigma
- Self-efficacy and the willingness to advocate for improved change
- Lack of support systems

- Advocacy
- Improved access to testing and counseling services
- Culturally appropriate care
- Addressing language barriers

Anticipated Trends

The SCSN is conducted every three years and as we look towards the next three years, what trends can we see emerging that will need to be addressed. The following list was generated from a large group discussion and determined to be the most important anticipated trends issues:

- Health Care Reform
- Politics – different views, shifts in elected officials, balance in power
- Decreased funding
- Population changes – influx of people to Utah
- Needs of undocumented individuals
- Advances in treatment, increased costs associated with new treatments
- New illegal drugs – how they affect the mind and behavior risks
- Hooking up online – advancing technology
- Increased apathy

Participant Input Incorporated into the SCSN Process

1. Entities

- Ryan White Part A Program:
Utah does not receive Ryan White Part A funding.
- Ryan White Part B Program:
Five representatives of the Ryan White Part B Program attended this meeting. The Part B Administrator was responsible for organizing this meeting and writing this report. Two of the representatives were presenters at this meeting and all 5 Part B representatives facilitated separate small group discussions. The Part B Administrator also facilitated the larger group discussions. Many Ryan White Part B providers also attended this meeting and are addressed in the Provider section below.
- Ryan White Part C Program:

Two representatives from the Ryan White Part C Program attended this meeting. One is the Part C Coordinator, and the other is the Administrative Manager for the Part C Program. Both individuals participated in separate small groups and offered insight to both the small and large group discussions.

- Ryan White Part D Program:

One representative specific to the Ryan White Part D Program attended this meeting. They are a Part D case manager. In addition to this representative, the 2 Ryan White Part C representatives mentioned above are also responsible for the Ryan White Part D Program administration duties and offered insight specific to the WICY populations. All Ryan White Part D representatives participated in separate small groups and offered insight to both the small and large group discussions.

- AETC Administrators:

The program manager for the Utah AIDS ETC Program was unable to attend this meeting and sent a proxy, who is member of the Utah AIDS ETC Program. This individual participated and gave insight to both the small and large group discussions.

- People living with HIV/AIDS:

It has been difficult for the past several years to get PLWH/A to attend meetings and serve on committees sponsored by the Utah Department of Health. With the closure of many of our supportive services programs, many PLWH/A don't feel that they have much input and therefore do not see the value in attending meetings. For this meeting, there were invitations sent to 6 PLWH/A and providers were asked to invite any PLWH/A they thought would like to participate. Two individuals responded to the invitation that they would attend. One individual called the day before and was too ill to attend. The other individual did not show up to the meeting. This problem has also been noted by the HIV Prevention Program and we are working together to find ways to get PLWH/A more involved and willing to participate in our meetings and committees.

- Providers and Advocates:

There was great support and participation in the SCSN meeting by our providers. The following is a breakdown of how many providers attended and the agencies they are affiliated with:

- 3 Ryan White Part B case managers and a case manager supervisor from the Division of Infectious Diseases at University Hospital;
- A Ryan White Part B case manager and a case manager supervisor from the Utah AIDS Foundation;
- An RN providing HIV-related care at the Utah State Prison;
- 2 representatives from a Salt Lake Valley Health Department offering HIV testing services;
- A Clinical Social Worker from Volunteers of America offering counseling services for HIV+ individuals;
- A representative from the Urban Indian Center of Salt Lake offering education and referrals for HIV+ individuals;
- A representative from the Utah Pride Center supporting and serving the Utah LGBTQ community;
- A representative from the Utah Medicaid Program at the Utah Department of Health;
- The Quality Improvement Contract representative for Part B medical care; and
- 5 Utah Department of Health representatives from the Bureau of Epidemiology, including the Communicable Disease Prevention Program and the Treatment and Care Services Program.

These individuals participated individually in the various small groups and gave valuable insight to both the small and large group discussions. It was extremely helpful to have so many different perspective and experiences from these providers and advocates. Their viewpoints are reflected throughout this SCSN document.

2. 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 small groups (since this was the largest focus of the SCSN meeting). A copy of the Evaluation Worksheet can be found in Appendix D. 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. For this purpose, a value of 5 indicated that the respondent was “Very Satisfied” and of 1 that the respondent was “Very Dissatisfied.” Sixteen committee members filled out evaluation worksheets. It is important to note that Ryan White Part B Program

representatives did not fill out evaluations since they planned and facilitated the meeting. Results for the SCSN meeting can be found in the following table:

Topic	N	Minimum score	Maximum score	Mean
Satisfaction with your level of participation	16	4	5	4.75
Satisfaction with the small groups	16	4	5	4.69

The range of scores for individual participation is shown in the following table:

Level of Satisfaction with Individual Participation

Rating	Frequency	Percent	Cumulative Percent
Very Satisfied	12	75%	75%
Satisfied	4	25%	100%

As indicated, 100% of participants expressed satisfaction with their level of involvement in the SCSN process. They elaborated in the following comments:

“Very interesting. I learned a lot about barriers and needs of special populations relating to HIV testing and being HIV+”

“I was very involved – gave input in small groups, helped present our discussion, and acted as scribe in second small group. Also gave input in large group discussions.”

“Interactive. I gave feedback, helped writing notes, and presented to main group.”

The degree of satisfaction with the small group process was consistent with that of the individual participation. Here, too, 100% of attendees expressed satisfaction and none indicated dissatisfaction. The range of scores for satisfaction with the small groups is shown in the following table:

Level of Satisfaction with Group Participation

Rating	Frequency	Percent	Cumulative Percent
Very Satisfied	11	69%	69%
Satisfied	5	31%	100%

Among the comments about the small group functioning were the following:

“Interaction with many different professionals. Strongly positive. Able to present a broad view of the problems.”

“Everyone contributed in the discussions.”

“Lots of great ideas from people doing prevention and testing and care with different populations.”

“Good diversity; looked at solutions as well as gaps – how can we leverage existing resources.”

**Appendix A
Meeting Agenda**

Utah Statewide Coordinated Statement of Need (SCSN)

Tuesday, January 31, 2012
Utah Dept. of Health (288 N 1460 W)
Room 125

AGENDA

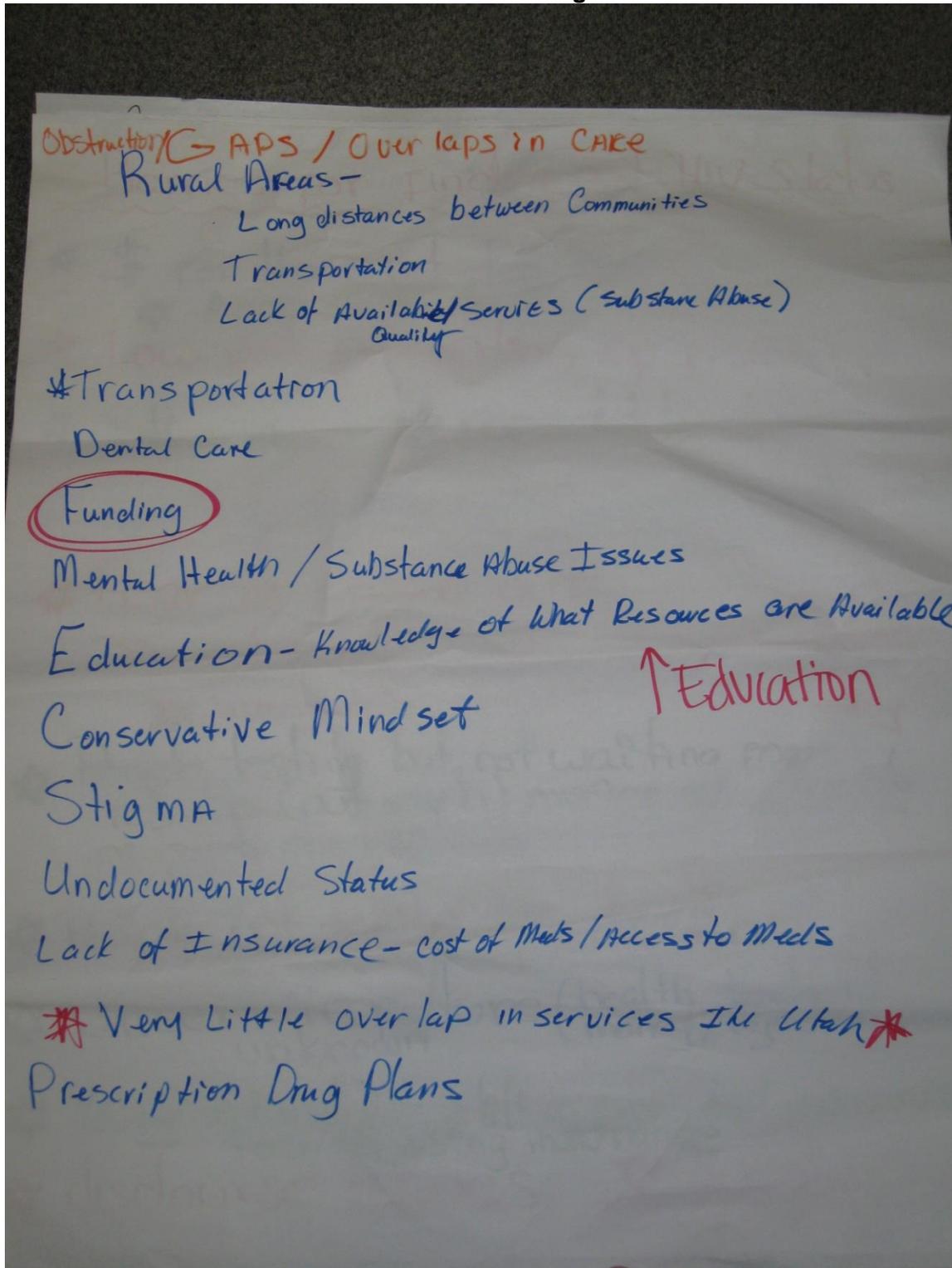
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|-------------------------|--|
| 9:00 a.m. – 9:45 a.m. | Welcome – Rachel Black <ul style="list-style-type: none">• Purpose of SCSN• 2008 SCSN Results• 2012 Expectations |
| 9:45 a.m. – 10:15 a.m. | Epidemiological Profile Highlights – Mike Lowe |
| 10:15 a.m. – 11:00 a.m. | Break into small groups representing: <ol style="list-style-type: none">1. Needs of individuals who are aware of their HIV-positive status but are not in care – led by Mike Lowe2. Needs of individuals who are Unaware of their HIV status – led by Autumn Gardner3. Obstacles to accessing care – led by Rachel Black |
| 11:00 a.m. – 11:15 a.m. | Break |
| 11:15 a.m. – 11:45 a.m. | Reports from small groups (10 minutes each) |
| 11:45 a.m. – 12:15 p.m. | Boxed Lunches |
| 12:15 p.m. – 1:00 p.m. | Break into small groups – Current/Emerging Needs by Special Population representing: <ol style="list-style-type: none">1. Homeless – Karin Parker2. Transgender –Autumn Gardner3. Rural – Rachel Black4. Injection Drug Users – Mike Lowe5. Adolescents – Erin Hellstrom |
| 1:00 p.m. – 1:50 p.m. | Reports from small groups (10 minutes each) |
| 1:50 p.m. – 2:30 p.m. | Discussion – Rachel Black <ul style="list-style-type: none">• Cross-cutting Issues• Shortfalls in Healthcare Workforce• Anticipated Trends (4-6 years) |
| 2:30 p.m. – 3:00 p.m. | SCSN Process Evaluation
Wrap-up & Adjourn |

**Appendix B
List of Attendees**

Name	Affiliation	Entity
Ana DeMelo	Clinic 1A, University Hospital	Provider - Case Manager
Linda Johnson	Health Insight	Quality Improvement
Kaleb Call	Clinic 1A, University Hospital	Part C & Part D
Mitzi Cheney	Clinic 1A, University Hospital	Provider - Case Manager
Tyler Fisher	Utah AIDS Foundation	Provider - Case Manager
Jacqueline Shirley	Urban Indian Center of Salt Lake	Advocate
Edwin Espinel	Utah Department of Health	HIV Prevention
M. Jann DeWitt	Utah AIDS ETC	AETC Administrator
Pauline Sturdy	Utah State Prison	Provider – RN
Geralynn Barney	Clinic 1A, University Hospital	Provider - Case Manager
Lillian Rodriquez	Utah Pride Center	Advocate
Monique Melnychuk	Salt Lake Valley Health Department	Advocate
Erin Hellstrom	Utah Department of Health	HIV Prevention
Robert Wheadon	Clinic 1A, University Hospital	Part C & Part D
Peter Danzig	Clinic 1A, University Hospital	Provider - Case Manager
Lynn Meinor	Utah Department of Health	HIV Prevention
Nena St Jean	Clinic 1A, University Hospital	Provider - Case Manager
Cristie Chesler	Utah Department of Health	Treatment and Care Services
Veronica Fire	Salt Lake Valley Health Department	Advocate
John Bonner	Vonunteers of America	Advocate
Deb Bennion	Utah Department of Health	Medicaid
Misty Thompson	Utah AIDS Foundation	Provider - Case Manager
Karin Parker	Utah Department of Health	Part B
Mike Lowe	Utah Department of Health	Part B
Ana Packer	Utah Department of Health	Part B
Rachel Black	Utah Department of Health	Part B
Autumn Gardner	Utah Department of Health	Part B
Jennifer Brown	Utah Department of Health	Epidemiology

Appendix C
Large Post-It Presentations from SCSN Meeting

Obstacles to Accessing Care



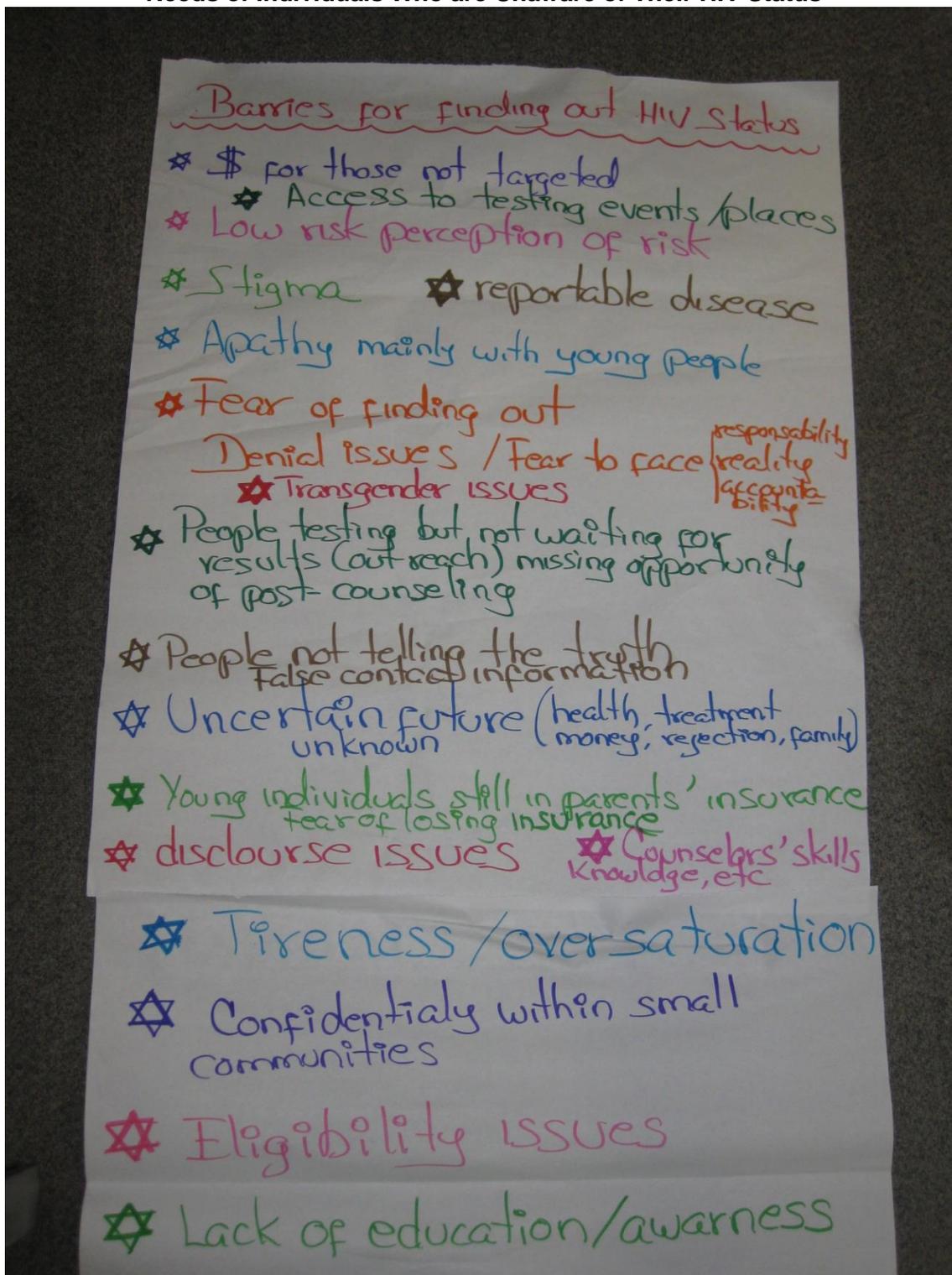
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Individuals Who are Aware of Their HIV Status but Not in Care

- Aware, but not in care
- * Fear of disclosing status
 - * Stigma
 - * ^{lack of} Privacy/Confidentiality
 - * Unaware of available help
 - * "How do I take care of myself?"
 - * Fear of Tx.
 - * Skills to cope.
 - * Cultural/linguistic barriers
- Prevention For Positives

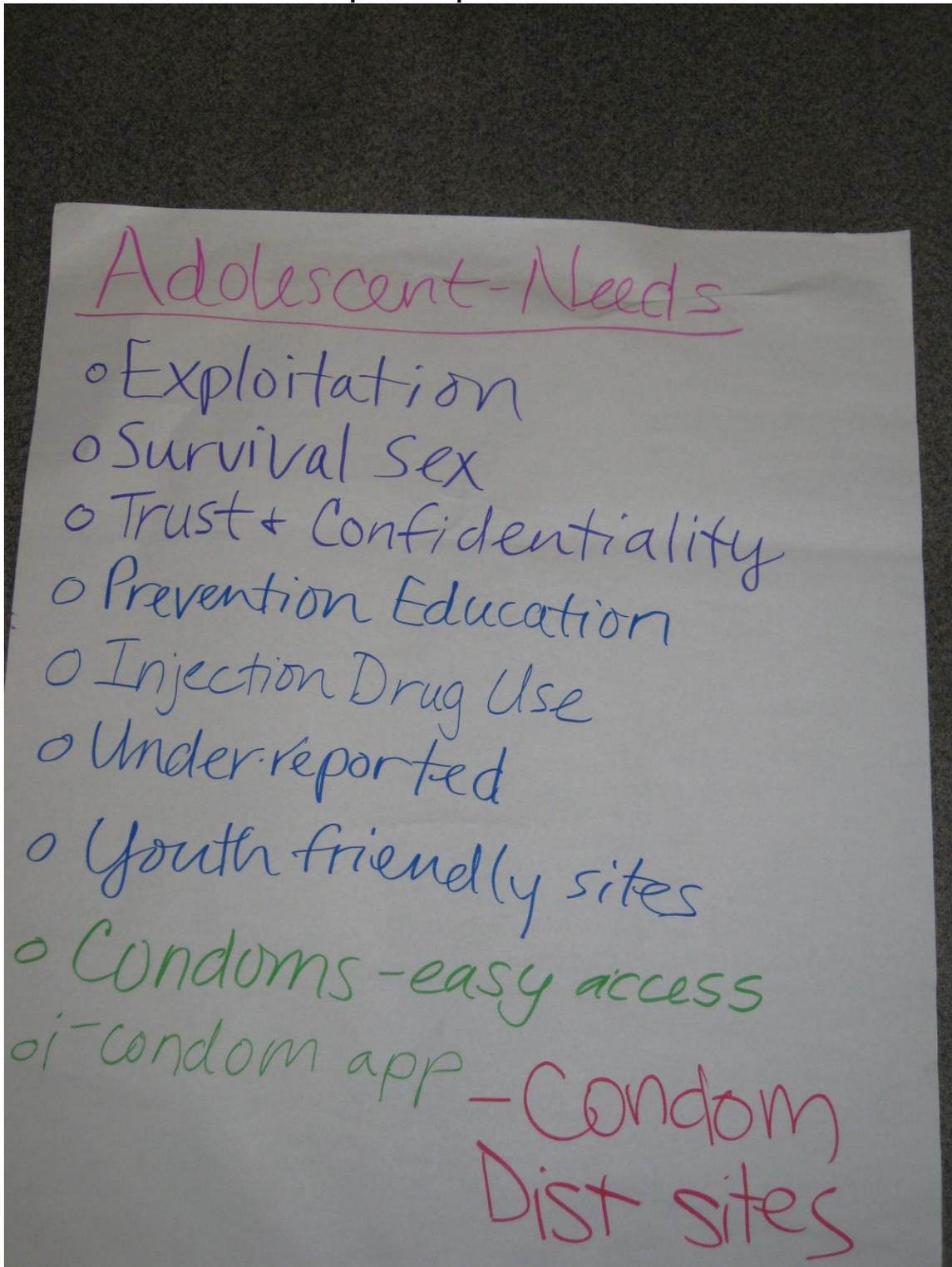
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Individuals Who are Unaware of Their HIV Status



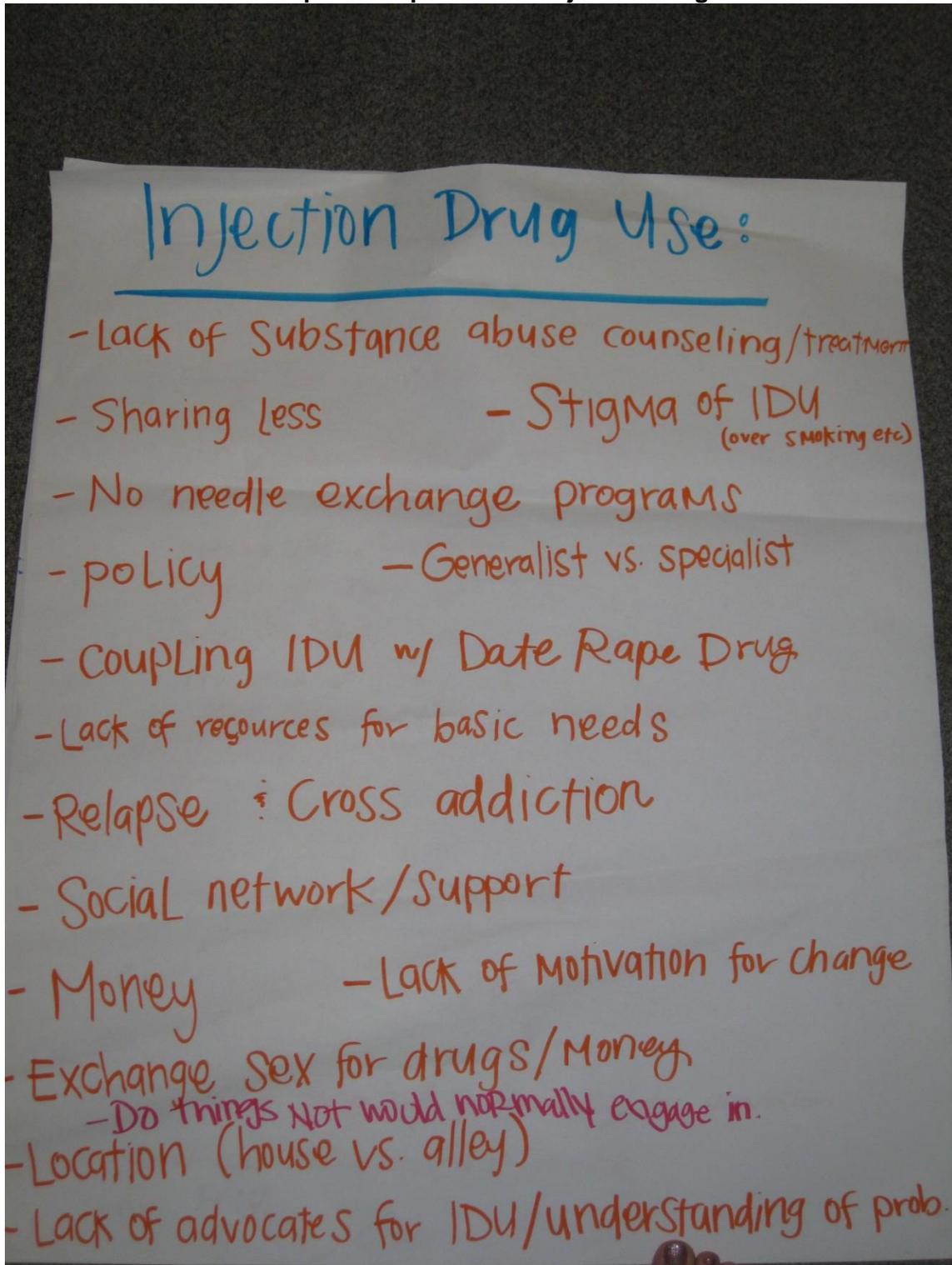
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Special Populations – Adolescents



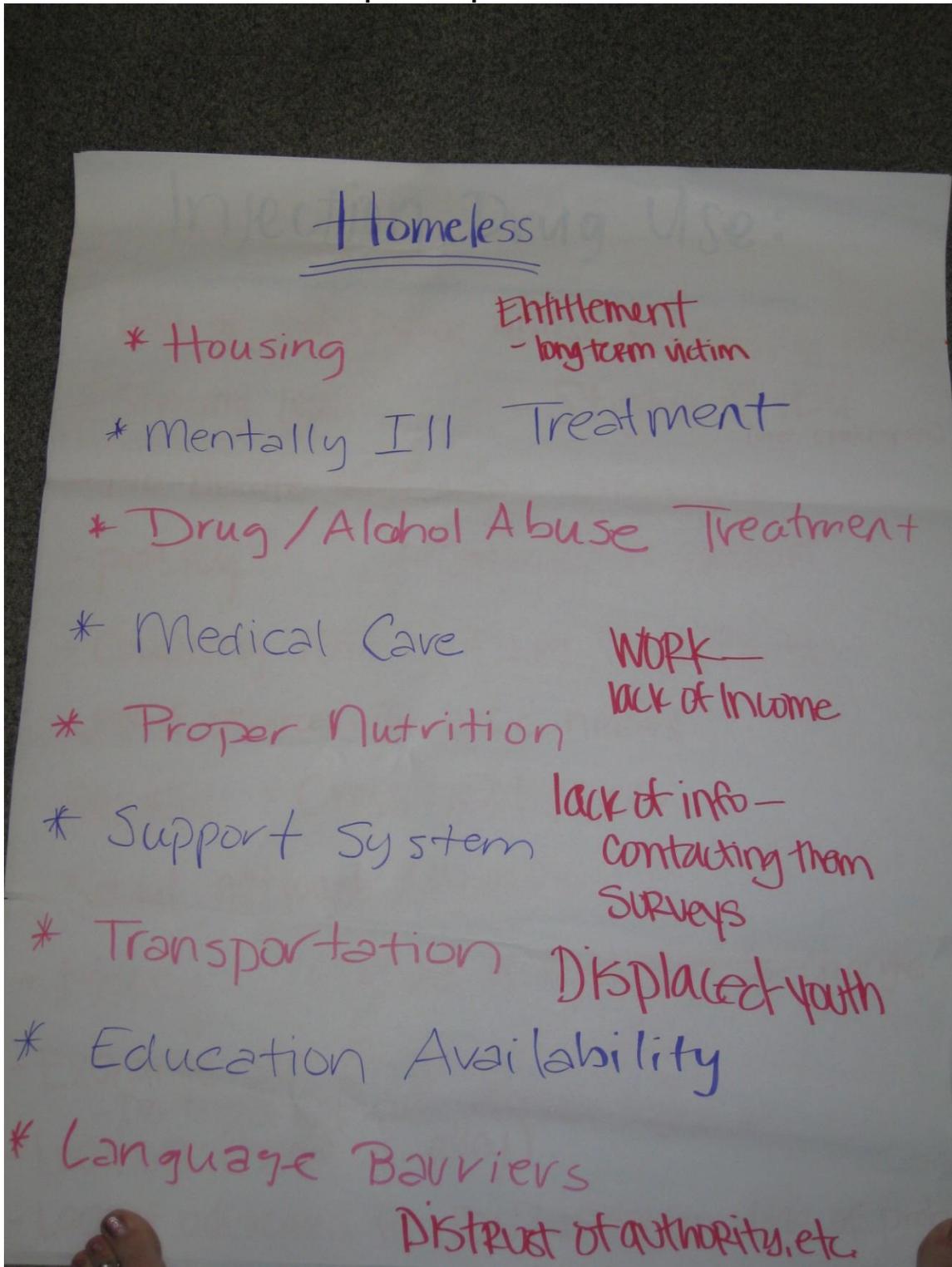
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Special Populations – Injection Drug Users



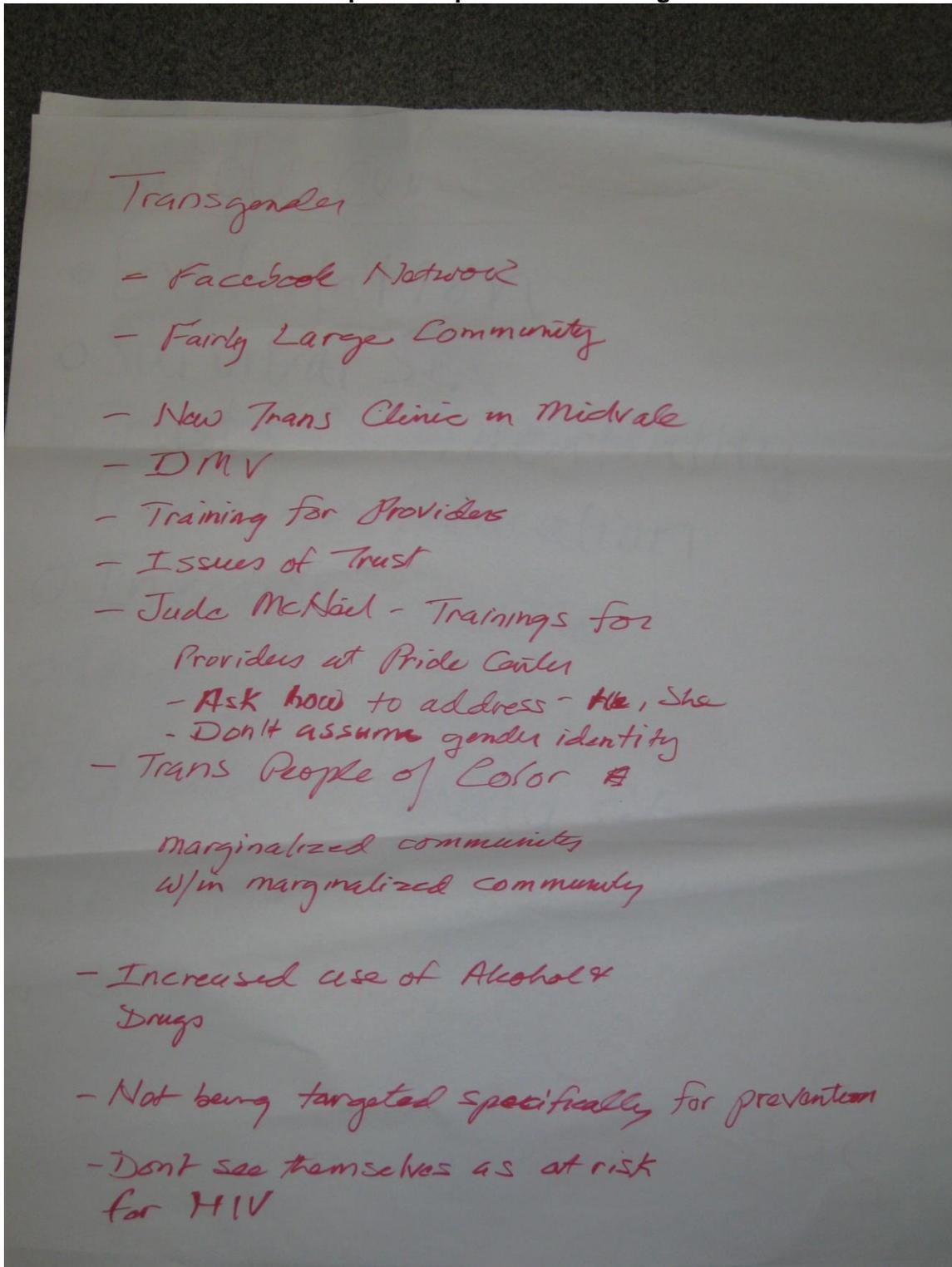
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Special Populations – Homeless



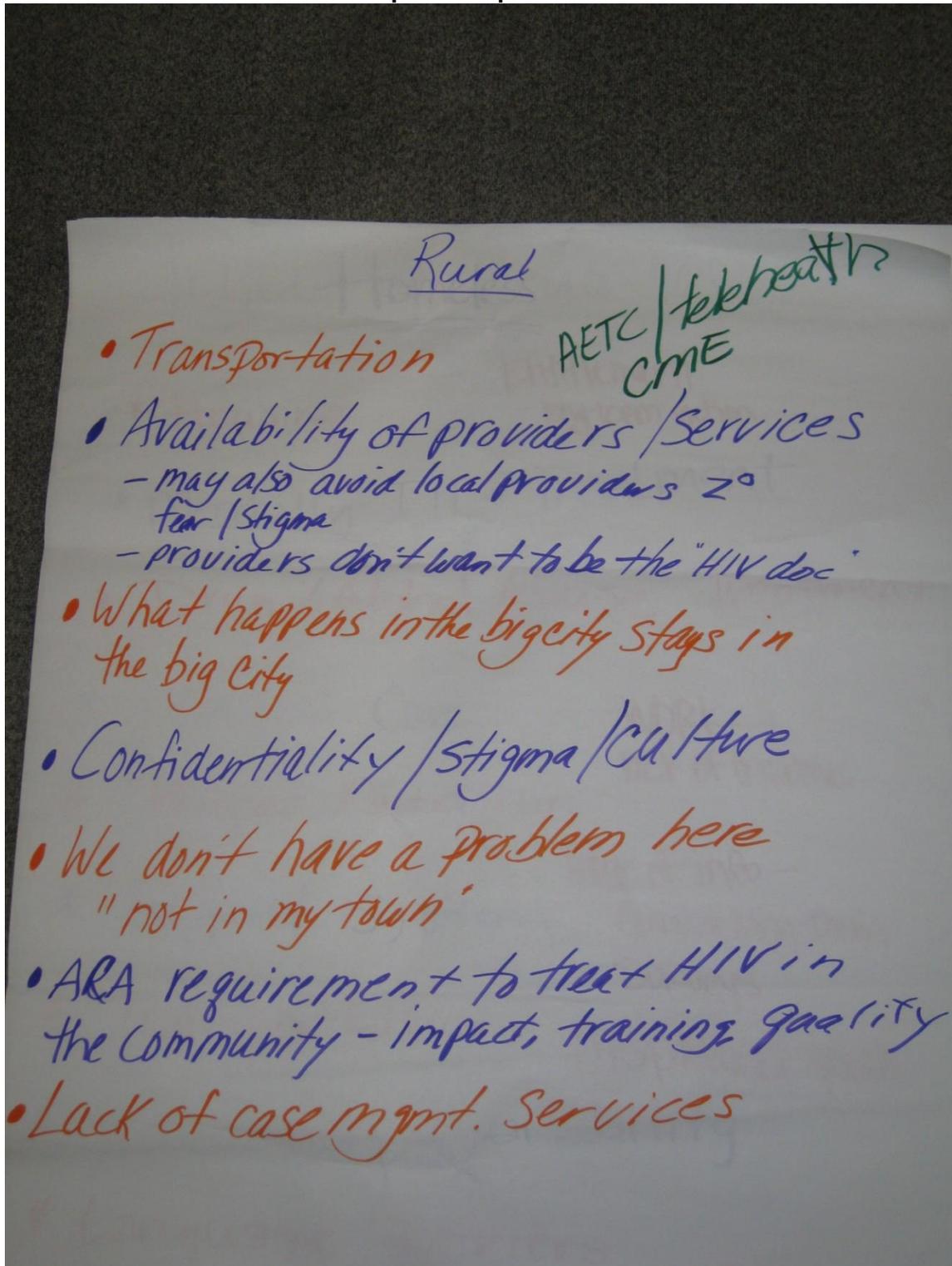
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Special Populations – Transgender



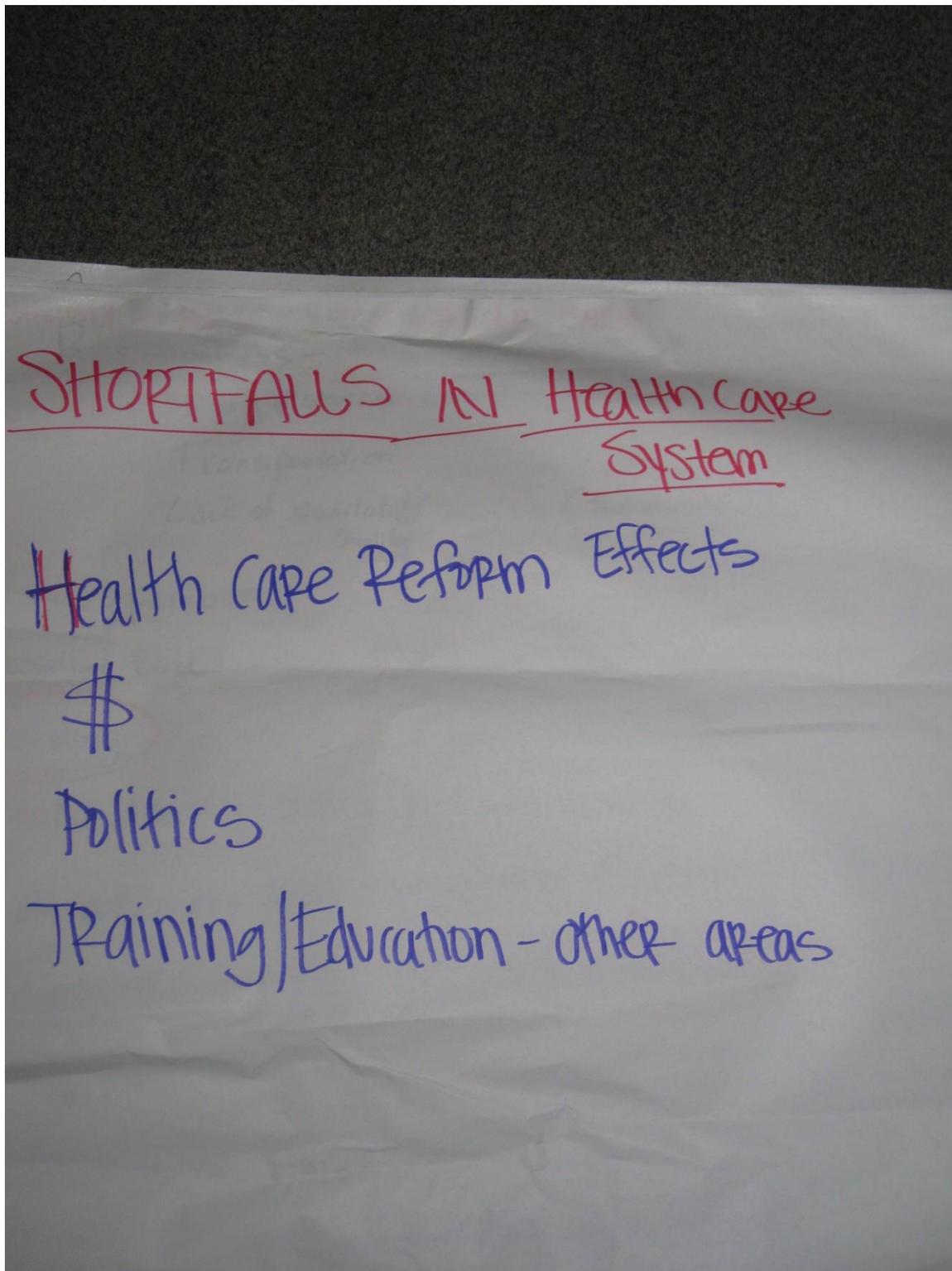
Appendix C
Large Post-It Presentations from SCSN Meeting

Needs of Special Populations – Rural



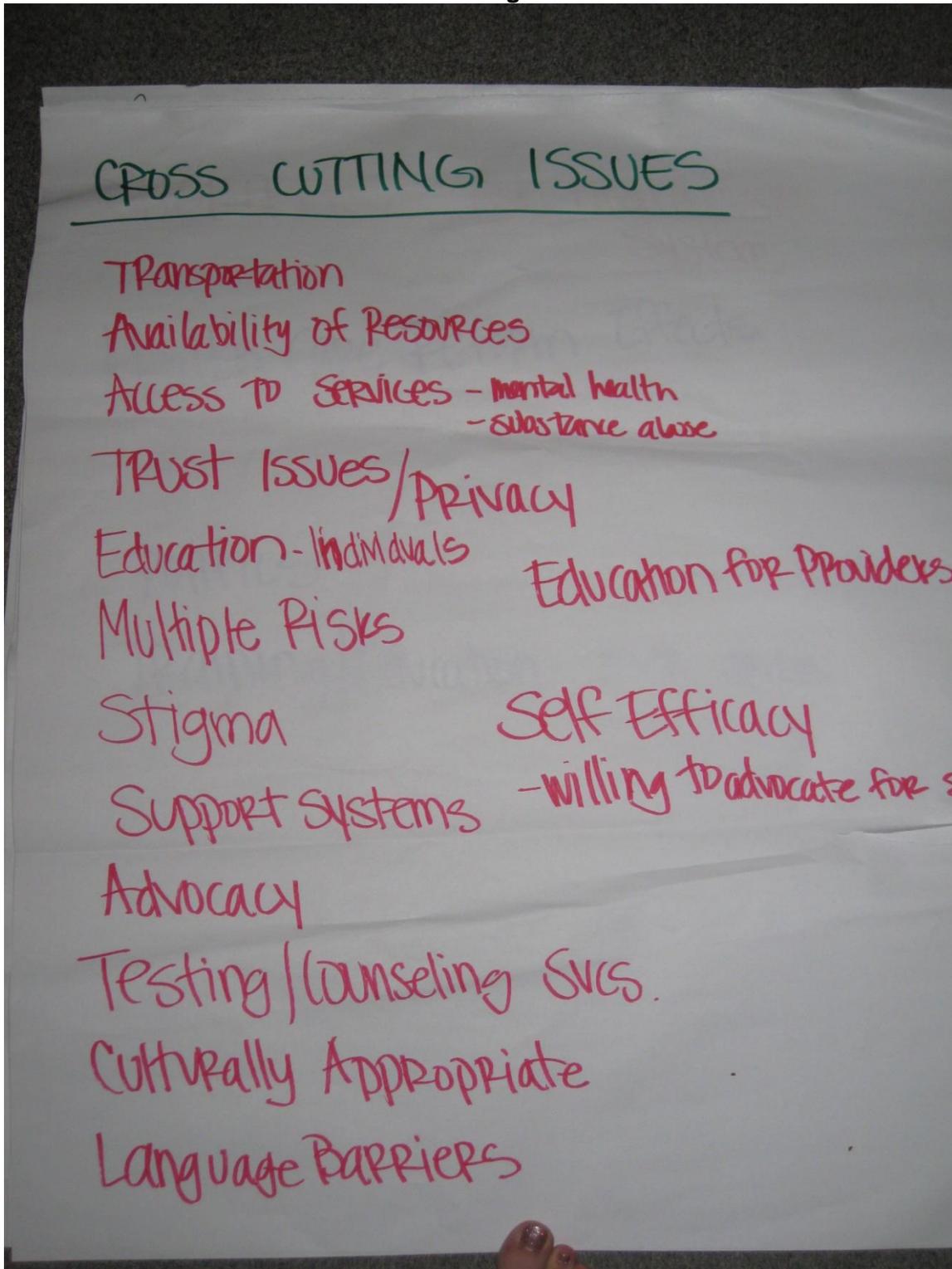
Appendix C
Large Post-It Presentations from SCSN Meeting

Shortfalls in Healthcare Workforce



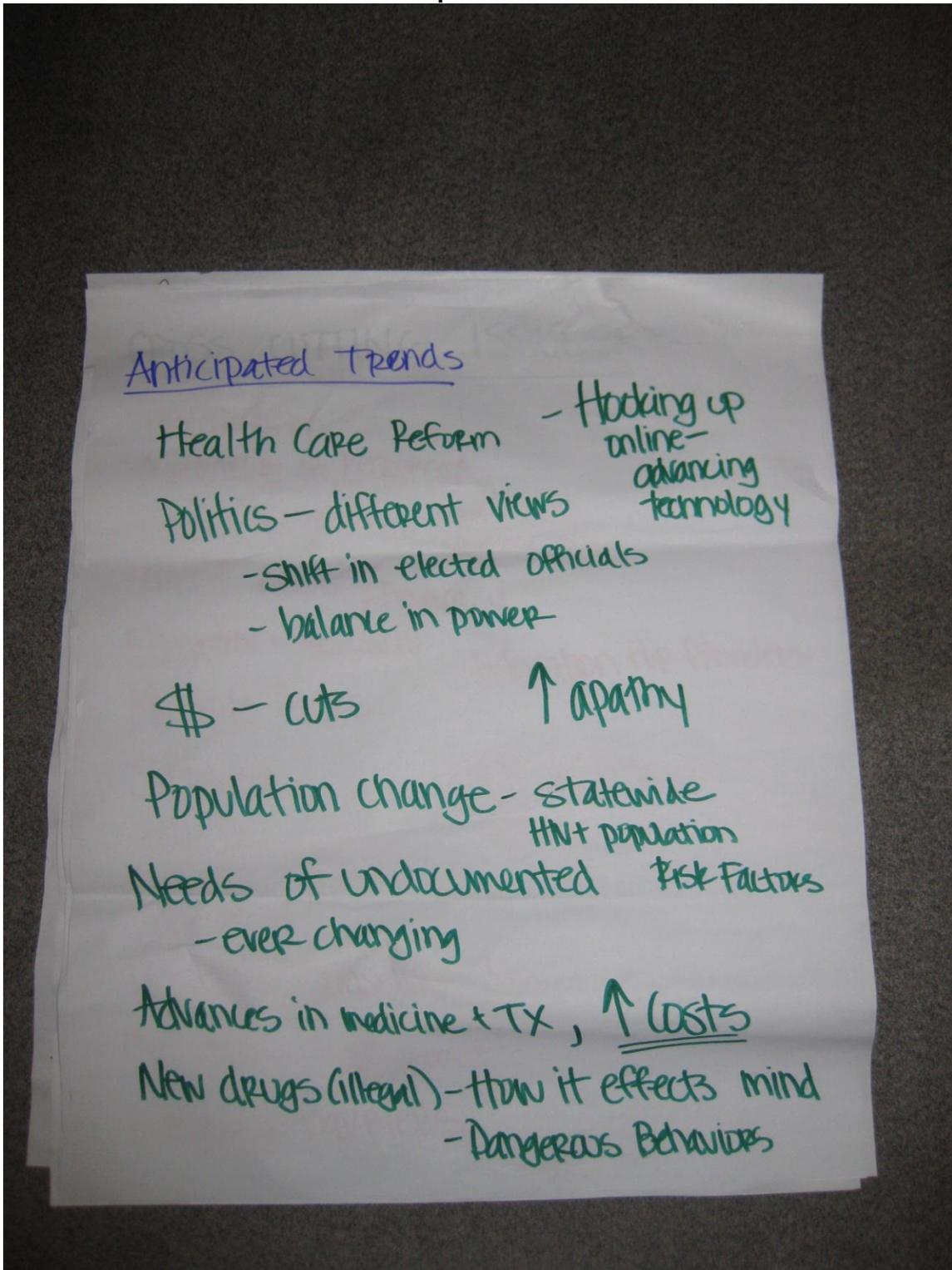
Appendix C
Large Post-It Presentations from SCSN Meeting

Cross-Cutting Issues



Appendix C
Large Post-It Presentations from SCSN Meeting

Anticipated Trends



2012 SCSN Evaluation Worksheet

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

- Satisfaction with your level of participation:
(please check 1)

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

- AM Group Topic _____

- PM Group Topic _____

- Please describe the effectiveness of your groups in the SCSN process: _____

- Satisfaction with the small groups: (please check 1)

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

THANK YOU FOR YOUR PARTICIPATION